AGEING IN AN INCREASINGLY SMART WORLD: AN ETHNOGRAPHY OF AGEING AT HOME WITH SMART AND ASSISTIVE DEVICES

Rachel Creaney

A Thesis Submitted for the Degree of PhD at the University of St Andrews



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Ageing in an increasingly smart world: An ethnography of ageing at home with smart and assistive devices

Rachel Creaney



This thesis is submitted in partial fulfilment for the degree of Doctor of Philosophy (PhD) at the University of St Andrews

March 2021

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Abstract

With increasing desires to live at home for longer and have more control of one's healthcare, coupled with rises in smart technology use and affordability, the drive for healthcare smart homes (HSH) from certain policymakers and technologists, particularly in rural communities, has heightened. These digitalised homes aim to enable older people to live independently at home for longer and potentially improve their wellbeing through the use of smart and assistive technologies. Much of the existing literature on the impacts of HSH living is from: healthcare or technocentric domains; shorter term or 'laboratory' settings with individual residents rather than more in-depth research including the wider networks. Furthermore, there is increasing development of DIY versions of HSH (i.e. portable smart and assistive devices gathered by the resident and their wider caring networks to be used in their homes, rather than a tailor-made HSH). Thus, in this thesis I use multiple ethnographic methods (visual, traditional and autoethnographic methods) to explore the longer-term experiences of five older people, and their wider caring networks, living within DIY HSH. I draw on theories and concepts relating to bricolage, dramaturgy, and simulations to explore the experiences of a sense of home, identity formation and future planning within DIY HSH living. I argue there are multiple (and potentially competing) experiences of DIY HSH living concerning sense of home, identity and envisioning the future. This range of experiences is connected to various levels and types of access to devices and technical support (what I term 'vertical noir hierarchies'), and the experiences and motivations of the wider caring networks. Ultimately, through use of multi-modal ethnographic methods and a new conceptual framework, I highlight that a singular experience of DIY HSH living is impossible. This is illustrated through understanding the (often conflicting) experiences of both older DIY HSH residents and their wider caring networks, and their types and levels of access to DIY HSH devices.

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I also want to thank my other supervisors Katherine and Kim who were involved at the start of my PhD. Without you Katherine I likely wouldn't have been able to undertake a research visit to Australia, and without you Kim I would likely not have engaged with Housing Studies Association so early in my PhD. The friends that I have made through HSA will likely remain throughout my career. It has been lovely to feel part of a wider housing studies community throughout my PhD.

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Of course, I am also eternally grateful to all of my participants. Without any of you I would have no thesis! I appreciate you letting me into your homes and your families with such hospitality, honesty and kindness. I hope that your experiences that I have illustrated in this thesis and film can help to improve the future options for ageing with smart and assistive technology.

Glossary

Alexa (or Siri): Voice assistant developed by Amazon (and Apple for Siri). It is capable of voice interaction, music playback, making to-do lists, setting alarms and reminders, streaming podcasts, playing audiobooks and providing real-time information. It is also capable of controlling other smart devices (i.e., doorbells, smartphones) and acting as a home automation system.

Assistive devices: These are assistive, adaptive or rehabilitative devices for older people or people living with disabilities which help them with everyday tasks (e.g., text to speech software, word prediction software, adaptive home modifications such as railings or modified kitchen spaces). They are not necessarily technological devices.

Charity commissioned devices: These devices are available through certain charities (e.g., <u>Scottish War Blinded¹</u>, <u>SeeScape²</u>) in which specialised publicly- and privately commissioned devices are available at a reduced cost, however specific criteria apply in order to access them.

Fall alarm: Button alarms worn as bracelets or necklaces which the wearer can press if they need assistance. The call will then be answered by the relevant care monitoring service. Usually these are publicly commissioned, available for no or nominal fee, but often have monthly subscription costs (i.e., similar to a landline phone contract).

¹ Scottish War Blinded: <u>https://sightscotland.org.uk/veterans</u>

² SeeScape: <u>https://www.seescape.org.uk</u>

Fitbit: Technology company that produces smart devices including activity trackers, watches and wireless devices to measure health data.

Healthcare smart home(s) (HSH): These digitalised homes aim to enable older people to live independently at home for longer and improve their wellbeing through the seamless use of smart and assistive technologies. HSH often contain a range of telecare, telehealth and smart technology devices.

Hive: Technology company that produces inter-connected smart home devices including thermostats, lights, plugs and motion sensors.

Internet of Things: A network of physical objects (i.e., things) equipped with sensors and applications which aim to connect and exchange data over the internet (e.g., wearable health monitors, connected kitchen appliances).

Key participants: The main participants of this research. Specifically, five older people living with a range of health conditions and smart and assistive devices within rural Scotland.

Privately commissioned devices: Devices available for private purchase by the user, with often substantial upfront costs (e.g., Alexa, specialised tablets).

Publicly commissioned devices: Devices available for no or a nominal fee through the local authority but may have longer-term running costs (i.e., fall alarms).

Remote cameras: CCTV type surveillance cameras that a family member/ allocated person can view to check on the resident from a distance (i.e., remotely from outside of the home).

Smart and assistive devices: Term used to signify (within this thesis) of all technology devices (i.e., telecare, telehealth and smart home technology devices) utilised by my key participants. Many of the devices connect to the Internet of Things to automate and monitor in-home systems, such as e.g., smart thermostats, energy monitors, lighting, home security systems, wireless speakers, Alexa/ Siri, remote door locks, and even the smartphone. Others are utilised more directly for healthcare purposes (i.e. telecare and telehealth devices).

Telecare: Telecare devices which monitor aspects of an individual's activity, or related activities, in the home e.g., fall alarms and motion sensors.

Telehealth: Telehealth devices require active involvement from the patient to take readings e.g., blood pressure, that are regularly submitted for review by health professionals.

Wider caring networks: The people who offer key forms of assistance to my key participants i.e., friends, family, neighbours or formal carers or organisations who help with everyday tasks, physical or emotional support or with technology device use. In addition, the dementia carers group members were each members of the wider caring networks for their family member living with dementia.

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Statement on collaborations and funding

This PhD was completed in joint-collaboration and supervision with the Social, Economic and Geographical Sciences Department, James Hutton Institute, Aberdeen. It was funded by the Economic and Social Research Council, via the Scottish Graduate School of Social Science.

Related publications and activities

Peer-reviewed journal articles

Creaney, R., Reid, L., Currie M. 2021. The contribution of healthcare smart homes to wellbeing: A new conceptual framework. *Wellbeing, Space and Society*. Online first. DOI: 10.1016/j.wss.2021.100031

Creaney, R. 2021. The potential implications and inequalities in the care of older people in a post-COVID world: An autoethnographic account. *Interdisciplinary Perspectives on Equality and Diversity*]. http://journals.hw.ac.uk/index.php/IPED/article/view/89

Other journal contributions

Creaney, R. 2021. Future(s) of Technology-Enabled Care. Sociological fiction story. *The Sociological Review*. https://www.thesociologicalreview.org/fiction/futures-of-technology-enabled-care/. This story can also be viewed in Appendix one.

Creaney, R. 2021. Book review of 'Using Technology in Dementia Care: A guide to Technology Solutions for Everyday Living' edited by Prof Arlene Astell, Dr Sarah Smith and Dr Phil Joddrell [Accepted Oct 2020 by *Journal of Enabling Technologies*]. In Press.

Conference presentations/ papers

Creaney, R. The role of smart homes in futureproofing the health of housing and older residents. *Housing Studies Association International Conference,* April 2021 [virtual due to COVID].

Creaney, R. The place of multi-modal ethnographic methods within housing research. *Housing Studies Association International Conference*, April 2021 [virtual due to COVID].

Creaney, R. 'It gives a sense of security that there's somebody there, but it chips away at the person': An ethnography of ageing at home with smart health technology - *Housing Studies Association International Conference*, November 2020 [virtual due to COVID].

Creaney, R. 'Presentations of the ageing self: the role of HSH in (re)producing notions of ageing' was due to be presented at *Royal Geographical Society Conference*, Sept 2020, London, UK [postponed until Sept 2021 due to COVID-19]. [Awarded competitive funding to attend through the University of St Andrews' School of Geography and Sustainable Development PGR Conference Fund].

Creaney, R. 'Living in a HSH: Home is where the smart is?' presented at *4S, Social Studies of Science International Conference*, August 2020 [moved online because of COVID-19].

Creaney, R. 'HSH: Troubling or reproducing the rural idyll' was due to be presented at *European Rural Geographies Conference*, June 2020, Groningen, Netherlands [cancelled - COVID-19]. [Awarded competitive funding through the University of St Andrews' Santander- St Leonard's Postgraduate College Research Mobility Award].

Creaney, R. 'The potential contribution of rural health smart homes to positive experiences of ageing in place' at *Housing Studies Association International Conference*, April 2019, Sheffield, UK. [Awarded competitive funding to attend through HSA's conference bursaries scheme].

Creaney, R. 'What is the connection between Health Smart Homes and user-wellbeing?' presented at *4S, Social Studies of Science International Conference,* August 2018, Sydney, Australia. [Awarded competitive funding to attend through James Hutton Institute's PGR travel fund].

Creaney, R. 'What is the connection between Health Smart Homes and user-wellbeing?' presented at *Housing Studies Association International Conference*, April 2018, Sheffield, UK. [Awarded competitive funding to attend through HSA's conference bursaries scheme].

Creaney, R. 'A typology of Smart homes and technology within Scotland', presented at *Royal Geographical Society Conference*, August 2017, London, UK. [Awarded competitive funding to attend through James Hutton Institute's PGR travel fund].

Blog posts

Reid, L. and **Creaney, R.** Co-authored blog for Geography Directions entitled, '<u>Home during</u> <u>COVID-19, and beyond'</u>. 2020.

Creaney, R. Blog for Housing Studies Association entitled, <u>'Scottish Housing Day: Housing is a</u> <u>Human Right</u>'. 2019.

Creaney, R. Blog for Housing Studies Association entitled, '<u>The (dis)empowering potential of</u> <u>health smart homes</u>'. 2019.

Other related activities

April 2018 – present: Early Career Researcher Communications Assistant for <u>Housing Studies</u> <u>Association</u>. Responsibilities: maintaining multiple social media channels and organising a coblog series between ECRs and more established housing scholars.

2021: Co-creating a 'Digital history of the HSA' through interviews with former Housing Studies Association chairs as part of the HSA's 30th anniversary celebrations.

Oct 2021: Co-organiser of Housing Studies Association's Autumn Lecture for 2021 entitled 'Looking Forward, Looking Back: The State & housing' (to be held in Northern Ireland/ online, Oct 2021). Co-organised with Dr Tom Simcock (Edge Hill University).

Sept 2021: Co-convener of Postgraduate Forum sponsored session at the <u>Royal Geographical</u> <u>Society's Annual Conference 2021</u> entitled 'Blurring the borders between researcher and participant: The role of autoethnography within geographical research'. Co-organised with Dr Sarah Huque (University of St Andrews). Nov 2020: Organisation of a Housing Studies Association 2020 conference event for Early Career Researchers entitled 'Generating Impact', in association with the <u>UK Collaborative Centre for</u> <u>Housing Evidence (CaCHE)</u>.

Oct 2018-Jan 2019: Awarded and undertook competitive internship (through the Scottish Graduate School of Social Science) with Scottish Government exploring 'What works within Shared Decision Making in Realistic Medicine?'.

1 Introduction

1.1 Context

Recently, there has been an increasing desire expressed by older people to live at home for longer (Van Dijk et al. 2015) and have more control of their healthcare (Beer and Owens 2018). Coupled with rises in smart technology use and affordability (Strengers and Nicholls 2017), and demographic ageing (van Hoof et al. 2016), the opportunities for continued home living (i.e., ageing-in-place) have increased. This came in response to, or as a potential product of, the increasing neoliberalisation of society (particularly in the global north) in which the State reduces its responsibility towards its members (Martin et al. 2005). With this increasing responsibilisation of the individual members of society, healthcare smart home(s) (HSH) have been suggested as an innovative solution to enable such ageing in place and offer more affordable healthcare at home through the assistance of smart healthcare technologies.

These digitalised homes aim to enable older people to live independently at home for longer and improve their wellbeing through the use of smart and assistive technologies. HSH often contain a range of telecare, telehealth and smart technology devices. Telecare devices monitor 'aspects of an individual's activity, or related activities, in the home (e.g. fall alarms and motion sensors)' (Currie et al. 2015: 2). Meanwhile, telehealth devices 'require active involvement from the patient to take readings (e.g. blood pressure), that are regularly submitted for review by health professionals' (Currie et al. 2015: 2). Finally, smart home devices are connected to the Internet of Things (Bennett et al. 2017) to automate and monitor in-home systems, such as smart thermostats, energy monitors, lighting, home security systems, wireless speakers, virtual assistants such as Alexas or Siris, remote door locks, and even the smartphone.

HSH remain a relatively new phenomenon. They build on telecare and telehealth activities, however, the focus on smart devices is a relatively new and evolving area. As such, HSH remain a concept, rather than a reality on a large scale. However, their opportunities for use in improving the experiences of older people ageing at home is important. This is particularly true within rural areas where health and social care services can be more expensive and require delivery at greater distances (Currie and Philip 2019), and where a move out of one's home and into full-time care would likely also mean a move out of one's community (e.g. into an urban care home).

Recently, within Scotland, there has been an increasing interest from policymakers and government organisations in HSH. Building on Scottish Government's (2018a) focus on digital enablement and empowerment within health and social care, the notion of the smart village (Philip and Williams 2019), and desires to improve the use of digital technology in housing across Scotland (Scottish Government 2018b), HSH offer an opportunity to put some of these ideas into practice. However, there are also numerous challenges facing these developments in terms of the digital divides (Philip et al. 2017). Specifically, these concern digital infrastructure, digital literacy, and the appropriate use and upkeep of digital devices. Furthermore, lower numbers of Scottish adults with chronic conditions use internet-connected and smart devices as opposed to Scottish adults without chronic conditions (Dowds et al. 2018). As such, this thesis offers timely research into a topic of high interest to policy and practice.

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This thesis contributes to the fields of geography and sustainable development in several ways. In terms of geography, it highlights the importance of place (Downs and Tuan 2006; Andrews et al. 2007; McCall et al. 2020) as both an important consideration for decisions around ageing, but moreover the role that place and the wider community can play in the making and unmaking of home. Looking to sustainable development, ageing in place, through the use of smart and assistive devices, has the potential to improve the sustainability and resilience of communities. This could contribute to the social and economic sustainability of wider society by enabling older people, and therefore communities, to age in place and reduce the financial societal burden of otherwise high costs of healthcare. Furthermore, this research area has the potential to address several Sustainable Development Goals (SDGs) (UN, 2016), namely: SDG3 – Good health and wellbeing; SDG10 - Reduced inequalities; and SDG11 - Sustainable cities and communities. This thesis critically interrogates these assumed positives through a consideration of longer-term indepth experiences of both older people and their wider caring networks who are ageing in place. In this introductory chapter I initially offer some context to this research (section 1.1), followed by my research aim, objectives and questions (section 1.2). Finally, in section 1.3 I outline the chapters of this thesis.

Although the body of literature is growing, to date, research around HSH has tended to focus on short term laboratory-type settings (Marikyan et al. 2019), single smart devices (Aceros et al. 2015) or specific health conditions (Amiribesheli et al. 2015), whilst longer-term critical social science research with both residents and their wider networks has been largely absent (as highlighted in Burrows et al. (2018)). The majority of research has tended to conceptualise experiences of ageing with assistance from technologies as quite normative (as suggested by Peine and Neven (2020)), with no expectation that these experiences with HSH devices may change over time. In reality, experiences in these homes may have knock-on effects on a resident's potential to maintain or promote their wellbeing or to feel empowered. As such, again building on the work of Peine and Neven (2020), I argue that the HSH vision suggested by some policymakers and marketing professionals is utopic and likely unachievable. In such situations, these homes are presented as an innovative one-size-fits-all solution to a multitude of existing societal issues.

To address these literature gaps and potential unrealistic visions of HSH, I explored the longerterm real-world experiences of both older DIY HSH residents and their wider caring networks (i.e., friends, family members, health and social care staff). I undertook ethnographic fieldwork (i.e., observations and unstructured interviews) with five older people (65+) living in DIY HSH across Scotland, with a focus on rural areas where possible. I visited each key participant between two and six times over a year (as access allowed), as well as undertaking interviews with multiple members of their wider caring networks. I also undertook observations (six visits over four months) at a dementia carers group, to better understand the experiences of the wider caring networks in caring for their family member, and the role that DIY HSH played within this relationship. Keen to add to literature gaps around HSH experiences and understand the multiple and potentially competing experiences of these homes, this thesis focuses on experiences of how people living in DIY HSH experience home, how DIY HSH shape the roles and identities of residents, and their wider caring networks, and how DIY HSH affect their planning for the future. Drawing on sensory and digital ethnography research (Sumartojo et al. 2016; Pink et al. 2018), I sought to undertake multi-faceted ethnographic data collection to capture more than the spoken and written observations of traditional ethnography. Thus, I also utilised visual and auto-ethnographic methods to create a multimodal thesis in the form of both the written

thesis and an accompanying digital story called <u>Smart Ageing</u>³. This film visually depicts many of the accounts offered within this thesis, as well as offering an opportunity to hear directly from my key participants. I recommend watching the film before continuing, however, I will refer to specific film clips throughout the thesis to offer an additional and perhaps more tangible account than simply a written one. The use of autoethnographic methods allowed me to draw on my personal experiences of bereavement and living within an evolving caring network, to highlight the links between the experiences of myself and my wider caring network and those of my key participants concerning changing ideas of home, identity and future.

In this thesis I highlight the multiple and (often) competing experiences that exist within DIY HSH living, both between residents and between and within their wider caring networks. I contribute to the growing body of literature on experiences of home, identity and future planning within DIY HSH living. Drawing on a range of methods, literature (e.g., geography, ethics of care, sociogerontechnology, futures thinking) and theories and concepts (e.g., dramaturgy, bricolage, the panopticon, anticipatory futures) I offer new thinking on what it means to age in a DIY HSH, both for residents and wider caring networks. I also offer a new conceptual framework for encouraging optimal experiences for older DIY HSH residents. Finally, COVID-19 has drawn increased attention to informal caring practices, the role of (healthcare) technologies and the importance of the home. As COVID-19 occurred during the write up stages of my research there was not an opportunity to explore it through fieldwork, however, my thesis provides insights into the design, value and limitations of DIY HSH living that could be applied to the current pandemic and its aftermath.

³ Film (33 mins) also available at <u>https://youtu.be/IB_HicR2ndQ.</u>

1.2 Research aim, objectives and questions

Overall, through this thesis I aimed to create and utilise a multi-modal ethnographic approach to examine the experiences of older people living in DIY HSH. This was addressed through several research objectives (ROs) and questions (RQs). These are detailed in Figure 1 (and Appendix two).



Figure 1: Research aim, objectives and questions

1.3 Chapter outline

In Chapter 2 (*Literature Review: Ageing and care within healthcare smart homes*) I situate this research within the existing literature around ageing, care and technology in the home, and noticeable gaps are identified. These gaps include a lack of critical social science research on longer-term experiences of DIY HSH, and little consideration of the role and experiences of the wider caring networks. In Chapter 2 I also introduce my conceptual framework as a tool for developing optimal experiences for older residents living with smart and assistive devices. In Chapter 3 (*Methodology: Creating a multi-modal ethnographic approach*) I introduce the research tools and methodology used in this thesis, justifying the multi-modal ethnographic approach. I also reflect on the study design and data collection. Finally, in this methodology chapter I also introduce my five key participants and the dementia carers group.

Chapter 4 (*Autoethnography: Troubling the field boundaries*) is a short autoethnography chapter in which I reflect on the unexpected death of my dad during this research. I highlight connections between my own experience and those of my key participants and their wider caring networks, including changing identities and roles and experiences of rural living. As well as recognising my positionality and the type of research methodology I undertook, this autoethnography chapter also contributes to RQ2c and RQ3a, regarding my role in my mum's evolving identity, and the potential futures that smart and assistive devices could have created for my parents.

Chapter 5 (*Results one: The home within healthcare smart home living*) is the first of my three results chapters, which explores the meanings of the home and how these may have changed for my key participants and their wider caring networks through the introduction of DIY HSH. In

section 5.2 I illustrate how the home is considered by my key participants and their wider caring networks. I argue that the multiple understandings of the home are built upon emotional connections to space and what it represents (i.e., relationships, capability, safety, identity). In section 5.3 I explore the multiple motivations for DIY HSH living, concerning experiencing the home as a place of consumption and the creation of the DIY HSH. Finally, in section 5.4 I highlight some contradictions from DIY HSH living including security breeding insecurity within the homes of my key participants. This results chapter contributes to RO1.

Chapter 6 (*Results two: Changing identities within healthcare smart home living*), my second results chapter, explores how DIY HSH living, and the dominant stereotypes of older people and ageing, have impacted the identities of my key participants and their wider caring networks in enabling performances of specific societal roles (i.e., good older person, good parent, good child, good partner/carer) which may encourage empowerment (section 6.2), and reducing the focus on disempowering roles (i.e., isolation, being a burden, and undertaking 'risky' activities) (section 6.3). Through this chapter I highlight that DIY HSH are changing the identities of my key participants in terms of the need to 'play' multiple roles at once, and in a more convincing manner than pre-surveillance focussed devices. Finally, through this chapter I illustrate the impact that different levels and types of access to smart and assistive devices can have on these identities. This results chapter contributes to RO2.

Chapter 7 (*Results three: Planning for the future in a healthcare smart home*), my final results chapter, explores how the older residents and their wider networks used their DIY HSH as a means for planning for the future. In this chapter I highlight the role of smart and assistive devices in futureproofing healthcare in the home in terms of improving capabilities and reducing the burden, but also in creating some fears of use and misuse. Overall, through this chapter I

highlight that DIY HSH enable a greater potential range of futures for older residents and their wider caring networks, but simultaneously these futures may require additional labour from the wider caring networks and heighten the fears of other older people concerning smart and assistive devices. This results chapter contributes to RO3.

Chapter 8 (*Discussion: Simulating experiences of HSH living*), my discussion chapter, highlights the key theoretical contributions of this thesis. I draw on a range of literature and concepts including bricolage, dramaturgy and future studies to argue that there are multiple (and potentially competing) experiences of DIY HSH living, especially within DIY HSH in terms of a sense of home, identity and envisioning the future. This range of experiences is connected to various levels and types of access to devices and technical support, as well as the experiences and motivations of the wider caring networks. I also revisit my conceptual framework to update it considering my empirical data to offer a more robust framework for encouraging more empowering and positive experiences of DIY HSH for older residents and their wider caring networks.

Finally, in chapter 9 (*Conclusion: Implications for the future of ageing within healthcare smart homes*) I offer some conclusions. I highlight the empirical, methodological, theoretical and policy and practical contributions of this thesis, and offer some research reflections and suggestions for future research. I also discuss the potential for my conceptual framework to act as a new theoretical framework for understanding DIY HSH living experiences. Ultimately in this thesis I argue, through multi-ethnographic methods, that a singular experience of living with smart and assistive devices is not possible, a finding that is made clearer through understanding the (often conflicting) experiences of both older DIY HSH residents and their wider caring networks, and their levels and types of access to various smart and assistive devices.

2 Literature Review: Ageing and care within (DIY) healthcare smart homes

In this literature review chapter, I justify the importance of exploring the longer-term real-world experiences of DIY HSH living, particularly for older people in rural areas. I also underline the importance of exploring the experiences not just of the residents but also their wider caring networks, both those living in the resident's home and further afield. Moreover, I highlight the relevant literature gaps for this thesis. Much of the existing literature on the impacts of HSH living has come from: healthcare or technocentric domains (Sixsmith and Sixsmith 2008; Mano et al. 2016); shorter term or 'laboratory' settings with individual residents rather than more indepth research including the wider networks (Marikyan et al. 2019); within urban rather than rural settings (Aceros et al. 2015; Marikyan et al. 2019); a singular focus on older people's desires to age-at-home (Vasara 2015; Liu et al. 2016); and, lack of acknowledgement that HSH experiences may be constantly unfolding and evolving. As such, there is a literature gap in critical social science research around better understanding what it means to age in a DIY HSH from the perspectives of the older resident and their wider caring networks. There is also a gap concerning how these experiences may evolve over time, especially regarding the sense of home, changing identities and planning for the future within more DIY forms of HSH.

Through this chapter I explore the key areas of literature that contextualise this research. As this thesis examines the experiences of older people living in DIY HSH, I draw on three main bodies of literature: ageing (section 2.1); care (section 2.2), and technology at home (section 2.3). First, in the ageing section (2.1) I provide context to, and for, this global ageing population, followed

by an exploration of how older people are 'framed' and discussed in society and the media (2.1.1), and then of the spaces and places in which ageing takes place (2.1.2). In section 2.2 I explore the literature around care during ageing, with a specific focus on the ethics of care (2.2.1), the connections between care and identity (2.2.2) and the taking place of care (2.2.3). I then offer some considerations on the future of care (2.2.4). In the third section (2.3) I explore the rise of smart and assistive technology within older people's homes (2.3.1), leading to a discussion on the current debates around uses of smart and assistive devices in rural Scotland (2.3.2). In section 2.4, I present my new conceptual framework for encouraging future research and practical development of living with smart and assistive devices that may offer more optimal experiences for older residents. Finally, in section 2.5 I offer some conclusions, highlighting the key findings of the chapter and the key literature gaps which I will address in this thesis.

2.1 Ageing

As is widely understood, globally the population is ageing, due to a combination of people living longer and lower fertility rates (ONU 2015). As people are living longer, they are developing a greater mix of long-term chronic conditions which require professional healthcare management (Harper et al. 2016). Generally, ageing, although biologically a process that occurs throughout the life course, is most frequently used within policy and the relevant literature to refer to the later life stages (Vincent 2008). Ageing has traditionally been associated with declines - in health (Moulaert and Paris 2013), or in mobility and freedom (Vasara 2015). Furthermore, there has been a focus on stigmatisation and attempts at othering (Fealy et al. 2012; Harper et al. 2016). More positive approaches have been taken within policy and the relevant literature and include successful ageing or active ageing; however, they also fuel the processes of stigmatisation and othering towards those older people who are unable to actively or successfully age (Bülow and

Söderqvist 2014). In this section I explore the key debates and discussions around conceptualisations of ageing (2.1.1) and where ageing takes place (i.e., ageing-in-place and otherwise) (2.1.2). I conclude (2.1.3) by arguing that all experiences of ageing should be considered as valid and the importance of place requires further interrogation, regarding the experiences of both older residents and their wider caring networks.

2.1.1 How are older people conceptualised?

There have been numerous attempts to define terms such as 'older people' and 'old age' via particular characteristics or age brackets (Harper et al. 2016). For many years, ageing was discussed in biological terms (Vincent 2008). However, ageing and old age are increasingly considered as socially (and culturally) constructed concepts (Plath 2008), for instance, to be old is partly dependent on your country of residence (e.g., differing pension ages). Or, in some countries and societies, old age is associated with wisdom and increased respect from younger generations (Takahashi and Bordia 2000), whilst in others, it is associated with reliance on others and the State (Bone et al. 2018). There are some attempts to distinguish between the various ages that fall within old age (i.e., the oldest-old to represent those over 85), however, often older people, generally considered to be those over 65, are simply considered as a singular homogenous group, as is critiqued by numerous authors (e.g. Hill et al. 2008; Wiles et al. 2012).

The use and reuse of the phrases 'old people'/ 'old age', particularly in western cultures, have been a means towards 'othering' – painting older people as unproductive and dependent and giving 'rise to the subjectivities that both stigmatise and sustain institutionalised ageism' (Fealy et al. 2012). As illustration, given the focus in western culture on 'productivity' framed within neo-liberal economic ideals, the contributions of older people to society in terms of unpaid or voluntary work is often not recognised, thus pigeonholing them as 'dependent' (Dosman et al. 2006). Ageing has also been adopted within policy domains and reframed to fit certain policy ideals and desires (Jolanki 2009; Neven and Peine 2017). To illustrate, they can be defined as frail and vulnerable, as victims of welfare cuts, or as undeserving or deserving older people (i.e., having 'earnt' their pensions (or not) through hard work (Fealy et al. 2012). This process of defining a group by age neglects to recognise that identity is culturally and historically defined (Östlund et al. 2015), and connected to individual desires and resource availability. More recently, Pack et al. (2019) have highlighted that positive ageing discourses (e.g., those in Table 1) shape how older adults consider themselves, their bodies and others in relation to ageing well. In other words, ageing is considered to be a relational activity which is 'exercised through an expansive set of practices, techniques and technologies' (Pack et al. 2019: 2090). Thus, the acceptability and ability of older people's bodies are key to understanding how they are framed within society.

Others (Amery 1994; Peace et al. 2006) have highlighted that many existing discussions around ageing and older people have painted such people as passive recipients of care, assistance and pensions. Their societal contribution is often framed negatively, given that 'contribution' tends to be considered in solely economic terms. Also, older people are often associated with their past, for instance, ageing-in-place to maintain a continued link to the past and their belongings (Peace et al. 2006). Simultaneously, ageing is not commonly understood as a continuous process (Amery 1994), rather it is constructed as a dichotomy between the young and the old (e.g. independent versus dependent members of society). I present several of these narratives below (Table 1). They represent the range of main conceptualisations of ageing, many of which I will critique throughout this thesis.

Table 1: The main framings of ageing

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Framings	Definition	Benefits	Drawbacks
Structured	The notion of dependency of older	-Recognises the	-Does not award any agency/
dependency	people is socially constructed via	power of external	control to older people.
	pensions and working condition	structures.	-What about those taking early
	reforms. Thus, undertaking paid work		retirement?
	after a certain age is difficult.		
	Key proponents: Pete Townsend		
	(1981).		
Third vs.	Categorises older people as	-Recognises that	-Dichotomy of third versus
fourth age	belonging to either the third (e.g.,	older people are not a	fourth age.
	choice, autonomy and self-	homogenous group.	-Hard to categorise older
	expression) or fourth age (e.g.,		people as fully belonging to
	dependency, decrepitude and death).		only one category.
	The third age refers to recently		
	retired older people who still have		
	adequate levels of financial and		
	health security to enjoy their		
	newfound retirement, before		
	experiencing the negative effects of		
	old age. The fourth age are those		
	further from retirement.		
	Key proponents: Laslett (1994),		
	Gilleard and Higgs (2014).		
Active vs.	Passive ageing considers older	-Recognises the	-Who defines meaningful
passive	people as mainly passive receivers of	importance of active	contributions?
ageing	care and supportor does not	participation in	-Dichotomy of passive versus
	identify them as actors at all. Active	society and life.	active ageing.
	ageing encourages active		-Hard to categorise older
	participation of older people in life		people as fully belonging to
	and thus still 'meaningfully		only one category.
	contributing' to the functioning of		-What about older people with
	society. (Lassen and Moreira 2014).		pre-existing health conditions?
			Can they meaningfully
	Key proponents: World Health		contribute to society?
	Organisation (2015).		
Successful	Successful ageing is the avoidance of	-Recognises the	-Who defines 'successful'
ageing	disease and disability, the	importance of active	ageing?
	maintenance of high physical and	participation in	
	cognitive function, and sustained	society and life, and	-Dichotomy of successful versus
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	engagement in social and productive	the importance of	unsuccessful ageing.
	activities.	good health.	-Hard to categorise older
			people as fully belonging to
	Key proponents: Rowe and Kahn		only one category.
	(1997).		-What about older people with
			pre-existing health conditions?
			Can they successfully age?
Assets vs.	Older people categorised as either	-Recognises the	-Who defines 'assets' and
burdens	assets or burdens to their families,	importance of active	'burdens'?
	communities, and wider society in	participation in life,	-Dichotomy of asset versus
	terms of undertaking volunteering	family and society.	burden.
	roles, designing new community		-Hard to categorise older
	services, offering care to		people as fully belonging to
	grandchildren (Hooyman and Kiyak		only one category.
	2011). Moves to considering age-		
	friendly living and communities		
	promote the idea of older people as		
	potential assets rather than burdens.		
	Key proponents: Wiles and Jayashina		
	(2013).		
Resilient	Recognises older people can	-Recognises that it is	-This still reinforces a
ageing	simultaneously age well whilst living	possible to live well	dichotomy, i.e., ageing
	with challenges. Does not	with challenges.	resiliently or not.
	discriminate due to health condition.		
	Key proponents: Hayman et al.		
	(2017).		

In this table I highlight the main conceptualisations for ageing and although each offer slightly different angles, most of these conceptualisations still focus on activity level as a measure of success within ageing. They also have numerous drawbacks relating to encouraging feelings of disempowerment and reduced wellbeing. Although there are numerous definitions of empowerment (Ridgway et al. 1994; Zimmerman 2000; Adams and Adams 2008), I consider it a

process 'by which people, organisations, and communities gain mastery over their lives' (Rappaport 1981: 122). Disempowerment then, is the absence of this mastery.

Ultimately, I argue these categorisations are not a helpful or productive way to understand the experiences of older people. It is, however, important to recognise them as a prominent way in which older people are understood and discussed within society. The framings of older people (Table 1) serve to highlight certain aspects of ageing, whilst drawing attention away from others, such as the non-economic benefits that older people can bring to society (Wiles and Jayasinha 2013). Often the biological effects of ageing (Vincent 2008), coupled with the wider structures in society (e.g. forced retirement, low pensions) dictate that older people become more dependent on others as they age. This can often compete with a desire to, drawing on Goffman (1971), present oneself as still as capable as in younger days, or to fulfil the criteria of a good older person (i.e., in ageing actively or successfully). However, such framings are narrow and difficult for older people to adhere to (Fealy et al. 2012), as people do not easily fit into preconceived boxes.

Resilient ageing is most convincing to me as it enables people to simultaneously age well and suffer hardships and allows for the inclusion of older people with ill-health or disabilities, which is not possible in most other framings. However, it also creates another dichotomy (i.e., resilient vs non resilient ageing). It is also vitally important to recognise the strong power dynamics that are at play within some of the dominant framings around older people (Fealy et al. 2012). All of these categorisations neglect to recognise that older people can be identified by more than one construct at a time, or their identity may change as they continue to age, for instance, their role at home changes (George 2003) once they are no longer required for spousal care or to look after the grandchildren (Hooyman and Kiyak 2011). However, these changes are still framing

identities in connection to activity level. As such, I do not adopt any of these framings within this thesis but do recognise the importance of awareness of them regarding furthering stereotypical and dichotomous views of older people.

This connects to Fealy et al.'s (2012) 'apocalyptic demography' in which older people are a problem and burden on society simply for living longer. Relatedly Neven and Peine (2017) have argued that such an apocalyptic notion of ageing and older people (i.e., disregarding any positives of ageing) legitimises the path for a narrative in which ageing and older people's health burdens can be solved by innovative means. Thus, several of these narratives can be understood as attempts to legitimise this responsibilisation, whereby older people are impelled to take increasing individual social and economic responsibility for their health and social care.

A consideration of Goffman may be useful when reflecting on aspects of older people's identities, particularly in recognising links to power and control that can manifest when considering the popular and powerful depictions of ageing (Fealy et al. 2012; Peine and Neven 2020). Thus, Goffman's ideas lend themselves well to studies around privacy and the home and may be especially useful to understand the impacts of multiple audiences and competing relationships within these settings. Through Goffman's (1971) dramatrugy approach, he argued that individuals perform their lives as though they were actors in a play. Within these plays, actors have on-stage roles or performances in public spaces (in which they, to perhaps varying degrees of awareness, modify their behaviour because they know they are being watched), and backstage performances in which individuals can 'drop their mask' and behave more naturally. Within these backstage spaces, actors know they are no longer being watched by an audience, i.e., in the home or other private spaces. For such performances to be convincing, four aspects are necessary: 1) a specific setting which represents the scene that enables the actor to perform

(e.g. an older person living in a DIY HSH); 2) appropriate appearance of items and equipment that are necessary for the performance to be convincing (e.g. an older DIY HSH resident would need to appear simultaneously old enough, capable enough to use the devices, and dependent enough to require the devices); 3) manners that highlight how the performer will conduct themselves and what the audience should expect from the performance (e.g. an older person would need to interact with the devices appropriately); and 4) the existence of a backstage where only performers and no audience is present. The front-stage portrayals of different roles are known as dramatic realisations (Goffman 1971). These are often idealised performances of aspects of their character they want to share with an audience.

Burrows et al. (2018) adopted a Goffman-inspired framework to understand how people negotiate new borders and boundaries created by smart and assistive healthcare technologies within the homes. They found that boundaries within the home (i.e., degree of privacy and control in the home) were being permeated due to lack of control of the interpretation of information generated about themselves and their households by their healthcare technologies. Given this lack of privacy it was difficult to know where the boundaries of the front and back stages fell. Meanwhile, Marson and Powell (2014) discussed the 'infantilisation' of older people within residential care settings, whereby older people are treated as child-like in their abilities. This study also highlighted how older care home residents tried to meet caregivers' expectations in fear of otherwise losing quality care. Furthermore, care recipients and caregivers had different impressions of their care interactions. Burrows et al. (2018) called for further research with wider caring networks, whilst Marson and Powell (2014) called for their findings to be tested within non-total institution settings (i.e., the private home rather than a care home). In this research 1 aim to answer both calls and address the issues of multiple audiences apparent through smart and assistive devices. Goffman (1971) recognised there is not always a singular

audience, and thus different performances and behaviours can be promoted for different audiences.

Before continuing it is important to address my conceptualisation of ageing and older people. Within this thesis, I use the phrase 'older people', not as a means of othering, but to recognise that age is a continuum where people are only younger or older regarding their relationship to others and the appropriateness of their spaces and places (Andrews et al. 2007; Wilton and Hall 2012). I argue that considering ageing through a more geographical and place-based lens (Currie and Philip 2019) may allow for greater recognition of the lived experiences of ageing, rather than a crude measure that attempts to categorise people by their reliance on the state or their numerical age. These various framings of older people, and particularly how older people present themselves to others, are also connected to the spaces and places in which they live. I now explore the key debates and discussions around the 'taking place' of ageing.

2.1.2 Where does ageing take place?

It is important to consider the various geographies of ageing, concerning where ageing occurs, and the various ageing impacts that these multiple spaces and places encourage. In this study, ageing is considered from the spatial perspective of an older person living in their own home, within a rural community. Cristoforetti et al. (2011: 225) define space as 'an objectively identifiable context, while *place* is described as a result of subjective re-involvement processes characterized by instability, mobility and continuous creativity'. The two are not interchangeable (Easthope 2004). Places are constructed through the social interactions and processes that occur within them, rather than being static entities (Thrift 2008). As such, a house does not necessarily translate into a home (Marcus 2006). In other words, perhaps the house can be considered as more of a space and the home as more of a place, in that the emotional connections and sense

of place are stronger toward the home than the house. The following subsections will highlight this geographical angle in terms of places for ageing (2.1.2.1), and an exploration of 'ageing-in-place', including the rural specificities (2.1.2.2).

2.1.2.1 Places for ageing

Places are socially constructed areas that are capable of change (Cristoforetti et al. 2011). For Massey (2005), place is a constant flux comprising of social networks, relations and processes that are continually interacting. Massey (2005) also argues that place is considered as a form of event, and the relationality of a place is key, regarding how individuals relate and connect within these places. As such, places can be shaped by society and vice versa (Valentine 2001). Places can increase in importance as people age when their opportunities for social interactions may diminish, for instance, post-retirement (Ewen et al. 2014), after a bereavement (Lowe 2011), or if family members move away (Anderson et al. 2018). Drawing from the field of emotional geographies, there are links between the levels of emotional wellbeing and connections to a particular place (Davidson and Milligan 2004). These may also change over time. As such, the idea of having a good 'sense of place', can provide a sense of belonging and of comfort (Easthope 2004), whereby our wellbeing can be shaped by our connection to a particular place (Horsfall et al. 2017).

Tuan (1980) considered places through topophilia, which is the affective bond between people and place, wherein the bond that people have to a place can help to change a place. This links to scholarship within emotional geographies whereby the body is the 'most immediate and intimately felt geography... [as] emotions, to be sure, take place within and around this closest spatial scale' (Davidson and Milligan 2004: 523). Meanwhile, scholars including Scott (2012) and

Ingold (2000) have focussed on the communal element of place. Scott (2012) emphasised the collective and community element within the idea of 'place', focussing on the communal idea of 'place-making' over time rather than 'place' itself. Similarly, Ingold (2005: 501) emphasised dwelling as 'a way of being at home in the world'. These discussions also connect to the subjectivity of a place (Ivinson and Renold 2013), whereby it can be experienced differently by each individual. This could be the subjectiveness in the sense of home derived from a place (Downs and Tuan 2006) or the extent to which a place feels rural (Halfacree 2006). Such subjective experiences can also relate to individual identity. Lengen and Kistemann (2012: 1162) found that sense of place 'comprises emotional bonds with places, with values, meanings and symbols of places, that are actively and continuously constructed and reconstructed within individual minds'. Although highlighting the importance of identity, they fail to recognise the role of wider networks and relationships in moulding these identities. Looking specifically to ageing, Andrews et al. (2007) highlighted that often place is treated merely as the context within which ageing occurs rather than recognising that places are made and remade in tandem with their inhabitants and wider communities. Also, I argue that places are a key factor in identity formation for older people. Furthermore, these homes are not necessarily comfortable, pleasant or even places with privacy. This idea of 'sense of place-making' is pertinent to this thesis whereby the notion of home can be continually transformed through interactions with multiple caring network members and smart and assistive devices under the guise of care.

Through their serious game methodology, McCall et al. (2020: 30) found that 'sense of place and belonging is articulated through the availability and accessibility of facilities and opportunities for active living, social participation and meaningful involvement in the community'. Moreover, promotion of sense-of-place and place-making highlight that places do not exist in isolation; they are shaped and influenced by multiple economic, social and environmental factors. The

concentration (from multiple angles and sectors) on ageing-in-place, which builds on the idea of a sense of place (Rose 1995) can satisfy the desires of older people who wish to feel empowered by living at home for longer (Milligan 2009), live in their communities for longer (Dowds et al. 2018) and reduce the economic and physical burden on health and care services (Kim et al. 2017). Without opportunities for rural ageing in place, older people would likely need to move out of their communities and into care homes (based outwith their communities) (Anderson et al. 2018). This is generally different to urban areas where moves to a care home would likely not constitute simultaneous moves out of their communities (Currie et al. 2015). For McCall et al. (2020), the preservation of empowerment is a goal of maintaining this sense of place through ageing in the right place. Thus, the connections between sense of place and empowerment can be very important and deserve further interrogation within this thesis.

2.1.2.2 Ageing in (the right) place

Ageing-in-place has recently emerged as an alternative to residential or infirmed care (Dyck et al. 2005), and as a way to sustain communities (Abramsson and Hagberg 2018), a sense of identity (Cristoforetti et al. 2011) and independence (Rubinstein and Parmelee 1992). The home as the site of ageing, especially within a policy context, is assumed but not made explicit within the discourse. Horner and Boldy (2008: 358) define ageing-in-place as a 'positive approach to meeting the needs of the older person, supporting them to live independently or with some assistance, for as long as possible'. Ageing-in-place can also enable more localised healthcare and active involvement of patients in their health and social care (Hillcoat-Nallétamby and Ogg 2014), and less reliance on public funds (Vasara 2015). With the rise of alternative models of health and social care provision such as telehealth and telecare (Golant 2017b), ageing-in-place has become more popular and routed within health and social care policies (Aceros et al. 2015), particularly in the global north (Sixsmith et al. 2017).

Older people's independence has been promoted as connected to continued home living by encouraging 'continued competence' (Rubinstein and Parmelee 1992: 140) and sense of identity as 'attachment to key former places is one way of keeping the past alive' (Cristoforetti et al. 2011: 226) through maintaining a sense of home and community. Within ageing-in-place, residents may be able to better support their own needs for 'dignity, independence and personal identity' (Forlizzi et al. 2004: 39) through living at home. Simultaneously, patient empowerment has often been advocated for with home-based, rather than hospital-based care (Schildmeijer et al. 2018), thus, potentially increasing the responsibility of an individual and their network in ensuring healthcare needs are met. Such approaches may be particularly helpful within rural communities where health and social care provision costs can be comparatively higher than in urban areas (Currie and Philip 2019).

Concurrently, other authors (Dewsbury and Linskell 2011; Liang and Luo 2012) have noted the potential risk of disempowering those individuals who cannot, or do not, successfully age at home, but rather receive substantial care in a hospital. Furthermore, Hillcoat-Nallétamby and Ogg (2014) point out that even if remaining at home is the older person's preference it may not be good for their wellbeing. Additional stress may be experienced as household tasks become more difficult (Fausset et al. 2011), as health and functional abilities decrease (Rubinstein et al. 1992) or as family roles change (e.g. grandchildren no longer rely on grandparents for support). These impacts may be experienced differently by individuals. Moreover, the decision to remain at home and age-in-place may not always be a choice (Vasara 2015). As such, certain authors have begun to discuss ageing in 'the right' place, rather than simply ageing-in-place. Golant

(2017a) argues that older people have often had to make do with less than favourable living conditions as they age, due to poorly implemented solutions or places which do not meet all of their needs. Ageing in the right place moves away from the assumption that staying put is always the right course of action, recognising that moving to tailormade smart homes (Golant 2017b) or community-based housing (Sixsmith et al. 2017) for instance may offer better experiences for ageing. However, in reality these 'right places' are not yet available on any great scale, leading to DIY versions which does not necessarily address all of the needs of older people.

Relatedly then, ageing-in-place can be viewed as idealised and romanticised (Anderson et al. 2018), but also a product of increasing the neoliberalised responsibility on (global north) individuals and communities, under the guise of community empowerment (MacKinnon and Derickson 2013). This is especially true within rural areas which until recently have been romanticised as places 'where civic harmony and inclusion triumphs and there is little room for power struggles, exclusionary tactics by privileged groups or ideological conflicts' (Shortall 2004: 110). However, in reality, this is not always true. As such, this narrative may be disempowering for some rural residents who do not experience this idyllic lifestyle.

The rise in ageing-in-place (at home) has prompted further discussions on the relationship between space and place, particularly when proposed alongside new health and social care practices (which have different requirements for users compared to traditional passive health and social care services and require a new set of skills and knowledge both in terms of use and provision). Policy and literature on ageing-in-place tend to characterise the place (e.g. the home) as a site of refuge, however, the inclusion of healthcare in the home may alter this idea as healthcare is associated with pain and heightened emotions (Dyck et al. 2005). Considerations of the benefits and feasibility of ageing-in-place need to be wider than merely housing e.g., consideration also needs to be given to transportation, recreation opportunities and amenities that facilitate social interactions (Wahl and Weisman 2003). There are also specific issues for rural ageing-in-place regarding access to resources and the digital divides. These challenges may make rural place-making (Currie and Philip 2019) simultaneously more difficult but also more valuable.

It is also important to recognise that ageing well may ultimately not always be possible within rural areas, particularly those that are very remote. Ageing-in-place should not strive to 'return to some imaginary past where people were nicer to their neighbours and the land flowed with milk, honey and social capital' (Skerratt and Steiner 2013: 335) and rather should recognise the complexities of community development and resilience (MacKinnon and Derickson 2013), especially within rural areas. More optimistically, exploring ageing through this place-based lens (Currie and Philip 2019), can be beneficial in identifying some of the intricacies and specificities of rural life, such as those specific to DIY HSH living. McCall et al. (2020) too have called for a focus on a place-based approach to planning within housing decisions related to ageing. Thus, there is justification for such an approach.

Finally, places and the connections that residents derive from them are important when promoting innovations to enable, or discourage, ageing-in-place. Without this recognition, there will be little consideration of the diversity of inhabitants' needs from a place. Recognition of such diversity will enable greater recognition that homes can be sites of conflict, especially when a major motivation of 'ageing-in-place' is due to lack of alternative desirable forms of care within ageing (Lowenstein 2009). Such diversity can be individually specific, but it can also be geographically specific, for example, to the needs of rural areas, or a particular country, in this case, Scotland. Ageing-in-place may also offer a more useful frame through which to

conceptualise ageing, regarding the appropriateness of place rather than the potential inability of the body.

2.1.3 Ageing Summary

Within this section on ageing, I highlighted how ageing and growing older has moved from a biological idea to a series of socially-constructed notions in which various framings and considerations of older people can be used to meet a specific aim. Within this thesis, I contest various framings of ageing (i.e., section 2.1.1), instead arguing that these offer dichotomous stereotypes of ageing. Instead, all experiences of ageing should be considered as valid, and as moulded through their relationships with their wider caring networks. However, I recognise these pre-existing framings of ageing may be prominent within the wider promotion of smart and assistive devices. I call for future research and discussions on ageing to utilise a more productive use of language (i.e., not stigmatising). Productive language will form the base of my proposed conceptual framework (section 2.4).

I highlighted the numerous spaces and places through which ageing occurs. These can change over time or as our desires and needs may change as we age. Particularly in western societies, there have been increased moves towards a consideration of ageing-in-place, at home, as the ideal. Yet there are important critiques of ageing-in-place regarding the role of the surrounding relationships, and interrogation of the place as more than the setting for ageing. Although this is slowly changing, a literature gap remains in considering the importance of the place and how this may change over time, various geographies or between connected individuals. This highlights the importance of RO1 (meanings of home within older people's DIY HSH experiences) and of a sense of home in creating optimal experiences of DIY HSH living for older people.

Important too is a consideration of the relationality of these DIY HSH living experiences regarding strong and positive relationships with place and people. Sense of home and relational living will take a prominent role in my proposed conceptual framework (section 2.4).

With any discussions on ageing, it is important to highlight the intertwined discussions on care. Discussions on and considerations of care are key within this research, be this informal or formal health or social care from person or device, a product of a lack of in-person care or a desire to have more involvement in one's healthcare. Such discussions of care are not timeless, so there is a need to consider and plan (care) for the future. I now explore these discussions.

2.2 Care during ageing: planning for the future

Within this thesis, a consideration of care is important. By this, I mean care regarding how older people and their wider networks look after each other as they age and consider the future, which is what this section will consider. Also important is the role of technology within decisions around the future of their care and more specific considerations of how care is enacted within communities and the home. First, I explore the context of care and caring (2.2.1), including definitions of care, expectations and anticipations of care, and connections to an ethics of care. Next, I consider the connections between identity and care practices, for both older people and their wider caring networks (2.2.2). Then, I specifically explore the literature on the spaces and places within which care takes place (2.2.3). Subsequently, I explore the narratives and literature around care in the future and future carescapes (2.2.4). Finally, I conclude that this thesis should be conducted through a place-based ethics of care lens to acknowledge a literature gap on the potential importance of relationships and identities within caring practices (2.2.5). DIY HSH experiences are one such practice.

2.2.1 What is care and caring?

There are multiple meanings of care (Paulsen 2011; Hooyman and Kiyak 2011). Care can represent feelings of affection and love (Held 2006), or a physical action towards friends and family members (e.g., offering assistance with daily tasks) (Power and Hall 2018). It can be performed on the self (e.g., self-care activities including yoga or meditation), or on somebody else (Dyck et al. 2005). It can be paid (i.e., formal care work) or it can be voluntary and undertaken by friends and family (i.e., informal care work) (Beer and Owens 2018). There is often a gendered aspect to the provision of care (Hooyman and Kiyak 2011), with most care work undertaken by women for free out of a sense of 'duty' to their children or parents. Even the establishment of the NHS relied on women taking on most of these care needs (Cottam 2019). As more women re-entered the workplace full-time there was increasing pressure on health and social care services to provide 'care' to greater proportions of society. Hence the increased attention on the potential of smart and assistive health technologies. Simultaneously with globalisation, care jobs (e.g., working in homecare and social care settings) were increasingly carried out by women from the global south countries (McEwan and Goodman 2010).

Societal acceptance of care as a term, value and practice has been very normative (Broese van Groenou and De Boer 2016) as it fits with the need to have older and younger generations looked after, for free or cheaply, without considering any further nuances. The term is widely contested by those who provide and receive care as it stigmatises people according to their capabilities and value to wider society (Katz 2000). Both receiving and undertaking care work

has been linked to feelings of disempowerment (Selman et al. 2016; Francescato et al. 2017). Kusmaul et al. (2020) used an organisational theory of empowerment to examine whether home care workers experienced empowerment through their jobs. Their findings demonstrated aspects of disempowerment and strategies to improve empowerment. However, Kusmaul et al. (2020) did not consider the (dis)empowerment of non-formal home care workers, instead focussing on paid and formal care workers. Also, disability studies researchers are critical of the term 'care' as it conceptualises disabled people as dependent and non-autonomous citizens (Kröger 2009). I argue that similar conceptualisations may be true of older people. This is also an interesting literature gap for this thesis.

Care work, especially informal versions, is often viewed as less important than work performed outside the home. It is often lower-paid or even unpaid and hidden. Simultaneously, there has been a reduction in public funds for those in need of care and support coupled with an increased need for care. This has led to a care deficit (Nguyen et al. 2017), and an increase on non-formal care provision. Ethics of care, which promotes the importance and interdependence of the caring relationship (i.e., between care giver and receiver) (Noddings 2002), is an important field of literature for this thesis. These roles are stigmatised within the neoliberal society (McEwan and Goodman 2010) as unskilled and secondary to those (predominantly men) who 'go out to work' and generate additional monetary value for society. This so-called 'women's work' (Kim 2010) is, however, fundamental to wider society in enabling work outwith the home and reducing the care burden on the wider society through informal care for one's family. As Folbre (2001: vii) attested, 'the invisible hand of markets depends on the invisible heart of care'. Care is a contentious and politicised term and arena, and multiple scholars such as Tronto (1998), Tronto and Fisher (1990) and Noddings (2002), have called for a consideration of an ethics of care rather than simply a consideration of care. Up until this point, care was mainly considered

as actions by autonomous individuals. However, the ethics of care highlights the importance of relationships and community within care.

Within ethics of care, people are relational and interdependent rather than distinct individuals who form relationships. People care for others not fully out of duty or altruism, but to preserve and foster good-quality human connections and relationships. These relationships can also be more-than-human as care is not simply something that is enacted by humans, but can be built through relationships with technology devices for example (Puig de la Bellacasa 2017). Care, in terms of building relationships, also serves as identity work as it builds and cements an individual's idea of themselves (self-identity) and the identity that they wish to portray to others.

There is a difference between care as a practice and a value. As a practice, care is labour. As a value, care is also a relationship (Held 2006). For Held (2006: 33), 'some caring relationships seem to have significance in excess of the labor they enable'. Those focussing on care ethics (Tronto 2005; Popke 2006; McEwan and Goodman 2010), highlight that care as a practice and a value should not be considered as an activity in itself, but a way of relating to others and a fundamental aspect of human life (Tronto 2005). Care as a practice and the crises of care (Kim 2010), just like ageing conceptualisations, have also created several boundaries and dichotomies in terms of how it is portrayed, i.e. public versus private care, within or outwith the home, via paid or unpaid sources or formal or informal carers (McEwan and Goodman 2010). The same is true for the promotion and distribution of technology for care whereby certain options are promoted or restricted to certain groups, dependent on age, social status/ degree of wealth, health condition severity or geographical condition. Such boundaries can also create hierarchies within existing and new relationships, in which emotional connections can be overly relied upon to offer care in response to a lack of alternative options. Furthermore, there are the impacts this

may have on informal carers regarding their wellbeing and subsequent experiences of employment (McKie et al. 2002) or family life. Care practices that are produced by and legitimised by pre-existing emotional connections are also sites of power (Lawson 2007), as they rely on these emotional connections to cement these informal and unpaid care practices. This then re-legitimises the care profession as unskilled and of low societal importance. I argue this reliance on informal care is simultaneously strengthening the view of care as relational, but also diminishing it as focussing on individuals. Most current use of smart and assistive devices at home is primarily based around devices from private commissioning sources which are fitted and maintained by informal caring network members, further stigmatising care as a personal rather than societal or relational pursuit. For England (2010), proposed solutions to the care crises, such as the use of smart technologies for health, are a product of the focus on neoliberalisation of spaces of responsibilities and care. The focus is on individual solutions and problems. In reality, people are comprised of multiple networks and levels of care. In other words, no one is fully independent.

With this in mind, this thesis adopts a critical approach to the ethics of care. Utilising a critical ethics of care lens enables focus on the relational and the story at hand, rather than the universal, abstract and theoretical (Ellis 2007) which is important for this thesis, in which I aim to better understand the long-term experiences of a small group of older DIY HSH residents and their relationships with their wider caring networks. Links can also be made between care practices and identity formation, as is now discussed.

2.2.2 Care and identity formation

Given the stigma that can exist with undertaking care practices, the connections between care and identity are important to highlight here. Identity 'relates to a sense of belonging, appreciation by others, and a positive construction of the self' (Bowes and McColgan 2013: 43). However, for older people, this sense of identity can be restricted within the positive and successful ageing agenda (e.g., as critiqued by Katz (2005)) and other societal understandings of older people (i.e., Table 1). Care routines can further restrict the abilities to positively and fully construct the self when older care recipients need to fit within carer schedules. Bowes and McColgan (2013) found that telecare could improve the potential for identity formation for older telecare users as they were less restricted by physical care schedules. Furthermore, they called for further telecare research exploring the specific 'contextual factors beyond the intrinsic capacities of a technological system and beyond the models of care developed' (Bowes and McColgan 2013: 46). This highlights the potential novelty of my research which explores these specific contextual factors. Additionally, Bowes and McColgan (2013) neglect the experiences of identity formation on the care workers, and the potential for identities to be specifically impacted by the digital health devices. Goffman's (1971) dramaturgy approach has been used to explore how people present themselves in online settings through editing a particular version of themselves (Bullingham and Vasconcelos 2013). These portrayals may impact the identity formation capacity, and the ability to develop feelings of empowerment, of both care recipients and care providers within the homes. Thus, there is an important angle here concerning undertaking informal or formal labour in private and emotionally driven settings which is now discussed.

2.2.3 Where does care take place?

In this section I highlight the existing literature that relates to the taking place of care in this thesis, namely the home, and digital spaces and places. The majority of care practices and labour occur within home or home-like (i.e. care home) settings, however, this impacts on the boundaries of places and spaces (Dyck et al. 2005). As England (2010: 134) attested, 'paid work in the home unsettles these idealized notions of home' because the home is mainly viewed as a site of non-work. There are emotional complexities associated with undertaking paid care work within someone else's home, as this is a space full of feelings, emotions and ideals.

Care provision within rural areas can be complex due to their vast geographies (Currie and Philip 2019). With the care deficit, formal care is increasingly delivered over increasing distances, meaning that care recipients have to travel greater distances for their care (Currie et al. 2015), pay a premium price for their care (Bailey et al. 2009), or move to a more urban area or into a residential care setting (Vasara 2015). Informal familial care is often more difficult to administer because children often live at greater distances from their ageing parents (Hine 2019). Relatedly, rural areas are often unrealistically considered as ideal and idyllic areas to live, particularly into older age with many people retiring to rural areas (Anderson et al. 2018). However, these geographical issues can have a particularly profound impact in terms of distance from hospitals or waiting times for ambulances (Currie et al. 2015).

With increasing desires to age-at-home and reduced funding of social care sectors, especially within the global north, there have been heightened attempts to alternatively offer care through smart and assistive technologies (Bennett et al. 2017). However, physical carers are still needed to undertake, control and maintain their technology devices. For instance, Hine's (2019)

autoethnography highlighted her role as an informal carer for her mum for smart device management. This care can be undertaken by the older resident, or via informal or formal care networks, which could include other residents within the home. Care can take place within almost any setting, but within the boundaries of this research, care takes place in several different, but overlapping spaces, or what Milligan and Wiles (2010) consider as landscapes of care, specifically: the home, rural areas and virtual spaces. As such, the boundaries of these spaces are permeable (Burrows et al. 2018; Maalsen and Dowling 2020), which may be particularly evident when planning for care in the future. This is important because the experiences of these spaces may connect to the types of futures that DIY HSH residents, and their wider caring networks, can envision (i.e., depending on the types of smart and assistive devices available or the appropriateness of the housing). These settings of care can also be defined by what McKie et al. (2002) consider as carescapes in which spatial and temporal characteristics are important. Bowlby (2012: 2110) utilised the 'metaphor of a terrain to illustrate the ways in which a person might think about current and future caring activities over their lifecourse'. They argue that caring activities directly correlate to many life decisions which are affected by both past experiences of caring and anticipations for the future. This all highlights another literature gap regarding the competing and increasing spaces through which care is enacted through DIY HSH, including a focus on the relationships and experiences of both older residents and their wider caring networks.

2.2.4 Care in the future

Discussions around care and ensuring an ethics of care relate to controlling and managing risks, as does planning for the future. In this thesis, this concerns, 1) ensuring adequate spaces and numbers of staff in the future as our populations age (Powell et al. 2016), 2) reducing the risks

of further overwhelmed health and social care services, 3) ensuring smart and assistive devices are well received by older people and their wider caring networks, and 4) the risks of disenfranchising and disempowering older people and their families by awarding them too much or not enough responsibility in their healthcare.

Discussions around empowerment also play into this future with technology-enabled care, whereby it is empowering for the recipient and their wider caring networks to have greater say in their care decisions, regarding the type (i.e., digital or in-person) and location (i.e., home or hospital) of their care. Empowerment is considered to be an important outcome of ageing-inplace and being able to receive any care in the confines of one's own home, as it suggests greater control over one's healthcare and housing desires (Aceros et al. 2015). Others (Lê et al. 2012; Liu et al. 2016) have argued that this may simultaneously be disempowering individuals who age elsewhere, such as within infirmed care (Aceros et al. 2015). Furthermore disempowerment may be experienced if there is disagreement between decisions concerning future care or, for instance, what if the patient/resident, family members and doctor disagree on the next steps whose view is adhered to (McAllister et al. 2012). Particular instances may arise concerning discussions on ideal, and less than ideal, deaths and dying (Brennan and Letherby 2017; Horsfall et al. 2017). Such ranging discussions of anticipations have been coined by Anderson (2010) as 'anticipatory actions' concerning how futures are anticipated and acted on. Anderson (2010: 793) calls for 'a greater reflection on the assumptions about the future that are embedded in our extant habits and techniques of thinking'. Anticipatory action is an important but paradoxical process whereby 'a future becomes cause and justifications for some form of action in the here and now' (Anderson 2010: 778). Within my research, the future can be understood as the negative aspects of ageing, and the anticipatory action is the readjustments made to reduce their impacts, for instance, lowering the expectations of our capabilities as we age, or even moving into a DIY HSH. Anderson (2010) argues that these futures are anticipated and acted on through the assembling of styles, practices and logics. Styles are the series of statements through which the abstract future is understood. Practices include acts of performing to realise these futures. For Anderson (2010), practices are either conceptualised as calculating, imagined or performing futures. Calculating futures occur through a range of modelling techniques including impact assessment, trend analysis and data mining to make present otherwise indeterminate or uncertain futures. Imagined futures are the representations of possible futures through visioning, scenario planning and forecasting (Anderson 2010). Whilst performing futures embody an 'as if' future through acting, simulations or war games. Logics are actions that aim to prepare or pre-empt specific futures (i.e., the actualised DIY HSH). Simulations or logics could include DIY versions of HSH to pre-empt a future without HSH living. Anderson's conceptualisation, although helpful, neglects to discuss the impacts of simulations, as actions of performing futures, becoming real-world futures.

Simultaneously, discussions of the future of care are often framed around apocalyptic geographies (Fealy et al. 2012; Neven and Peine 2017), whereby smart technology is touted to seamlessly fill the gaps and worries of the current care crisis. The potential use of such technology needs such a crisis of care to exist for technology to legitimise its potential future position and role (Neven and Peine 2017). In this narrative, technology is positioned as the utopian solution to the dystopian alternative of the impacts of the care crises. Such utopian discussions revolve around a consideration of hope. In other words, hope for a better future than one without care technology. For Bryant and Knight (2019) hope is something that does not presently exist but potentially could; hope is based on more than a possibility and less than a probability. In the context of this thesis, HSH are critiqued as a (potential) hopeful means for living at home aided by digital devices rather than personal care. They are pitched to reduce an

older person's burden on both their families and the State. However, as McCall et al. (2020: 28) ask, 'how do you plan for the future while addressing immediate chaos?'. Immediate chaos in this thesis could be health conditions, a home move or changing capabilities or relationships. Thus, understanding the potential role of anticipating the future is vital.

2.2.5 Care summary

This section has drawn on ethics of care and future studies literature to highlight the current state of the art on care literature and discussions around care. I highlighted that the history and rise of 'care' and the negative connotations and stigma that have emerged from a classification of care work as lower value to society. The care deficit has led to a blending of care labours, further stigmatising caregivers and care-recipients. I drew on sociology and geography of care literatures, and hence frame this thesis within a geographical place-based ethics of care lens. I also highlighted the key discussions relating to the carescapes of this thesis - the home, rural areas and virtual spaces. In terms of literature gaps, I highlighted gaps around the potential importance of relationships, empowerment and identities within caring practices, and the conceptualisations of older people within DIY HSH living. In this thesis I begin to fill these research gaps and highlight the potential importance of relational living, in connection to an ethics of care approach and spatial considerations of DIY HSH living. These concepts will take a prominent role in my proposed conceptual framework (section 2.4). Ultimately, the current discussions and expectations of care relate to two areas -1) preparing for various futures, and 2) managing and preventing risks including death – both in regard to the use and promotion of smart and assistive health technology in the home.

2.3 Technology in the home

The home, as a category distinct from housing, is considered by many (Dupuis and Thorns 1996; Lowe 2011; Clapham et al. 2012) as the place where we define ourselves as individuals. Thus, the home is a concept with multiple meanings. For some it is a site of safety and sanctuary - a retreat from the outside world (Lowe 2011); for others, it is an emotional state rather than a physical space (Cristoforetti et al. 2011), as a place to store their sentimental or traditionally valuable possessions (Miller 2001). Some view it as a place to build relationships, and others as a site of loneliness (Miller 2001; Sixsmith and Sixsmith 2008). Thus, the home does not always denote a positive place, it can also be a place of disempowerment if the home is no longer fitfor-purpose (Imrie 2004), a place of violence (Chapman and Hockey 1999) or pain when connected to home healthcare routines (Milligan 2009). More recently, through the COVID-19 lockdown, the home has become simultaneously more prominent as a place to shelter or quarantine from, or with, infection (Maalsen and Dowling 2020), but also a place for strained relationships or abuse (Sacco et al. 2020). For others still, the home, especially if it is owned by the resident, offers economic security regarding an 'alternative pension' (Lowe 2011; Colic-Peisker et al. 2015). Yet generally, the home is accepted within social science and housing studies literatures as more than the house. Such an understanding is particularly important with the inclusion of technology in the house/home as it may impact on a resident's sense of home. In this section I first highlight the context through which smart technology has arisen in the homes of older people (2.3.1), and then through healthcare technology in the home. Next, I offer some discussion on the rural specificities of technology in the home (2.3.2). Finally, in section 2.3.3, I conclude that several literature gaps remain around the sense of home by older residents and their wider caring networks within DIY HSH living, which may change over time.

2.3.1 Technology within older people's homes

HSH have emerged in recent years, although mainly to date in laboratory (Marikyan et al. 2019) or single-user or single device settings (Aceros et al. 2015), as a new form of 'smart home'. It is firstly important to consider and critique what is meant by 'smart technology' (2.3.1.1) and 'smart home' (2.3.1.2) within the existing literature. I then explore the rise of DIY HSH for older people (2.3.1.3).

2.3.1.1 Rise of smart technology use

Once reserved for the wealthier segments of society, smart devices such as Siri, Alexa and the smartphone, are generally becoming more affordable and available (Strengers and Nicholls 2017) to wider proportions of society. The concept of 'smart' has many connotations such as – intelligence, or specifically concerning connectivity or networkability (Berlo 2002), or technology devices such as smart televisions (Lyons 2018). Others still have argued it is a notion driven by corporate interests and power to promote certain political agendas (Neven and Peine 2017), means of surveillance (Sadowski 2020) or economic efficiency e.g. smart energy meters (Horne et al. 2015). Given the multitude of connotations of 'smart', this has created difficulties concerning its understandings and applicability (Boait et al. 2017; Gram-Hanssen and Darby 2018). So the term can be applied to multiple contexts and sectors, including the fields of energy efficiency, entertainment or safety (Boait et al. 2017; Gram-Hanssen and Darby 2018). Darby (2018) highlighted that the devices to which the term smart is applied vary greatly concerning the relationship between the devices and the user. Furthermore, she highlighted the time-sensitive nature to smart technologies as what is currently 'smart' may not be similarly considered so in five years' time. Rather, devices should be considered as smart for their time.

Thus, future research needs to recognise how these definitions of smart, and motivations for use, may change over time.

Smart devices include those perceived as social or entertainment objects, e.g., smart televisions, those for lower carbon-footprints or costs, e.g., automatic lighting or smart energy meters, or for healthcare, e.g., motion sensor and automatic pill dispensers. Given the range of smart devices, their motivations for use may change over time or not be so clear cut (Strengers and Nicholls 2017), for instance, smart wearable technologies (e.g., Fitbits) may be used for both healthcare monitoring and entertainment. These benefits of energy efficiencies, healthcare monitoring and entertainment have been widely discussed in the literature (Wilson et al. 2017; Strengers et al. 2019), however, more critical social science accounts of these technologies are emerging, including the creation of new forms of (more transactional) relationships (Goulden 2019), and the creation of new forms of silences, with smart technologies running (apparently seamlessly) in the background making work invisible (Hine 2019). Thus, the boundaries for what characterises a piece of technology as 'smart' are not fixed and there is flexibility regarding the (un)intended uses of such technology. This is also known as interoperability or re-appropriation of technology (Strengers and Nicholls 2017), whereby technology is used for different purposes or not used at all.

The use of smart devices necessitates the creation and collection of increasing amounts and types of data for an individual. Smart devices may collect and analyse data on numerous aspects of an individual's life and routines including activity levels, food habits, and viewing habits, to create digitalised versions of individual users which, in theory, can be scripted. This collection of data and surveillance of life has been coined as data colonialism, whereby social life is captured as new territories of accumulation and in extending the normal domains of digital markets to everyday life (Goulden 2019). So, there may be a reworking of society to make it more suitable

for economic markets, e.g., the collection of data for more appropriate advertising or even an addiction to collecting fitness data. This surveillance capitalism 'knows everything about us, whereas their operations are designed to be unknowable to us' (Zuboff 2019: 11). Although such technology may not initially appear as linked to such new forms of capitalism, Zuboff challenges her readers to 'delete the word "technology" from our vocabularies in order to see how quickly capitalism's objectives are exposed' (Zuboff 2019: 16). Others such as Sumartojo et al. (2016), have coined the term datafication in relation to smart technology, whereby many aspects of life can be transformed into digital data which will then be analysed and used to understand, predict and guide interventions within society. Many such interventions have been developed for use at home whereby the digital world has become increasingly intertwined with the home space.

The digital world has also become intertwined with the person, through social media and the range of self-tracking apps. Such media and apps enable (to an extent) the user to control which version of the self is published on social media through careful construction and architecture of this digital presence (Walsh and Alice Baker 2016). Drawing on Goffman (1971) again, social media and digital devices offer the user more opportunities to offer a 'performance of the self' through the frontstage role (i.e., social media profiles). Simultaneously, multiple digital presences offer audiences more opportunities to potentially peer into the backstage, especially if a social media post or digital device is updated incorrectly or inaccurately (Kerrigan and Hart 2016). Kerringan and Hart (2016) identified difficulties in maintaining a digital version of oneself over time if it was not an authentic presentation of the self. Studies utilising Goffman's approach have often neglected to explore the experiences of and impacts on the audience. Meanwhile self-care practices such as those promoted through health, fitness and wellbeing apps and devices (e.g., Headspace, Fit Bits, calorie counting apps) offer opportunities to improve one's

health and wellbeing through a virtual health assistant (Lupton and Jutel 2015) which is always watching or monitoring.

These devices also offer what Pantzar and Ruckinstein (2017) define as situated objectivity. They are designed (and sold/advertised in ways which imply that they offer the ability to objectively) to show users how much they 'really' walk, sleep or eat through objective and virtual means. In reality, these virtual views are situated and subjective (i.e., they only offer a partial view) but have nevertheless often been taken as wholesome and objective. Thus Pantzar and Ruckinstein (2017) have argued that these so-called objective views are partial and do not take account of the full context such as activity which is not captured by the smart and assistive devices, or the context of why specific readings were recorded (i.e. why their sleep or diet was bad). Furthermore, such devices offer an alternative to self-perception which can be easily over or underestimated depending on an individual's level of satisfaction with their own health. However, Pantzar and Ruckinstein (2017) discussed situated objectivity from the perspective of self-monitoring rather than devices being used to view and monitor someone else from afar, which creates further intricacies which will be explored in this research. Simultaneously apparent in this research is the degree to which those doing the external monitoring (i.e., the formal and informal carers) are aware that the data which is produced is partial, and in fact not fully objective. The surveillance of our virtual selves has simultaneously called into question the authenticity of this digital/ virtual presence and enabled surveillance from afar whereby users can track the health data of others (i.e., older relatives). Katz and Marshall (2018), also highlight how these dataveillance practices have also provided a method to quantify the bodies of older people. Such qualification can also now occur more easily in the home with rises in home broadband.

The rise of home broadband has meant that the use of data and smart technology at home is more commonplace (Hargreaves et al. 2018). The increase in possible uses of smart home devices has created a space for varying motivations for, and practicalities of, using smart technology at home. Lupton (2016a: 114) has argued that digital data assemblages, such as those occurring with smart technologies in the home, are 'configurations of discourse, practices, data, human users and technologies' and so the experiences of using such devices may be complex and time and context-dependent. As many of these devices include elements of selftracking data gathering, the process of gathering data often creates an inclination to collect more and more data, obtaining new and additional smart devices. Akrich and Latour (1992: 208) highlighted that technologies are created for a purpose that comes with directives, or scripts, of expected behaviours of users vis-à-vis the piece of technologies whereby, 'like a film script, technical objects define a framework of action together with the actors and the space in which they are supposed to act'. Thus, the experiences of using and living with such technologies may be constantly unfolding (Bergroth 2019). This signifies the need for additional research within real-world, rather than in laboratory settings (Marikyan et al. 2019) and over a longer period, as the majority of existing empirical research has neglected to consider that motivations may change over time. This is an important topic for interrogation within this thesis. The move to smart devices at home and smart homes is now discussed, regarding the key debates and critical thoughts within the literature.

2.3.1.2 Rise of smart and assistive technology use in the home

The idea of the 'smart home' first emerged in the 1930s within discussions of the home of the future (Wilson et al. 2017) and in connection to luxury and ease of living (Strengers 2013a). More recently, the smart home idea has intertwined with energy efficiency, safety regarding smoke

and fire monitoring, and with communications and entertainments (Balta-Ozkan et al. 2013). Aldrich (2006) defines them in terms of a hierarchy of five levels of complexity and innovation with homes: intelligent objects; homes with intelligent, communicating, objects; connected homes; learning homes; and, attentive homes. Others (Darby 2018; Gram-Hanssen and Darby 2018) purport two existing definitions of smart homes – one which is home or user-focussed and another which is building-focussed. Both notions highlight the importance of ICT networked appliances that allow remote access and control of services in the home. Balta-Ozkan et al. (2013: 364) meanwhile, define it as a 'residence equipped with a high-tech network, linking sensors and domestic devices, appliances and features that can be remotely monitored, accessed, or controlled, and provide services that respond to the needs of [their] inhabitants'. Others (Wilson et al. 2017) argued that smart homes are designed to respond to the needs of non-residents (e.g., policymakers or developers). There is perhaps a need for a new a definition of the smart home, or a redefining of what should be classed as a smart home, regarding who is involved in influencing the residents' experiences of such homes. This may also change how a smart home is considered.

According to Kitchin and Dodge (2011: 3), the move of data and thus smart technology into the home impacts on everyday life whereby, 'the practices of everyday life have become increasingly infused with and mediated by software'. This links to Pink et al.'s (2017; 2018) consideration of the entangled nature of digital and the material (i.e. the home). Moreover, although much smart technology is utilised within the home, it is 'not so much a clearly defined phenomenon as a fluid and unstable field of possibilities' (Berry et al. 2007: 242). Some authors define the concept from a focus on home entertainment (Balta-Ozkan et al. 2014), others from a focus on the electricity-system (BPIE 2017). The rise in the internet is one way in which the boundaries of the home have been extended (Gram-Hanssen and Darby 2018) as it is now

possible to control and monitor aspects of home life remotely through smart home devices. This surveillance has been another key area of smart home research. Sadowski (2020) explored who benefits from the data collected in a smart home, and Strengers and Kennedy (2020) explored the gender roles perpetuated through this surveillance. However, existing studies have mainly focussed on single residents, neglecting the potential for multi-resident smart homes or the impacts of this surveillance on wider caring networks.

Barad (2007, 2014) has explored the multiple experiences of a single object through her notion of diffraction. Diffraction is the 'cutting together-apart in the (re)configuring of spacetimematterings' (Barad 2014: 168). Barad draws on the physics-borne concept whereby light diffracted through a prism appears differently depending on the specific viewpoint. In other words, all experiences are based on their specific viewpoints (both pre- and post- prism). Each actor perceives the experience differently and so different materialities emerge. Diffraction makes these different materialities visible. Similarly, for Haraway (1988), much like Barad's (2014) considerations of diffraction, considering an issue from multiple perspectives is a more effective route to solving such issues. Recognising these multiple perspectives will be key in this thesis.

As housing and technology standards rise, 'everyday' housing and technology is becoming increasingly smart, until it eventually becomes commonplace, such as smart meters (Strengers 2013a). One prominent narrative for the promotion of smart home devices is the pursuit of convenience. Yet as Strengers and Nicholls (2017) have argued, the pursuit of convenience is not an attainable endpoint, as more convenience will always be sought. Many existing modern devices have had complex narratives as they have simultaneously made life easier and also more complex as they have become normalised and moved between spaces of novelty and normality.

As illustration, it was initially hoped that the electric iron would reduce the manual labour load of women, but now ironing is often once-again considered time-consuming. Additionally, the bath was once associated with cleaning oneself, but now is more often associated with relaxation.

Clarke (2001) and Miller (2001) argue that the home represents the discrepancies between its actual state and its idealised version of itself. This is important for discussions of smart home technologies as they can highlight idealistic notions that both developers and residents may have for what such devices may be capable of. Parallels can also be drawn with the rise in popularity in the 1990s of DIY at home, which simultaneously gave (often) men a greater household role and allowed residents greater control of the aesthetics of their homes (Miller 2010). Similarly, smart homes have given (often) men new roles in the household in terms of maintenance and upkeep of devices (Strengers and Nicholls 2018).

Yet authors such as Wilson et al. (2017), Berry et al. (2007) and Darby (2018), have called for more research on who smart home technology users are and how they use their devices in reality. There is a need for greater understandings of what home means to smart home residents and prospective residents. Such research needs to come from social science perspectives so that we do not risk not noticing the socio-political implications of such homes in favour of the overtly technological impacts (Goulden 2019). Better understanding of the socio-political implications of these homes is particularly key as smart home developments move into new territories such as healthcare. Furthermore, greater understanding of the impacts of smart home living on multiple residents or co-residents is important (Wilson et al. 2015). These impacts may change over time, particularly as smart homes seek to assist with varying mixes of chronic health conditions as we age.

2.3.1.3 Rise of HSH for older people

Building on advances in smart home technology, desires for ageing-in-place and requirements to administer more healthcare at home, smart homes for healthcare began to emerge (Sixsmith and Sixsmith 2008; Mano et al. 2016). Prospective residents of these homes are mainly older or have specific chronic health conditions including high blood pressure, diabetes or dementia. Examples of such devices include wearable fall alarms, remote GPS trackers and portable heart rate monitors, and smart technologies such as Alexa and Siri. Some devices necessitate active resident participation (e.g. remote blood pressure monitor), but others are passive as they monitor and collect resident data without their active participation (e.g. fall alarms) (Lê et al. 2012).

Continued focus on independence is problematic. Instead, the focus should be on relational living, to buffer the impacts of potential social isolation from too independent a life within HSH living, linking to the ethics of care discussions. Le et al. (2012: 609) take a more pragmatic approach suggesting that 'there is no one single type of smart home for older people as actual design should vary according to users' needs, characteristics and embrace the concept of adaptability as these change over time'. Le et al. (2012) argue that a HSH needs to be capable of automation; multi-functionality; adaptability; interactivity; and, efficiency. HSH often combine telecare, telehealth and smart home technology devices to enable 'ageing-in-place' (Golant 2017b). Within much of existing literature on HSH (Dewsbury and Linskell 2011; Ehrenhard et al. 2014; Wilson et al. 2017), the idea of independence appears to be simply considered as the ability to live at home with ease. However, a wider consideration of independence is required. Independence is also the ability to feel a part of your wider community and maintain a sense of home. Such abilities could include maintaining routines

through active rather than passive interaction in one's home, such as through turning off lights and actively locking the door. Strengers and Nicholls (2017) highlight that residents have to become passive actors in smart homes to enable simplification and automation of domestic tasks. However, this may discourage a sense of home and encourage disempowerment of residents.

Within this thesis I understand security in terms of an emotional feeling of security in the home, relating to feelings of at easeness, familiarity and stability within the home (Downs and Tuan 2006; Wiles et al. 2011; Thielke et al. 2012). HSH, thus, have the potential to enhance the ontological security of residents. Ontological security (Giddens 1991) is a sense of order and continuity with regards to an individual's security. The concept has been frequently utilised within housing studies (Padgett 2007; Colic-Peisker et al. 2015; Stonehouse et al. 2020) and security studies (Subotić 2015) to examine individual and state behaviour. Studies adopting ontological security have done so from the understanding that an actor (i.e., individual or state) has a singular behaviour or viewpoint, failing to consider the potential contradictory experiences which may be uncovered when exploring the impacts on the wider relationships. Uses of ontological security within housing studies focus on the inherent and unquestionably positive nature of the home, and an understanding that a whole household experiences the home in the same way. This leaves questions over the role of relationality and relational aspects of living in connection to ontological security. I will explore this further in this research.

Some authors argue that HSH may disadvantage those who cannot or do not remain living at home (Wiles and Jayasinha 2013). Others believe the HSH innovations may further the rich-poor divide in society, in terms of those who can afford to age-in-place (or not) with smart technology (Graybill et al. 2014). Digital divides may then become more apparent, particularly for older

residents of rural areas (Philip et al. 2017). Additionally, there is concern that the sense of home may be altered by smart and assistive devices, or that the boundaries of the home and the hospital, or the technology and the resident's body through wearable technologies, may be altered. This concern has not yet been widely researched or understood (Aarhus and Ballegaard 2010; Aceros et al. 2015; Burrows et al. 2018).

Currently, HSH remain more of a concept than a large-scale reality. Thus, the current mix of devices which residents use to create a HSH often come from a range of commissioning sources. This can be understood through Levi-Strauss's (1962) idea of 'bricolage' (French for DIY) whereby people make do with the tools they have to address an immediate problem or need. In such processes, tools can be used for unintended purposes. Other authors (Greenhalgh et al. 2013a; Gibson et al. 2016), have utilised bricolage to discuss the use of assistive technology, whereby people use combinations of technologies in new ways to fit their specific needs. However, with the exceptions of Greenhalgh et al (2013b) and Gibson et al. (2015), there has been little critical social science research conducted on how well these mixes of devices work together. For example, mixing devices that are publicly and privately commissioned may lead to issues of interoperability. Or smart devices may not be able to talk to one another, reducing the resident's feelings of capability and control. Simultaneously, if these devices talk to each other passively then residents may feel more out of control and disempowered as decisions were being made on their behalf, rather than through their active involvement. Furthermore, they encouragingly explored the experiences of wider caring networks, they did not explore the concept specifically within smart homes, instead looking more broadly at uses of assistive technology not necessarily in connection to sense of home. Use of a mixed approach to device use within smart homes has been made possible due to the encouragingly large number of devices being developed to suit a range of budgets and needs (Wilson et al. 2017). However, the

process of bricolage has not been well utilised to understand how outcomes of such a process may differ according to personal circumstances or inequalities (Phillimore et al. 2016). Through this thesis I offer one such utilisation through multiple experiences of DIY HSH living.

DIY forms of HSH may also create specific experiences of these homes, and anticipations of the future for both residents and wider caring networks. This requires further research. The existing literature on HSH living tends to highlight a linear process of HSH leading to increased independence and empowerment of users and increasingly resilient communities and unburdened healthcare services (Neven and Peine 2017; Bergschöld et al. 2020). However, the roles and experience of the wider caring networks are largely absent, instead, painting the picture of the technology as a solution in itself. This consideration is important given that these network members may have competing and conflicting experiences of the home, particularly when technology devices are introduced. There may also be unequal access to technologies, which Graham (2016) has referred to as vertical noir. Although discussed predominantly in terms of speculative fiction and the notion of the smart city, Bina (2020) and Graham (2016) highlight how the impacts and benefits of information technology in general can often be morally ambiguous (hence 'noir'), deepening social divisions within the city, with a clear separation (or 'vertical' hierarchy) between elite wealthy residents who can live in luxurious conditions with technology 'while the majority live in abandoned and poor neighbourhoods (slums, underground spaces and / or under developed areas). These features are frequently translated into what Graham (2016) calls 'vertical noir' where profound social inequalities are underpinned by ubiquitous and unequal access to technology' (Bina et al. 2020 9).

Considerations for this technology use in future have been the subject of speculative dystopian fiction (Abbott 2007; Bina et al. 2020; Harrigan et al. 2020). In these speculative futures, urban
areas are painted as distinctively 'bad' areas taken over by machines, compared to the idyllic rural areas untouched by the negative impacts of smart technology. Such reliance on DIY attempts at HSH may be an attempt to achieve or counter these speculative futures depicted in speculative fiction. Concerning the smart city imaginary (SCI), Bina et al (2020 n.p.) highlight that 'imaginative representations of extreme technologically-driven urban transformations can contribute to social scientific understandings of the SCI'. Although an important concept for this thesis, these speculative futures and fiction leave little room for human agency, painting members of society as being passively carried along and impacted by technologies. Exploring the human agency within these futures is a key literature gap which this thesis can begin to fill.

Ultimately, given that this is a relatively new area of innovation, with few examples of existing real-world fully-functioning HSH, there is a lack of empirically-based research around the impacts of, and motivations for, using these devices at home, specifically from social science perspectives (see (Powell et al. 2016; Wilson et al. 2017; Marikyan et al. 2019). This lack of real-world examples has paved the way for increased DIY attempts at HSH, for which there is also little research in terms of the experiences of residents and their wider caring networks.

2.3.2 Rural homes and technology

In this thesis I am especially (but not exclusively) interested in rural DIY HSH for older people, given both the potential need and desires for these homes within rural areas. Although research has been conducted around the feasibility and acceptance of telehealth and telecare technologies in rural areas (Currie et al. 2015; Philip et al. 2017; Dowds et al. 2018), there is little existing research on older people's experiences of fully-fledged HSH (Aceros et al. 2015; Park

2017; Philip et al. 2017). This section explores some of this existing research, and the context of this research – rural Scotland.

Recently, the Scottish Government have been promoting the use of technology-enabled care at home through their enablement agenda (Scottish Government 2017). Scotland regards itself as a leader in Technology Enabled Care (Scottish Government 2018b), with numerous examples of successful uses of smart health technology, such as community alarms and Florence⁴. In March 2019, the Scottish Government-funded Technology Enabled Care at Home Charter (2019) was launched. This programme and charter were designed to help housing associations and the wider population to better engage with technology-enabled care at home. This is especially pertinent given that nearly two-thirds of people in Scotland aged over 65 live with at least one chronic condition (Scottish Government 2015), and the majority of these people live in rural rather than urban areas. There have also been increasing desires to treat these conditions within the home (rather than hospital), which can require home adaptations and technology use.

In Scotland, a commonly utilised definition of rural is the Scottish Government's 6-fold urbanrural classification. This is illustrated below (Table 2).

Class	Class Name	Description			
1	Large Urban Areas	Settlements of 125,000+ people.			
2	Other Urban Areas	Settlements of 10,000 to 124,999 people.			
3	Accessible Small	Settlements of 3,000 to 9,999 people, within a 30-minute drive time of a			
	Towns	settlement of 10,000+ people.			
4	Remote Small Towns	Settlements of 3,000 to 9,999 people, with a drive time of 30-minutes+ to a			
		settlement of 10,000+ people.			

Table 2: Scottish Government Urban Rural Classification (Scottish Government 2018c)

⁴ <u>Florence</u> is a telehealth mobile phone-based programme which enables patients to increase their involvement in the management of their treatment, condition or lifestyle.

5	Accessible Rural Areas	Areas with less than 3,000 people, within a 30-minute drive time of a settlement of 10,000+ people.
6	Remote Rural Areas	Areas with less than 3,000 people, with a drive time of 30-minute+ to a settlement of 10,000+ people.

There has been an interest in rural HSH in Scotland because of two specific factors. Firstly, rural Scotland has a relatively large and extensive population, housing 17% of the country's population over 98% of the land (Scottish Government 2018d). This poses particular challenges regarding travel and access to services, with many rural residents living outwith reasonable travel times to key services such as GPs and shops (Scottish Government 2018d). Rural Scotland is home to larger proportions of over 65s, with 25% of the remote rural populations and 21% of accessible remote populations aged over 65, compared to 18% across the rest of Scotland (Scottish Government 2018d). Secondly, there has been a recent focus from Scottish Government (through Digital Scotland) to improve the use of digital technology in rural Scotland (Philip et al. 2017) through the smart village idea, in which rural areas are equipped with the same technologies as urban areas such as high-speed broadband.

There are challenges associated with this drive towards rural HSH in Scotland concerning what Philip et al. (2017) term the three pillars of digital divides, specifically digital infrastructure, digital literacy, and the appropriate use and upkeep of digital devices. Rural infrastructure improvement programmes have focussed on shallow but more populous, rather than deep but sparsely populated areas (Philip et al. 2017). In other words, rural infrastructure improvement projects tend to be carried out in accessible rural areas rather than remote or very remote rural areas of Scotland, which are often the areas in which HSH are most warranted because of large distance to healthcare services. Across the UK, superfast broadband services were available to 98% of UK urban premises in January 2019, compared to 76% of premises in rural areas. An Ofcom survey (2019) highlighted that 32% of rural-based respondents in the UK received average download speeds of less than 10 Mbit/s (i.e., the speed required to enable full participation in digital society). Finally, within Scotland, 23% of the population did not have internet access either via broadband or a mobile phone in 2017 (Ofcom 2017).

Adults with a chronic physical or mental health condition are less likely to use the internet for personal use given the links between digital and other forms of social exclusion such as a physical or mental disability (Dutton and Blank 2013). Within Scotland, only seven out of ten adults with a chronic condition use the internet for personal use, compared to nine out of ten adults across the whole population (Scottish Government 2016). Thus, the rollout of rural HSH in Scotland is not a simple procedure given the issues around the three pillars of the digital divide (Philip et al. 2017).

2.3.3 Technology in the home summary

In summary, the home has a multitude of definitions. With advances in the digital revolution and home healthcare, the meanings of home have increased further with the home now being viewed as a site of healthcare, public interactions and the performance of digital identity. With increased consideration of ageing-in-place and smart technology, DIY versions of HSH have started to emerge, however, research gaps remain around who will maintain the smart and assistive devices. There is little empirical research conducted with both residents and their wider networks over a longer period. Such research could account for potential changes over time as health conditions worsen, as residents become more or less accepting of their smart healthcare devices, as motivations for use evolve, or within specific (remote) geographical locations. Hence this research focuses on rural Scotland, which is well-placed as a setting due to its relatively high proportions of rural areas and population, ageing population and recent push towards the enablement agenda through smart healthcare devices. However, many of the experiences and findings will often be relevant for older people in non-rural areas. Such a variety of potential experiences of DIY HSH highlights the need for a new conceptual framework to encourage optimal experiences (of home and place) for older residents through smart and assistive devices. There are a range of potential impacts of DIY HSH on older residents and wider caring networks, including sense of home (RO1), identity (RO2), and future planning (RO3).

2.4 Proposed conceptual framework

I developed a new conceptual framework (Figure 2) to focus research about smart and assistive device use at home and discussions concerning older residents on the current areas which require greater interrogation, namely: the potential multifunctionality and multioccupancies of DIY HSH; the assumption that older people have only a singular desire to age at home independently; and, the extent to which a sense of home remains and/or changes through DIY HSH living. A focus on these issues may improve the experiences of older people within DIY HSH living, and an absence of the consideration of the framework criteria may serve to worsen the experiences for older DIY HSH dwellers. Focussing DIY HSH research and development more on the experiences of older residents and their networks may also heighten the potential for greater feelings of empowerment.

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Figure 2: New conceptual framework: For encouraging optimal experiences (of home and place) for older residents through smart and assistive devices

My framework was derived from the gaps and important aspects of DIY HSH living identified in my literature review and helped to inform my ROs and RQs. I identified three key criteria which appear of key importance for older people interested in ageing-in-place through smart and assistive devices. Specifically, these were: the promotion of relational living; individual and geographical circumstances; and the sense of home. All of these criteria also recognise the importance of not only place, but 'the right place' for ageing. In addition, how the media, policymakers and wider society discuss and consider older people can affect how they are regarded in society in terms of their abilities and even rights (Townsend 1981; Fealy et al. 2012; Weicht 2013). Thus, the use of more productive language is also assumed throughout my framework. The relative importance of these criteria will vary according to each individual, time and place, but all three criteria are necessary to encourage optimal experience for older DIY HSH residents. The framework will be further tested through my empirical research, and subsequently updated through this research. My updated framework is offered in Chapter 8 (section 8.5).

2.5 Conclusions

In this literature review chapter, I introduced the dominant debates and gaps in the three main literature areas related to this research (i.e., ageing, care and technology in the home). Within the ageing section (2.1) I highlighted the main ways older people are discussed in wider society and the media. In the case of DIY HSH, older people are considered as both dependent and capable regarding their need for and ability to utilise smart and assistive devices. So, ageing here takes place 'at home' and in (rural) communities, and the notion of ageing-in-place as the singular main desire of older people is promoted.

The second main body of literature was care within ageing, regarding how care is understood, and discussed in relation to the specific spaces of this research – the home, communities and digital spaces. In this section (2.2) I drew on scholarship from ethics of care, highlighting some of the contentiousness that exists around such discussions of care. Regarding the locations of care, I identified that the boundaries of care spaces/places are permeable, particularly as we look to future potential carescapes. Finally, I explored discussions of future care, concerning how the planning of care is often intertwined with utopian visions of smart technology and smart homes as ideal future solutions to the 'impending care crisis'. Such visions do not account for spatial differences, competing care recipient and giver motivations, or other existing negatives of smart technology use such as unequal levels of access in terms of health condition, age or financial status. Hence, this future vision of care through smart and assistive devices may be unrealistic. In section 2.3 I explored the literature around technology in the home further, through the context within which smart health technology use has risen, firstly more generally, and then specifically relating to rural Scotland. In this section I demonstrated that as HSH tentatively emerge as more than merely a concept, research gaps remain about who will maintain the associated devices, particularly in spaces where more privately commissioned devices are used. There has been little empirical research conducted with both residents and their wider networks over a longer period, to account for changes that may occur over time as health conditions worsen, as residents become more or less accepting of their smart health technology, or within specific geographical locations such as particularly remote areas.

Simultaneously, in this chapter I introduced my conceptual framework (section 2.4). This framework demonstrates the potential importance of a sense of home, relational living and spatial specificities and will be further tested through my empirical research. Finally, regarding specific literature gaps, although the desire of older people to age-at-home is well documented (Vasara 2015; Sixsmith et al. 2017; Visser 2018), the use of smart and assistive devices to enable such preferences has predominantly been based on idealistic marketing visions, and not the lived experiences of older residents. The consistency and quality of research about user perceptions and experiences of healthcare technology have varied. Existing research tends to neglect the range of desires that residents and their wider networks may hold, beyond the simple desire to age-at-home (Vasara 2015; Liu et al. 2016), and an understanding that experiences of using and living with smart and assistive devices may be constantly unfolding. Much of the existing literature on the impacts of living in HSH has come from: healthcare or technocentric domains (Sixsmith and Sixsmith 2008; Mano et al. 2016); shorter term or 'laboratory' settings with individual residents rather than more in-depth research including the wider networks (Marikyan et al. 2019); and, within urban rather than rural settings (Aceros et

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al. 2015; Marikyan et al. 2019). Thus, there is a gap in critical social science literature around better understanding what it means to age in a DIY HSH from the perspectives of the older resident and their wider caring networks, and how such experiences may evolve over time, especially regarding the sense of home, changing identities and planning for the future.

3 Methodology: Creating a multi-modal ethnographic approach

3.1 Introduction

In this chapter I outline the methodological approach of this thesis. In section 3.2 I outline my research paradigm and ethnographic approach. In section 3.3 I detail the data collection regarding recruitment strategy, ethical considerations, my sample of participants and the specific research tools used. In section 3.4 I introduce my key participants and their wider caring networks, and the dementia carers group in more detail. Through section 3.5 I outline my approaches to analysis, and in section 3.6 I offer some methodological reflections. The purpose of this chapter is to establish a suitable methodology to better understand the experiences of DIY HSH living for both older residents and their wider networks.

3.2 Study design

In this section I highlight and justify my research paradigm (3.2.1) and ethnographic methodology (3.2.2).

3.2.1 Research paradigm

A research paradigm is a set of commonly held beliefs and assumptions within a research community about ontological, epistemological and methodological concerns (Patel 2015). There are five main research paradigms, each with their own ontology, epistemology, and common methods. Ontology concerns the nature of reality, and epistemology concerns how the researcher understands their reality or knowledge (Silverman 2010). Table 3 highlights the main paradigms and their associated ontologies, epistemologies, theoretical perspectives, methodology and methods.

Paradigm	Ontology	Epistemology	Theoretical	Methodology	Method
	(What is	(How can I know	Perspective	(How do you go	(What techniques
	reality?)	reality?)	(Which	about finding	do you use to find
			approach do	out?)	out?)
			you use to		
			know		
			somethina?)		
Desitivism	Thoraica	Deality can be	Decitiviem	Functimental	Mainly guantitatives
POSITIVISM	There is a	Reality can be	-Positivism	-Experimental	wanti quantitative:
	single reality/	measured.	-Post-positivism	-Survey	-Sampling
	truth.			research	-Statistical analysis
					-Questionnaire
Constructivist	There is no	Reality needs to	-Interpretivism	-Ethnography	Mainly qualitative:
/ Interpretive	single truth or	be interpreted, to	-Critical inquiry	-Grounded	-Qualitative
	reality. It is	discover	-Feminism	theory -	interview
	created by	underlying		Phenomeno-	-Participant
	individuals in	meanings of		logical research	observation
	groups.	activities.		-Discourse	-Narrative
				analysis	-Theme
					identification
Pragmatism	Reality is	A method that	-Deweyan	-Mixed	Any of the above
	constantly	solves problems.	pragmatism	methods	methods, and/or:
	renegotiated,	Finding out is the	-Research	-Design-based	-Data mining
	debated,	means, change is	through design	research	-Usability testing
	interpreted in			-Action research	-Physical prototype.

Table 3: The main research paradigms (Patel 2015)

	light of its	the underlying			
	usefulness in	aim.			
	new				
	unpredictable				
	situations.				
Subjectivism	Reality is	All knowledge is a	-	-Discourse	-Autoethnography
	what we	matter of	Postmodernism	Theory -	-Semiotics
	perceive to be	perspective.	-Structuralism	Archaeology	-Literary analysis
	real.		-Post-	-Genealogy	
			structuralism		
Critical	Realities are	Reality and	-Marxism	-Critical	-Ideological review
	socially	knowledge is both	-Queer Theory	discourse	-Civil actions
	constructed	socially	-Feminism	analysis	-Open-ended
	entities that	constructed and		-Critical	interviews,
	are under	influenced by		ethnography	questionnaires or
	constant	societal power		-Action research	observations
	internal	relations.			-Focus groups
	influence.				-Journals

I do not believe there is a single reality, and rather situate myself between the critical and constructivist/ interpretivist research paradigms, believing that realities are socially constructed entities under constant internal influence, by both individuals and power relations from within society. In other words, reality is constructed by individual members of society, and influenced by power relations (e.g., governments, media, more powerful members of one's network such as friends and family members) within society. This view differs from positivist, pragmatic and subjective paradigms, as I highlight in Table 3. A more positivist paradigm conceives of a single discoverable reality and is more suited to methods of data collection wherein findings can be quantified (rather than qualified) such as survey or experimental research (Silverman 2010),

whilst the pragmatic paradigm, although in some ways helpful as it is uses methods that are appropriate to the research questions rather than coming from a singular worldview (Bryman 2012). However, I found such an approach difficult to utilise as I could not ignore my particular worldview. Finally, a subjective paradigm considers all knowledge to be a matter of perspective, which although I would agree with to an extent, I think a subjective paradigm downplays the potential role of power relations in maintaining these perspectives and realities of knowledge.

Following my hybrid constructivist/ interpretivist – critical research paradigm, I do not believe it is possible to separate the experience of a phenomenon or subject from the world within which it exists, as experiences are created through social interactions (Detel 2015), and then managed and controlled through internal power relations. In other words, this approach to knowledge attempts to understand rather than explain human behaviours, as these behaviours are experienced differently for every individual and need to be interpreted accordingly. To illustrate, I do not believe that I, as a relatively young and healthy individual, can claim I would have the same experiences of DIY HSH living as an older person. This is due to several differences regarding health and age, the specific societal view concerning older people, and my connections to home and my (perhaps) better understandings of smart and assistive devices. I do however have experience as a member of my mum's wider caring network, and further reflect on this changing positionality in my autoethnography chapter (Chapter 4).

Although a feminist theoretical approach could have been another interesting avenue, I wanted to understand the phenomenon of DIY HSH living from a range of experiences based on the potential power imbalances of age, rather than gender (Wigginton and Lafrance 2019). Other approaches such as critical theory, focus on changing rather than merely understanding and explaining society (Bronner 2009). Thus, as I wanted to understand the phenomenon of DIY HSH

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living from a range of experiences, I adopted an interpretive phenomenology theoretical approach. Specifically, 'phenomenological approaches, broadly conceived, can get at the richness of people's lives, concerns, and engagements in direct and incisive terms' (Desjarlais and Throop 2011: 97). Phenomenological approaches are concerned with the lifeworld of a person. The lifeworld relates to how individuals experience and share the world regarding other humans (Van Manen 2014). The lifeworld of a person is defined as lived time, lived body, lived space and lived human relations (Orbe 2009). Phenomenological approaches assert that individuals should be the subject of exploration as they reflect their experiences of a phenomenon and society in unique ways. Such an exploration consists of a consideration of how an individual considers a phenomenon through time, body, space, and human relations (Van Manen 2014). In this thesis, I explored time through repeated visits, the body through the connections between the body and health technology, space through how my key participants lived in and used their homes, and human relations through interactions with the wider caring networks. Furthermore, phenomenological approaches reject that research can be objective given that results will to some degree depend on how I experienced the world through my positionality as both a researcher and a person (Menon et al. 2014).

3.2.2 Ethnographic methodology

In this thesis I sought to critically interrogate some of the assumptions that have been frequently promoted within HSH and ageing-in-place narratives. Specifically, these were the importance of independence (Hillcoat-Nallétamby and Ogg 2014); continuation of sense of home (Darby 2018; Gram-Hanssen and Darby 2018); promotion of the rural idyll (Cristoforetti et al. 2011); and, impacts of technology on the boundaries of the body and the home (Lupton and Maslen 2018). Chapter 2 (section 2.4) introduced my conceptual framework which was developed from my review of the existing literature. This conceptual framework identified several criteria that could be followed to create more realistic narratives for living with smart and assistive devices-relational living, a maintained sense of home, and a consideration of spatial inequalities. These assumptions and framework criteria were explored through evolving and multi-modal ethnographic methods⁵ which necessitated longer-term fieldwork, in this instance over approximately six months.

My research primarily involved longer-term multi-modal ethnographic research with five residents and their wider caring networks. I considered wider caring networks to be friends, family or professional contacts of the key participant who played a substantial or important role in the care of that resident (e.g., children, partners, professional carers/ home-help, their smart and assistive device support staff). Ethnographic fieldwork consists of long-term observations (of at least six months) (Moeran 2007) and is most frequently utilised within anthropological research (Silverman 2010). It often refers to long-term immersion within a cultural group or society to gain an understanding of local knowledge, values and practices from the native's point of view (O'Reilly 2012). Traditionally it was used for geographically distant societies, however, recently it has gained traction as a method of understanding the perspectives of a group or society from a broader range of criteria (i.e., locally based groups and communities of interest) (O'Reilly 2012). Domestic spaces such as the home and the kitchen have also become subjects of anthropological studies to better understand how people utilise and make sense of such spaces (Cieraad 1999; Pink et al. 2017; Lupton and Maslen 2018), especially as these (mainly) private spaces are where we spend much of our time. Ethnographic research may create more robust and accurate research findings through potentially building more trust between

⁵ By multi-modal ethnography I mean the amalgamation and utilisation of different ethnographic research methods over the course of 6+ months (specifically traditional, visual and auto-ethnography).

researcher and participant. Geertz (1973) referred to this as 'thick description'. This approach was useful for my research for several reasons: to build up a more trusting relationship with key participants (Fetterman 2009), to observe; how the residents lived in their DIY HSH; how they interacted with the technology; and how these interactions may change over time. It also adds to the literature gap around critical longer-term studies of the experiences of living with smart and assistive devices. Given that ethnographic research takes place within the subject of study (e.g., in this case, the house/home), it enabled me to observe and better understand some everyday interactions. The addition of a visual angle (digital storytelling) (De Jager et al. 2017) enabled the capture of another level of interactions and experiences (i.e. some sensory and tactile experiences).

I also extended this ethnographic research to the key participant's wider caring networks. Wider caring networks have shown to be potentially more important for people as they age, particularly if they have to undertake new activities (e.g. technology use) (Currie et al. 2015). Conducting research with wider caring networks enabled the issue to be viewed from multiple perspectives to gather more robust findings (Silverman 2010). Similarly, research within other sectors of housing research (e.g., energy use) highlighted the benefits of undertaking research with whole households (Zuckert 1995; Ellsworth-Krebs 2016) as this can lead to greater emphasis of the (dis)comforts of the shared reality of domestic life. As my research sought to gain a deeper understanding of the experiences of living in DIY HSH through an ethnographic approach, I used qualitative methods to achieve a depth rather than breadth of understanding (Silverman 2010). I wanted to obtain deep-description and build fuller narratives of a few individuals, rather than fully generalisable findings (Fetterman 2009). To have rich and detailed data I deliberately chose a small sample size of five key participants, approximately five members of each wider caring network, and observations and interactions at a dementia carers

group. I deliberately chose this number of key participants because I wanted to focus on a deeper understanding of the older resident's experiences and their relationships with their wider caring networks. Other longer-term studies within the setting of the home have used similar sample sizes. Visser (2018: 292), who explored the experiences of homemaking with eight older adults through multiple visits, remarked that her sample size enabled a more 'indepth description of a social phenomenon'. Multiple methods were utilised to create a triangulated approach (Silverman 2010). My methods and other data collection considerations are now justified.

3.3 Data Collection

In this section I justify and summarise my data collection process. In the following sections I outline my ethical consideration and risks (section 3.3.1), my recruitment strategy (3.3.2), my sample (3.3.3) and the range of research tools I used (3.3.4).

3.3.1 Ethical considerations and risks

I obtained ethical approval for my fieldwork from the University Teaching and Research Ethics Committee (UTREC). My ethics approval form is included in Appendix four. Ethical considerations and risks are present in all research (Hay 2016), but this research had particular considerations and risks. By undertaking research with key participants and their wider caring networks, it was necessary to gain consent from all participants, and in the form of fully identifiable data. Specifically, the responses of the key and wider network responses were not anonymised and could be attributed back to them. This was because I had to gain consent to discuss the responses and experiences shared by my key participants with their wider caring networks, and vice versa. Due to the filming, it would have been difficult to anonymise my key participants in outputs, highlighting another reason for attributable consent⁶. This attributable consent still enabled participants to withdraw from the process at any point during the fieldwork.

As I was undertaking research with potentially high-risk groups (i.e., due to their age and health condition), some of whom lived in more remote and distant locations, I completed a three-day first aid training course, and carried a first aid kit, to act as the first responder to any health emergencies emerging during fieldwork. Fortunately, no such health emergencies occurred. With conducting research in people's home, I was aware my presence might be a risk to my key participants, as at least initially I was a stranger coming into their home (Hay 2016). I attempted to help key participants feel more comfortable in my presence by, 1) obtaining a Protection of Vulnerable Groups (PVG) certificate; and 2) initially meeting most of my key participants in a more public setting such as their lunch club. In other instances, I was introduced to my key participants through a gatekeeper (e.g., daughter, charity worker), who could then at least to some degree attest to my non-threatening character having already met with me. There were also risks to me as the researcher in entering these private homes alone (Hay 2016), so I always let someone know when and where my visits were taking place, when I expected to finish and the steps to take if I did not get in touch when expected. Again, this situation did not arise.

Finally, I shared the progress of the research during my visits and agreed to send a research summary and the digital story (for those involved) to each key participant (if interested) after project completion. I assured all participants that I would store all data on a secure server and delete the interview recordings as soon transcription had occurred.

⁶ Consent to collect fully identifiable data i.e., data that can be directly linked to an individual.

3.3.2 Recruitment strategy

As highlighted in Chapter 1, I consider DIY HSH to contain a mixture of telecare, telehealth and smart technologies, but on a more informal and mix and matched basis than in a tailormade HSH. There have been increasing attempts to utilise these technologies within Scotland to encourage ageing-in-place and more involvement in one's healthcare. Recognising the research gaps around long-term experiences, rural living and the experiences of multiple occupants and visitors (i.e., wider caring networks), I aimed to address these gaps through my data collection. To understand the range of experiences of older people in DIY HSHs, I sought to identify older rural DIY HSH residents across Scotland. I planned to conduct in-depth ethnographic fieldwork with roughly six older (expecting that 1-2 may drop out) people living with DIY HSH, and selected members of their wider support networks (approximately 5 people per key participant). Given that this research focussed on the experiences of these homes for rural older people, I was keen to have key participants from a range of rural areas and different ages. I aimed to select key participants according to the Scottish Government's 6-fold urban-rural classification (Scottish Government 2018c) and therefore have key participants from both accessible and remote rural areas (see Chapter 2, Table 2).

I wanted a mix of male and female key participants from both the 'old' (60-79 years old) and 'oldest-old' age cohorts (85+) (Lee et al. 2018). Given my fieldwork entailed multiple visits with the same individuals and their networks over an extended time and my small budget for fieldwork travel, I planned to select key participants that lived in accessible and remote rural locations (Scottish Government 2018c) near to where I lived (i.e. for ease of access). I planned to initially access the key participants through social workers and third sector organisations, as I envisaged that they would have the best knowledge of willing DIY HSH residents who may participate in my research, given that they worked more closely with potential key participants than NHS staff for instance. In terms of the smart and assistive devices, I aimed for my key participants to own at least one piece of telecare, telehealth and smart technology, to highlight the potential range of experiences of different devices, but also devices with different commissioning sources (e.g., privately or publicly commissioned)⁷. Table 4 offers some examples of these devices that are already utilised in Scotland.

Smart and assistive	Examples used in Scotland
technologies	
Telecare (all	-Fall detector
publicly	-Smoke detector
commissioned)	-Flood detector
	-Gas detector
	-Occupancy detector
	-Door contacts (to raise alert when door is opened)
	-Pressure mats (to detect movement or lack of movement)
Telehealth (all	-SMS services (e.g., Florence) which send reminders on specific conditions e.g.,
publicly	hypertension, COPD, heart failure
commissioned)	-Computerised cognitive behavioural therapy
	-Wearable technologies
	-Video conferencing services (e.g., Attend Anywhere) to attend video clinics at
	home or from a care home (publicly commissioned)
Smart technology	-Smart energy meters
(all privately	-Smart televisions
commissioned)	-Smartphones
	-Smart home devices such as Alexa and Siri

Table 4: Smart and assistive devices

Some difficulties with recruitment are expected within any research study (Silverman 2010; Bryman 2012). Initially, I had some difficulty in finding key participants who fulfilled all the desired criteria. As I aimed to find key participants who were over 65 and lived rurally with at

⁷ Devices that are privately commissioned are (generally) developed and paid for by the resident out of their own funds. Whilst publicly commissioned are (generally) developed and paid for by the health and social care provider at no- or lower-cost to the resident.

least one piece of each of telecare, telehealth and smart technology, I was already searching in a small pool of potential key participants. Many potential key participants fulfilled several but not all criteria.

In the end, I relaxed the criteria around the amount of required technology that they used and their degree of rurality. In other words, key participants did not need one telecare, telehealth and smart technology device, and rather could participate even if they did not have a telehealth device, for instance. Furthermore, key participants could also live in a remote small town. On reflection, this was a positive move as I considered it more important to have engaged and interested key participants rather than less engaged key participants who fitted all criteria. Such an approach also allowed me to understand the various ways in which key participants became interested (or not) in the potential changes that such technology could make to their lives. In the following section I highlight how my specific sample of participants mapped onto my recruitment strategy.

3.3.3 Participants

Through my recruitment strategy I aimed to recruit key participants through social workers, however in reality it was difficult to get a hold of social workers or for them to identify potential key participants who both met all my recruitment criteria and were willing to take part in longerterm research which required involvement of themselves and their wider caring networks. As such, I relaxed my recruitment strategy as mentioned in the previous section. Through visiting several lunch clubs, advertising on Twitter and mailing lists, visiting men's sheds and speaking to social workers and occupational therapists, I identified five willing volunteers for my research.

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Overall, I recruited three key participants through two different lunch clubs, one through Twitter (via the key participant's daughter) and one through an occupational therapist.

These additional avenues of recruitment allowed me to gain key participants whose experience with smart and assistive devices was much more self-identified and the technologies that they used were perhaps more DIY (e.g., Alexa, remote cameras) rather than ones prescribed by a social worker or doctor (e.g., fall alarms). These key participants were all aged over 73 and lived across Fife (George, Geoff, Angela), Moray (Iain) and the Highlands (Georgette) with a range of telecare, telehealth and smart technologies in their homes. However, the split of these devices differed between key participants. In Table 5 I illustrate this split according to each key participant and their location according to the urban-rural classification (Scottish Government 2018c). I also offer a breakdown of the number and length of visits. I order the rows of this table (and each subsequent table) according to the number of times I visited (and length of time spent with) my key participants.

Кеу	Location	Number of	Telecare	Telehealth	Smart devices	Other
participant		visits (Total	devices	devices		devices
(Age)		number of				
		hours spent)				
George	Cupar (Class	6 visits	Assistance fall	ECG heart rate	Smart phone;	
(79)	3 –	(Totalling 18	cords;	monitor	Voice	
	Accessible	hours)	Assistance		assistant	
	Small Town)		intercom		(Alexa);	
					Laptop; Smart	
					TV; Fitbit	

Table 5: Specific devices used by key participants

					activity	
					tracker	
Geoff (77)	St Monans	4 visits			Speaking	Tabletop
	(Class 5 –	(Totalling 8			tablet;	magnifier;
	Accessible	hours)			Speaking	Liquid
	Rural Area)				watch;	level;
					Speaking	Audio-
					alarm clock	book
						reader
Georgette	Invergordon	4 visits	Fall alarm		Voice	Electric
(77)	(Class 4 –	(Totalling 8	bracelet		assistant	wheelchair
	Remote	hours)			(Alexa); CCTV	
	Small Town)				remote	
					cameras;	
					Kindle; Tablet	
lain (73)	Birnie (Class	2 visits			Voice	Electric
	5 –	(Totalling 3			assistant	wheelchair
	Accessible	hours)			(Alexa);	
	Rural Area)				Specialised	
					smartphone	
					(for	
					dictation);	
					Tablet; Kindle	
Angela	Pittenweem	2 visits	Fall alarm	Remote blood	Laptop	
(93)	(Class 5 –	(Totalling 2	bracelet	pressure		
	Accessible	hours)		monitor		
	Rural Area)					

I visited each key participant several times throughout 2019. I had intended to visit each key participant once a month for six months, and conduct interviews with five members of their

wider caring networks during this time. In reality, I conducted between two and six visits with the key participants and conducted interviews with between 0 and 4 wider caring network members per network. For Geoff and Georgette, multiple interviews were undertaken with members of their wider caring networks. In Table 6 I highlight the number of wider caring network members I interviewed for each key participant. The wider caring network members were identified through conversations with the key participants. The number of network members involved in this research reflects partly my ability to access their network members, the number of visits with key participants and the willingness of my key participants to initially suggest members.

Key participant	Number of wider caring network members involved in this research	Relationship (to key participant) of the wider caring network members involved in this research
George	2	Daughter; Lunch club manager
Geoff	4	Wife; Lunch club manager; Two charities for people living with sight-loss
Georgette	4	Daughter; Home-help; Dog-walker; Wheelchair assistance team
lain	0	none
Angela	1	Lunch club manager

Table 6: Number and role of wider caring network members involved in this research

Section 3.3.4.2 will give further information on the types (and numbers) of interviews conducted with the wider caring network members, and they will subsequently be further introduced in section 3.4.

Although my key participant and wider caring network interactions were generally very rich and in-depth in terms of data collection, I also visited a dementia carers group to gain additional new participants living with dementia who potentially had alternative experience with their technologies. I was introduced to this group through a local social worker. The group was very interested in my research, but all ended up declining participation on behalf of their family members as they were worried about my presence, as a stranger in their homes, causing stress to their partner or parent. Similar experiences were found with other studies trying to undertake ethnographic research with people with dementia or Alzheimer's (Gibson et al. 2015, 2016). This highlighted to me the specific importance of routine and having a home as a site of safety (Cristoforetti et al. 2011) for people living with and supporting people with dementia. Also, it made me more aware of my 'outsider' position and cognisant that my presence in someone's home would not, and could not, be neutral; it would inevitably have an impact on the residents and the research (Hammersley 2018). So, instead, I undertook observations with this group as is detailed below. This gave me additional perspectives and experiences of additional wider caring network members.

3.3.4 Research Tools

In this section I detail the research tools used within this thesis. The methods used were observations (3.3.4.1); unstructured and semi-structured interviews (3.3.4.2); autoethnographic and reflexive journaling (3.3.4.3); and digital storytelling (3.3.4.4). Table 7 highlights these methods and their rationale for use.

Method/ research tool	Rat	Rationale				
Observation	•	To gather observations on mundane activities				
	•	To observe DIY HSH residents in their homes and with their smart and assistive				
		devices				

Table 7: Key methods and their rationale for use

Unstructured and	The basis for tours of DIY HSH and their smart and assistive devices
semi-structured	• To understand the changing relationship between DIY HSH residents and their
interviews	wider caring networks
	• To understand DIY HSH residents and wider caring networks anticipations/
	expectations for their future
	• To make connections/ comparisons between key and wider caring network
	participants
Autoethnographic and	To better understand my positionality as a researcher
reflexive journaling	• To make connections/ comparisons between key and wider caring network
	participants
Documentary-style	To capture non-verbal interactions with their smart and assistive devices
digital storytelling	To capture changes over time
	To add to the open-science research agenda
	Verification of my interview and observational data
	Public engagement
l	

3.3.4.1 Observations

Observations are primarily associated with qualitative research and 'entails the relatively prolonged immersion of the observer in a social setting in which he or she seeks to observe the behaviour of members of that setting and to elicit the meanings they attribute to their environment and behaviour' (Bryman 2012: 273). I conducted ethnographic research with five residents of DIY HSH, spending between two and six days with each resident across six months. Spending extended periods with these key participants allowed me to create more meaningful and trusting relationships with them (and thus better-informed research) (Fetterman 2009). I conducted observations with the residents in their homes, and recorded fieldnotes through a mix of written accounts directly after my visits, or via my Dictaphone (which I subsequently transcribed) whilst returning home after my visits. I recorded interactions on all the activities undertaken, even if they seemed mundane (Mackley et al. 2013). I also recorded my thoughts and feelings in line with a sensory ethnographic approach (Pink 2009) to add to my reflexive journal (Hay 2016). Additionally, I undertook observations at a dementia carers group (6 visits across 4 months) (see section 3.4.6 for an in-depth introduction to the group).

Numerous authors (Gold 1958; Moeran 2007) suggest a range of possible roles for a researcher within (participant) observation, namely: complete observer; observer-as-participant; participant-as-observer; and, complete participation. My fieldwork incorporated observations as both 'complete observer' (e.g., observations through a camera) and 'observer-as-participant' (e.g., observations in the home and community). However, my role became somewhat more 'participant-as-observer' as the research process continued, and my key participants became more familiar with me and vice-versa. Thus after a while, I was trying to understand increasingly familiar places (e.g. the key participants in their homes) in a new light (Kearns and Fagan 2014). In other instances, this mix is referred to as moderate participation whereby there is a good combination of the researcher as 'insider' and 'outsider' (Cohen 2000) allowing the researcher the necessary involvement and detachment to understand both the 'front-stage' and 'back-stage' roles that an individual portrays. However, for simplicity, I still refer to all these interactions as simply 'observations'.

3.3.4.2 Interviews

I conducted two forms of qualitative interviews with my participants. The interviews with key participants were mainly unstructured (section 3.3.4.2.1), and the interviews with wider caring networks comprised of both semi-structured (formally organised) interviews and unstructured interviews (section 3.3.4.2.2) which may relate more closely to ethnographic encounters as they happened by chance during my visits with my key participants. In this section I justify these two approaches. A topic/question guide for the relevant interviews is included in Appendix three.

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3.3.4.2.1 Unstructured key participant interviews

The key participant (i.e., the older DIY HSH residents) interviews were unstructured (Hay 2016). Within anthropology, these are known as informal interviews when they 'seem to be casual conversations, but whereas structured interviews have an explicit agenda, informal interviews have a specific but implicit research agenda' (Fetterman 2009: 290). Although I had broad topics which I wanted to cover across the course of my visits (e.g., gathering information around their wider caring networks, sense of home, the importance of independence and interactions with the technology), the specifics of each visit were fairly unstructured (i.e., no formal interview structure). Sometimes these visits took the form of video home-tours (go-along interviews) led by the participants who showed me around their homes and their smart health devices to highlight how they experience and interact with their devices and homes. These home tours were conducted more than once if possible, to see if and how these experiences had changed throughout my visits, or as circumstances within their home changed (i.e., the introduction of new devices). This highlighted the importance of a longitudinal methodological approach for capturing change over time (Chapman and Hockey 1999; Visser 2018). Generally, these walkabout home tours had to be adapted when they were logistically difficult, for instance, if they had difficulties with walking (George, Georgette, Iain) or their vision (Geoff). Instead, I asked these key participants to give me a tour of their technology, in which they would explain and show me how and why they used it and for what purposes. You can view some examples of these within my results chapters. Each visit took place in my key participant's own home, so they were still able to offer a sense of and description of their home whilst in-situ.

Throughout these unstructured interviews, I used sensory ethnography approaches (i.e. focussing on sight, touch, sound etc. to spark conversations), building on the work of Leder Mackley et al. (2013) who examined everyday routines via a focus on the home environment

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through sensory ways of knowing and the practical activities that the residents undertook at mundane moments of the day. Most of these informal interviews/ visits were recorded using a Dictaphone (with later visits also recorded via a camera) and subsequently transcribed.

3.3.4.2.2 Unstructured interviews/ ethnographic encounters with wider caring network members

Unstructured interviews with wider caring network members were conducted when, for example, they visited my key participants whilst I was undertaking my visits. As mentioned above, unstructured and informal interviews still have an explicit research agenda (in this case to understand the multiple experiences of home, identity and futures in relation to DIY HSH living). However, as the encounters with these wider caring network members were often unplanned or unexpected (for everyone involved) they can also be understood as ethnographic interviews. Ethnographic interviews 'takes place in a naturalistic setting and is often the result of participant observation....[they] often occur spontaneously, and the goal of these interviews is to learn more about the members of a community from the members themselves, in their own words and in a natural setting' (Allen 2017: 455). In this case, the setting was mainly the key participants' homes. This was different to the semi-structured interviews which (with the exception of Geoff's wife Anne who lived with Geoff) took place in the offices or homes of the wider caring networks. By the nature of these interactions, most of these unstructured interviews were only recorded via fieldnotes given their unexpected and opportune nature.

3.3.4.2.3 Semi-structured interviews with wider caring network members

Semi-structured interviews were also conducted with other wider caring network members to better understand the role of these networks, and if and how these networks and roles changed with the introduction of smart and assistive devices. Semi-structured interviews allowed for some flexibility in the process as an interview guide rather than specific set questions was used (Hay 2016). Having this structure enabled easier cross-analysis within and across the networks. Most of these interviews were recorded using a Dictaphone and subsequently transcribed.

The breakdown of these wider caring network interviews, both semi- and un-structured, are recorded below (Table 8). I conducted nine semi-structured interviews and six unstructured/ ethnographic interviews within the wider caring networks of my key participants, and several informal interviews throughout my dementia carers group visits (recorded via fieldnotes).

Кеу	Total	Wider	Relationship	Type and	How was	Total length
participant	number of	caring	to key	number of	interview	of interview
	wider caring	network	participant	interviews	recorded	
	network	members				
	interviews					
George	2	Kate	Daughter	1 x Semi-	Dictaphone &	1.5 hours
				structured	fieldnotes	
		Anne	Manager of	1 x	Fieldnotes	.5 hour
			lunch club	Unstructured		
Geoff	6	Anne	Wife	4 x Semi-	Dictaphone &	4 hours
				structured	fieldnotes	
		Evelyn	Works for	1 x Semi-	Dictaphone &	1 hour
			Seescape	structured	fieldnotes	
		Stephen	Works for	1 x Semi-	Dictaphone &	1 hour
			Scottish War	structured	fieldnotes	
			Blinded			

Table 8: Breakdown of interviews with wider caring networks

		Ruby	Manager of lunch club	1 x Unstructured	Fieldnotes	.5 hour
Georgette	4	Lynne	Daughter	2 x Semi- structured	Fieldnotes	2 hours
		Danielle	Home-help	1 x Unstructured	Fieldnotes	.5 hour
		Sarah	Dog-walker	1 x Unstructured	Fieldnotes	.5 hour
		Unknown	Wheelchair assistance team	1 x Unstructured	Fieldnotes	.5 hour
lain	0	n/a	n/a	n/a	n/a	n/a
Angela	1	Ruby	Manager of lunch club	1 x Unstructured	Fieldnotes	.5 hours

With the informal interview with Ruby (part of Angela and Geoff's network), I conducted one informal interview in which Ruby discussed both Angela and Geoff. Throughout all of these various forms of interviews, I kept both detailed fieldnotes on the encounters and a field dairy on my thoughts and feelings of the evolving research process (and my roles within it). This is now introduced further.

3.3.4.3 Reflexivity and autoethnography

Reflexivity 'involves a process of on-going mutual shaping between researcher and research' (Attia and Edge 2017: 33), whilst a reflexive diary acts as a recording aid for this process. This diary differs from a field diary which contains fieldnotes and qualitative data, whilst a reflexive research diary contains thoughts and ideas about the research process, its context and my role

within it (Hay 2016). Reflections recorded included the power dynamics, my role as an insider and outsider, ethical issues, if and how my perspective changed during the research process, recognition of impacts of my gender, age or nationality and considerations during the writing stage around my theoretical assumptions and the degree to which I was reproducing stereotypes. Relatedly, autoethnography seeks to describe and systematically analyse personal experience to understand cultural experience (Ellis et al. 2011). It blurs the boundaries of autobiography and ethnography, as within an autoethnography the researcher is also the research subject. This allows for reflection on positionality, the experience of being a researcher, the process of doing research and emotional responses to data collection (Ellis et al. 2011). Autoethnography is often described as falling along a spectrum, from 'evocative,' (i.e., emotional narratives) to 'analytical,' (i.e., theoretical discussions). For Naess (2016), the boundaries of 'the field' in ethnographic research are not always clear at the outset of the research. Instead, the boundaries emerge and are moulded as the data and research is encountered. This notion was clear in my research. As my time 'in the field' continued, I began to see similarities between some of my own experiences and those of my key participants, and as such the boundaries of the field became increasingly unclear (Naess 2016). Thus, through keeping a reflexive diary and full fieldnotes, I captured these personal experiences via autoethnographic accounts (Delamont 2009; Lake 2015; Hine 2019).

3.3.4.4 Digital storytelling

As this research concerned the interactions between user and technology it was important to use methods which most appropriately capture these interactions (and answer my research questions) and thus, I also undertook digital storytelling to capture the interactions with technology in an audio-visual form (Pink et al. 2017; Lupton and Maslen 2018). Digital storytelling involves the recording of a short video of (often) photographs, voice-over narratives, and film clips (De Jager et al. 2017). Benefits of digital storytelling are numerous and include feelings of empowerment for those involved (Brushwood Rose and Granger 2013); therapeutic benefits for the participants (LaMarre and Rice 2016); and, communicating stories in a way that was not possible by solely interview-based research (Rice et al. 2015). Some disadvantages have also been suggested, including trauma for those involved if the subjects are difficult (Spector et al. 2011); and stigma if the public viewed their stories and were critical of the content (Willis et al. 2014).

I created <u>Smart Ageing</u> based on the experiences of (most of) my key participants. By carrying out long-term ethnographic fieldwork I built up trusting relationships with my key participants so that towards the end of the data collection some of them were happy to interact and participate with the creation of the digital story. I tried to reduce any potential trauma and stigma by introducing the filming aspect to our interaction only after I had developed a more trusting relationship with the key participants, as well as only filming interactions when my key participants agreed. As illustration, I did not undertake any filming with Georgette on my visit directly after her fall, because she had lost some confidence in her abilities and as she had bad bruising on her face. With participant consent, I filmed most of our interactions to create an additional layer of data that supplemented and verified the other methods. Their visual stories (as a single film) serve as an audio-visual representation of the main themes emerging from this thesis, to highlight the lived experiences of DIY HSH living. I analysed the film clips in the same way as my other forms of data (as highlighted in section 3.5) in terms of comparing and contrasting experiences and themes across cases (i.e., key participants). The additional layer of data (over and above written fieldnotes and interviews) highlights the sensory and tactile interactions between my key participants and their homes and devices (i.e., to highlight

potential frustration of using devices or to highlight potential pain or struggles when trying to walk around or move from wheelchair to armchair). Furthermore, they offer a better understanding of how experiences change over time, by highlighting how my key participants interacted with their devices across visits and how their stories around their DIY HSH living experiences evolved.

<u>Smart Ageing</u> has been shared with the involved key participants and uploaded to YouTube. I am currently distributing and advertising more broadly to academic, third sector and public audiences. It is a piece of data in itself, and links this research more clearly to the open science agenda (Friesike et al. 2015) which aims to make science and knowledge generation publicly available and free to all. I have included direct links and analysis of this digital story throughout this thesis to offer an additional layer (and voice) to my written findings.

3.3.4.5 Summary of research tools

Each research tool actively added to the construction of narratives (Gubrium and Holstein 2012) around each key participant's experience of DIY HSH living, and recognition of the role and impacts on the wider caring networks. The collation of a reflexive autoethnographic diary enabled me to reflect on my positionality and experiences and how this may affect and effect the wider research. I aimed to be as consistent concerning methods and methodological process as possible throughout the process of data collection and analysis by introducing various methods at the same time. For example, I discussed their wider caring networks on visit two and the digital storytelling and filming on visit three. In Table 9 I highlight the number and length of visits, and indicate the specific methods used for each key participant.

Table	9: Number.	lenath and	content	of visits	with	kev	participants
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Key participant	Number (and length) of visits	Total hours spent with each key participant	Methods used
George	6 visits (3 hours each)	18	Observations (including home tour), unstructured interviews, reflexive and autoethnographic reflections, digital storytelling.
Geoff	4 visits (2 hours each)	8	Observations (including smart and assistive device tour), unstructured interviews, reflexive and autoethnographic reflections, digital storytelling.
Georgette	4 visits (2 hours each)	8	Observations (including partial home and smart and assistive device tour), unstructured interviews, reflexive and autoethnographic reflections, digital storytelling.
lain	2 visits (1.5 hours each)	3	Observations (including home and smart and assistive device tour), unstructured interviews, reflexive and autoethnographic reflections, digital storytelling (only audio).
Angela	2 visits (1 hour each)	2	Observations (including partial home tour), unstructured interviews, reflexive and autoethnographic reflections.

My data collection, at least those methods which directly involved my participants, took place between June 2019 and January 2020. In general, richer data emerged with the key participants that I spent more time with (i.e., George, Geoff and Georgette) as this enabled me to better understand potential changes over time and to use an increasing range of methods. However, interesting data was gathered from all participants given that each key participant was visited on at least two occasions. Timelines of my data collection activities are presented below to highlight when the visits (and the use of specific research tools) occurred (Figures 3 to 8). Figure 8 explicitly focuses on my interactions with the dementia carers group.



Figure 3: Timeline of research interactions with George and his network


Figure 4: Timeline of research interactions with Geoff and his network



Figure 5: Timeline of research interactions with Georgette and her network



Figure 6: Timeline of research interactions with Iain



Figure 7: Timeline of research interactions with Angela and her network



Figure 8: Timeline of research interactions with the dementia carers group

From these timelines, you can see the range of methods that were undertaken for each key participant (and dementia carers network) and when. The timelines also indicate when wider caring networks were approached and interviewed. My key participants, their wider caring network members, and the dementia carers group are introduced more fully in the next section. My autoethnographic reflections continued after the fieldwork with my participants ended, to capture reflections on my evolving positionality and my data analysis.

3.4 Introducing my key participants

In this section I introduce my key participants and the dementia group in greater detail. These introductions are taken from my fieldnotes. I introduce each key participant via a short biography, the various devices they used and indicate their wider caring networks. I then introduce my dementia carers group.

3.4.1 George



Figure 9: George in his home in Cupar, 2019

When I first spoke to George (Figure 9), he told me he would likely be an anomaly in my research and in many ways he was right. A former teacher and social worker, George was very interested in smart technology and had the latest models of many devices.

I was put in touch with George through a lunch club in Cupar, Fife which he attended every weekday. George was 79 when I first met him and lived by himself in the basement flat of an old Georgian mansion house that had been converted into sheltered accommodation in Cupar. His

flat was one of about ten in the building and each provided extra support to people with physical or mental health difficulties. George rented the flat from the Council. He moved to the area about two years ago (from another part of Fife) after separating from his wife of 50 years; he wanted to move to a smaller house with some additional support. The house had a telecare intercom system linked to a care organisation that he could contact if needed, and they would check in on him if they did not hear from him each morning. There were also a couple of assistance cords (publicly commissioned) in his home. In terms of telehealth, George had an ECG heart rate monitor from the doctor (publicly commissioned), and other smart technology devices that George bought and installed himself – a laptop, voice assistant (Alexa) and Fitbit activity tracker (all privately commissioned).

I visited George six times between June 2019 and January 2020. In recent years, George's health had deteriorated somewhat with several small heart attacks, and before that, he had a stroke and had developed a bad back. He also wore hearing aids. George had a keen interest in politics and philosophy and for years was an avid cyclist, spending his summers cycling around France. He attended a creative writing and poetry group once a week and even read me some of his poems on one visit.

He spent his professional life helping others through social work and teaching children of all ages and abilities, but mostly children with behavioural difficulties who had been expelled from mainstream schools. After taking early retirement he moved to France which he thought would be permanent, however, this was more short-lived than he had planned. On his return to Fife, he chaired several charities and taught primary one at his local school. He would often go off on tangents about his time in France and experiences of teaching. These were very important to him. In terms of his network, George at first appeared to not have much of a network apart from his daughter Kate who lived near Inverness. After a while, I began to understand that for George his caring network was more of a two-way relationship, as he offered support and assistance to those in 'worse' situations at his lunch club and makes sense of ageing through his creative writing and poetry group. George needed his caring network to somewhat reinforce and maintain his place in society. The care organisation that provided the sheltered aspect of his accommodation were also part of his network, although he admitted that thankfully he did not have to see them much. Finally, his friends and family were also a form of support. He tried to attend local cycle meets when he could, and he spoke with Kate most nights and they would go on short breaks together a few times a year around Scotland. Between my second and third visits George had his fifth heart attack, and on my final visit he spoke about wanting to get a small dog for company. I illustrate George's network in Figure 10. The network members in grayscale (i.e., Kate and Age Concern) highlight George's caring network members that I had interviews or ethnographic observations/ unstructured interviews with. Those members that I did not talk to are included in white. The same format is utilised for each of the wider caring network figures throughout section 3.4. These networks likely do not recognise the full caring network of each key participant, but highlight those members with which I had interviews, or that the key participant referred to during my visits.



Figure 10: George's wider caring network

3.4.2 Geoff



Figure 11: Geoff in his home in St Monans, 2019

I met Geoff (Figure 11) at his lunch club in Anstruther, Fife, which I attended in the hope of gathering some willing key participants. This lunch club met once a week and transport to and from the meetings was available for those who required such assistance. I first met with the organiser of the lunch clubs who told me a bit about the members and the other activities that they run in Fife (i.e., befriender services). She then introduced me to the group. They had just finished their meal, and so whilst having tea and coffee I introduced my project and explained I was looking to recruit willing volunteers. Most members were initially quite sceptical saying that they did not use technology, either because they did not see the need for it or did not know how to use it. Geoff, however, who was visually impaired, came up to me and proudly showed me his voice-assisted watch and phone and said he was happy to participate. We arranged to meet at his house the following week.

Geoff lived in St Monans, a coastal village in the East Neuk of Fife, with his wife Anne and Cavalier King Charles Spaniel 'Charlie'. They owned their home outright. Originally from the South of England, they moved to St Monans in 2015 to be closer to Anne's daughter and her family who lived around the corner. Geoff was roughly 77 and retired, but previously he had worked as an aircraft engineer in the RAF for many years. He spoke with fondness about his time in the RAF and often regaled me with stories of the places he had visited. He had been registered as visually impaired for roughly five years, although did have limited sight remaining. He had several bouts of chemotherapy and wore hearing aids. Having served in the RAF, Geoff obtained several smart technology devices (either for free or for a small donation via Scottish War Blinded) to help him live as independently as possible with his visual impairment. In terms of smart devices, he had an adapted tablet, a talking watch and alarm clock, all of which were charity commissioned. He also used some devices that could not be classified as specifically telecare or telehealth including a table-top magnifier, a liquid level to make tea and coffee and an audio-book reader for visually impaired users. All of these were charity commissioned devices. I met with Geoff five times (including the initial lunch club visit) between June and October. Throughout my visits he also obtained a larger table-top magnifier to help him read newspapers and crosswords and an Alexa. On one of my final visits with him, he excitedly answered the door and straightaway showed me these new pieces which he appeared to love.

In terms of his network, there was his wife Anne and his family (Anne's daughter and her husband and their two children). In some ways there was also his dog Charlie, as Charlie allowed him to maintain his routines (dog walking) and motivated him to leave the house. There was also his lunch club and more formal network members including Scottish War Blinded and Fife Blind Society who put him in touch with support workers and specialised devices when he was first diagnosed as visually impaired. Geoff's wider caring network is depicted below in Figure 12.



Figure 12: Geoff's wider caring network

3.4.3 Georgette



Figure 13: Georgette in her home in Invergordon, 2019

Georgette (Figure 13) was 77 years old when I first met her and lived with Charcot's Marie Tooth disease which creates nerve damage and muscle loss. She had used a wheelchair for the last 26 years, and a motorised wheelchair full time since her husband died 10 years ago. I recruited Georgette through Twitter when her daughter Lynne answered my request for key participants. Lynne was an e-health facilitator in the Highlands so had a lot of working knowledge of the healthcare services and various remote technologies and remote working, and she got in touch with me to say that her mum would be a great key participant. I visited Georgette four times between June and November 2019, and each time we would chat for several hours. Georgette lived by herself with her West Highland Terrier, Molly, in a wheelchair-adapted housing association flat in Invergordon, a small rural town 25 miles north of Inverness. She had lived in Invergordon for most of her life, with some periods spent living in the Western Isles. In terms of a career, she spent some time working as a hospital nurse, so knew about being both a patient and an employee.

On first meeting Georgette, she introduced me to the devices in her house. In terms of telecare, she had a community fall alarm bracelet (publicly commissioned). In terms of smart technology, she used a Kindle tablet and computer (privately commissioned). Even her wheelchair (publicly commissioned) was an important health technology device of sorts. Between my first and second visits with Georgette she had a bad fall in which the wheels of her wheelchair jarred, and she fell out onto the floor and her chair then landed on top of her. She had to get several stitches on her face, and it knocked her confidence for a while. Thankfully, she had her fall alarm. She was not wearing the bracelet when she fell but she pulled herself along the floor to the alarm base unit and called for help. Nevertheless, the fall motivated Lynne to add more devices into her mum's house, specifically an Alexa (privately commissioned smart technology) and a pair of CCTV cameras (privately commissioned telehealth/ smart technology).

In terms of a wider caring network Lynne was a huge support, frequently phoning and visiting her mum, but additionally, Georgette had carers twice a day to help her get dressed. She also had a home-help, Danielle, who helped with errands and cleaning a few hours each weekday and appeared to go 'above and beyond' in terms of her duties. Her 94-year-old brother and her nephew also lived close-by. When I first spoke to Lynne, she told me that it was in fact Georgette's older brother who taught her mum to use Facebook. One of Georgette's young neighbours, Sarah, also came to walk Molly now and again, and she had a gardener visit once a month. Finally, she remarked on the importance of the wheelchair maintenance team and of care and repair for odd jobs around the house. All of these individuals had role in Georgette's network (Figure 14).



Figure 14: Georgette's wider caring network

3.4.4 lain

lain was first suggested to me by a local occupational therapist. Iain was 73 when I first met him, and he lived by himself in a rural area of Moray overlooking his trout fishery business, which he was currently trying to sell along with his existing house. He was suggested to me as, since his Multiple-Sclerosis diagnosis about 10 years ago, he had been building a new house nearby fitted with smart technology, to better suit his needs as his condition deteriorates over time. He was a solicitor and retired to spend more time fishing, his lifelong passion. This desire for fishing seemed to have driven many decisions throughout his life on where to live and work. I met with lain twice over a few months and during this time he was busy finalising his new home and starting to plan and install some of the (privately commissioned) smart technology. By now, lain should be living in his new smart home, but unfortunately, I was unable to get in touch with him once he had moved so did not get to hear about his experiences after his move or gather any photographs. As with Georgette, Iain had assistance from an electric wheelchair (publicly commissioned). He was still able to drive and had an adapted car which allowed him access in his wheelchair (privately commissioned). Iain had the help of carers three times a day to help with cooking and personal care, but he often remarked about his hopes to live in a house with more technology so he could have less reliance on carers and more independence in his routines. He designed his current house himself to overlook the fishery and take advantage of the spectacular views.

When I first met lain, he had already been using quite a bit of (privately commissioned) smart technology including an Alexa, which he referred to as Fred so as not to wake it up every time we mentioned it. Also, he used special software on his phone for voice dictation and had a tablet and Kindle. He did not use any telecare and telehealth devices.

In terms of his network, Iain did not have any immediate family apart from two brothers, one of whom lived in Stornoway and one in the USA. His brothers were a support; however, he did not see them often. He had a good friend (Lynn) who he saw regularly who also had MS. He relied on the help of 'kind strangers' such as getting his builder to help put away his wine delivery during one of my visits. Iain seemed to rely most heavily on formal care network members including carers, social workers, and charities such as Ability Net who help people with disabilities to better utilise their technological devices. This formal reliance was a key motivator for building his new DIY HSH. He was an active campaigner, in part due to his law background, in trying to improve the uses of blue badges and community facilities for disabled residents and played an active role in his community centre, in which there is a technology demonstration kitchen. Iain's wider caring network is depicted below (Figure 15).



Figure 15: Iain's wider caring network

3.4.5 Angela

I first met Angela at the same lunch club as Geoff. Angela was 93 when I met her, and she lived alone in a large three-storey house that she owned which overlooked the sea in Pittenweem, Fife. She had lived there for over twenty years and moved to the house and village (from Sanna, on the West of Scotland) with her husband before he died in 2000. She often spoke at length and with a fondness of her family and neighbours. She had five children and numerous grandchildren and great-grandchildren, most of whom live in Scotland and several within Fife itself. I met with Angela three times (including the initial lunch club meeting) between May and August 2019, but unfortunately do not have any photographs of her as illustration.

Given that she had a large family, she spent most of her working life looking after her children, rather than in paid employment, however, she was involved in several development boards and charities. In terms of telecare, Angela had a publicly commissioned community fall alarm (bracelet), and telehealth, a remote blood pressure monitor. In terms of privately commissioned smart technology, she used a laptop. Angela did not have as many devices as some of my other key participants, but I think this was a product of her large surrounding support network of family, and her good health. Angela had an active social life and even still swam in the sea in Scotland at least once a year. She was very active in her community, making use of community transport, coffee morning and the other benefits of living in her tight-knit rural community. She enjoyed family holidays once or twice a year to Greece and back to Sanna.

In terms of her wider caring network, she had a carer/ cleaner that visited once or twice a week to do the hoovering and some deep cleaning. She also had a gardener that visited when necessary. She was very close to her family and remarked that if it came to it a different member of her family could stay with her one night a month and have a whole floor of her house to themselves. Her neighbours were also a great help in terms of helping in the garden, making meals and just generally 'being there' if she needed them. Fife Council were also a great support, providing community transport and organising local events. Angela's wider caring network is depicted below (Figure 16).



Figure 16: Angela's wider caring network

3.4.6 Dementia carers group



Figure 17: Some of the dementia carers group members during a meeting [photo taken by group organiser]

I was directed to this dementia charity organisation through an Angus social worker because they had a technology demonstration centre in which community members could trial and borrow devices that may assist those with dementia, and their caregivers, to live a more independent life. Devices available here included publicly commissioned telecare such as motion and bed sensors, and privately commissioned smart technology such as voice assistants (i.e., Alexas). The dementia carers group (Figure 17) met once a week and was facilitated by either a carer support worker or the centre manager. Most weeks there were guest speakers on a range of topics relevant to the carers, such as will-making and power of attorney, hand massages and cookery classes. The group comprised of roughly ten carers, whose husbands, wives or parents had developed dementia. Generally, the same carers attended each week and also made use of the other activities and support offered by the dementia charity (e.g., gardening groups, farmer memories groups, craft groups). Also, three days of the week they offer the option for the individual with dementia to spend the whole day at the centre in what is known as 'Meeting Centres'. I initially wanted to conduct similar research (as with the other key participants) with those with dementia, but the carers group thought this would be hard for their care-recipients to understand and accept, and so we decided I would observe the carers group over four months (6 visits in total).

From attending this group, it was clear that as well as being a part of the caring network of their partner or parent, the carers relied on this group for their own support network, so they did not 'lose themselves' to dementia too. They spoke of difficulties getting their relatives with dementia to use wearable technologies because they (i.e., the relatives with dementia) often did not believe or accept that they had dementia. For many of them, neighbours, friends and family were of better and more useful support than any technology devices. They spoke of their

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difficulties in struggling to take on new roles that their partner used to do for the family, such as cooking or cleaning. During my time with the carers group one member decided to move their husband (who lived with dementia) into a care home, another experienced the death of their partner after a bout of additional illness, and another experienced their partner becoming increasingly violent and stubborn – characteristics which were not present before the dementia diagnosis.

3.4.7 Summary

In this section I introduced my five key participants and their wider caring networks, and the dementia carers group. I also indicated the devices used by my key participants. Table 10 summarises the specific devices used, the data each device collected and the commissioning source. I was already familiar with public and private commissioned devices before conducting the fieldwork, however, a third commissioning source – via charities, became apparent during my fieldwork. Charity-commissioned devices were available through specific charities (i.e., according to career background or specific health condition). Only Geoff was eligible/ availed of these devices.

Types of technologies	Details	Data collected	Used by	Funding Source
Voice assistants	Speakers such as Alexa and Siri to help with reminders, play music, conduct phone calls	Capable of recording all sounds i.e., speech, phone calls	George Geoff Georgette Iain	Private
Community fall alarms (necklaces/ bracelets and main handset)	Button alarms worn as bracelets or necklaces which the wearer can press if they need assistance – call will be answered by the relevant care monitoring service	When alarm button is pressed	Georgette Angela	Public
Assistance cords	Can be located in various rooms for resident to pull if	Monitored by the housing association/ care provider	George	Public

Table 10: Devices used by my key participants

	they urgently require assistance			
CCTV/ remote cameras	Cameras that a family member/ allocated person, can view to check on the resident	Data on movements	Georgette	Private
Activity trackers	e.g., Fit Bits/ phone pedometers to measure activity levels	Data on movements, location	George Geoff	Private
Table-top (and handheld) magnifier	Large scale magnifier that can be used to assist partially sighted individuals to read newspapers, magazines, books	None	Geoff	Charity
Synaptic tablet	Samsung tablet with application overlayed to transform tablet into talking tablet for Geoff who is registered blind	Similar data to generic tablets, as well as voice recordings	Geoff	Charity
Talking watch	Speaking watch that will physically read out the time when requested by wearer	None	Geoff	Charity
Audiobook reader	Simple audiobook reader that can be used by partially sighted/ those registered blind	None	Geoff	Private
Laptops, tablets and smart phones	Variety of laptops, tablets (and kindles) and smart phones to keep maintain hobbies and social connections	Data on browsing habits, specific apps may collect further data	All	Private
Home adaptations – i.e., for MS (including voice activation technologies)	These were planned for lain's new DIY HSH – i.e., pocket doors, movable walls, voice activated blinds	Can depend on the specific adaptation, but capable of collecting data on routines and patterns of movement and activity	lain	Private
Smart heating	e.g., Hive thermostat to offer 'smart' heating capabilities	Data on heating patterns	lain	Private
Home adaptations – i.e., for wheelchair	Hollowed out cupboards, specialist cookers and pots	None	Georgette (and lain to an extent)	Public

Through this table I highlight that there are a variety of devices available under the guise of healthcare smart homes, however the access to these range of devices can differ from individual to individual. Additionally, a single device can be used in different ways (by different people) resulting in different outcomes. In connection with RQ1b (How do those living in a DIY HSH interact with the various technological devices?), the range of devices and commissioning sources summarised in Table 10 indicate that there are likely to be multiple experiences of DIY HSH living. The range of devices indicates the creation of a range of both identities (RQ2a) and

futures (RQ3a). Finally, these experiences may differ according to the connections and make-up of the wider caring networks and the extent to which these devices can mediate these different networks and relationships. This will offer potential answers for RQ2b (How do DIY HSH shape the identities of wider caring networks?), RQ2c (To what extent are wider caring networks important for the identities of DIY HSH residents?) and RQ3b (How does planning for the future differ between older people and their wider caring networks?).

3.5 Approach to analysis

In this section I will justify my approach to analysis. I adopted an interpretative phenomenological analysis approach (Smith et al. 2009; Desjarlais and Throop 2011) as it aligned with my theoretical approach and research questions which sought to gain a better understanding of the lived experiences of a phenomenon. There are seven flexible stages to interpretative phenomenological data analysis, as highlighted in Figure 18 which is adapted from Smith et al. (2009).



Figure 18: Seven steps of interpretative phenomenological analysis

First, drawing on Smith et al.'s (2009) flexible framework, I immersed myself into my original data (e.g., observations, interviews, autoethnographic and field dairy and film footage) and then (step 2) began to make a connection between and within my different data sources (i.e., making notes as I went along, of things that were frequently mentioned or seemed unusual). Thirdly, I tried to focus on large chunks of data to develop both emergent themes and vignettes. Step four was to search for connections across these emerging themes. Step five was to try to keep an open mind when moving onto another piece of data. Step six involved looking for patterns across cases. Finally, step seven involved the importing of theories to act as a lens through which to view the analysis (highlighted in my upcoming results and discussions chapters). I undertook this process both throughout and after my fieldwork. Within this research, data was displayed in the form of several overarching codes that aligned to my ROs and RQs (e.g., home, identity, futures) from which conclusions can be drawn. These codes represent descriptions of the phenomenon (of DIY HSH living) which describe the 'essence' or core commonality and structure of an experience. These are then verified through the degree to which the meanings emerging from the data were plausible, sturdy and valid (Miles et al. 2017). Conclusions were drawn around what emerged from the data in relation to lived experiences and the answers that they provide for the overarching research questions.

3.6 Methodological reflections

In this section I reflect on the limitations and implications of this methodology, specifically, study design (3.6.1) and data collection (3.6.2). These reflections offer a methodological contribution around creating a multi-modal ethnographic approach for researching the experiences of both key participants and their wider networks. Furthermore, they highlight the novelty of

researching DIY versions of HSH, in obtaining perhaps more realistic understanding of living with smart and assistive devices.

3.6.1 Reflections on study design

As I was interested in people's experiences of a phenomenon in-depth and over a longer time, some of which may be non-verbal experiences (given that residents are interacting with technology), I found a qualitative methodology to be appropriate, however, there are still underlying limitations. In terms of methods, the use of ethnographic methods, as with any method, can have several limitations in terms of: intensive use of time (Silverman 2010); difficulties for the researcher in balancing the roles of 'outsider' and 'insider' (Fetterman 2009); and making sure that I was understanding the realities of the phenomenon, rather than the reality that the participant would like me to see (Goffman 1971). Ethnographic approaches offer flexibility in terms of data collection (e.g., seeing what emerges over time), however, the presentation of this data by way of storytelling again highlight that the subjective assumptions of the researcher and participant need to be recognised and that replication and quantification of results are difficult (Delamont 2009).

Utilising a triangulated approach to methods (Silverman 2010) reduced the impact of these limitations, however, they will never disappear fully as they are present in every method given that methods and methodologies are lenses through which we view and study the world, simultaneously focussing on and blurring other certain aspects. As with most research, I present a snapshot in time of the experiences of my key and wider caring network participants which may not be representative later. By undertaking data collection over six months, I reduced the impact of this limitation to an extent, but it is nevertheless an issue for all research.

3.6.2 Reflections on data collection

In terms of participant recruitment, as an ethnographic approach was most appropriate, a key limitation was the financial constraints in terms of my research budget. Fully-fledged HSH (and use of the HSH concept) are still rare in Scotland, and thus I had to recruit key participants who used smart healthcare technologies at home but did not necessarily consider themselves to be resident of a fully-fledged HSH. By fully-fledged HSH, I mean new homes which are specifically designed and built by professionals (rather than residents and their wider caring networks) for the purpose of incorporating health and smart technology devices to seamlessly allow independent and safe living. Within Scotland, examples include some of those built by Blackwood care⁸ or Albyn Housing's 'Fit Homes'⁹. Residents of these few existing Scottish rural HSH developments were already involved in other research studies (TEC 2019), and thus, as one gatekeeper put it, 'they've been interviewed to death'. I was also conscious that in such existing HSH developments the participants were often contractually required to participate in the connected research as a condition of obtaining and maintaining their homes. I was wary of this as I did not want any potential participation in my research to feel like an obligation (Hammersley 2018). As I could not necessarily offer key participants anything in return in terms of definitive beneficial impacts, 'I just wanted to learn more about their experiences', it was a 'tough sell' (Bryman 2012).

Identifying key participants through social workers was also tricky. I was often reliant on social workers as gatekeepers in these situations, and there was a worry that they may promote or hide certain potential key participants (Emmel et al. 2007), however, I was not explicitly aware

⁸ https://www.blackwoodgroup.org.uk/blackwood-house

⁹ <u>https://carbondynamic.com/fit-homes/</u>

of this in my research. In some cases, it was hard to get hold of social workers because they were so busy, however, I did recruit one key participant through an occupational therapist. I also visited a rehabilitation care home which utilised smart health technology with a social worker (Glenda) to try to identify new key participants. However, this was unsuccessful, as outlined in the following excerpt from my field diary.

The centre acts as a gateway between hospital and home, where residents can have some time (usually a few weeks) to rehabilitate further before heading home. Each room is equipped with some smart technology and monitoring equipment such as an Alexa and motion sensors, which the residents can take home with them for up to four weeks for free once they leave the centre. On this occasion there were five residents in the centre, one was sleeping so I spoke with four of them. I spoke with one resident for quite a while, she was 67 and had recently had a stroke at home and broken both her arms which meant that she had to spend some time here in rehabilitation. She spoke at length to me about all the smart technology she used at home, and how she thought there was not enough support available to help people use such technology. However ultimately, she said she couldn't participate because she needed to fully concentrate on getting better.

(Fieldnote from my visit with Glenda to the rehabilitation centre, June 2019)

This anxiety that my research would be 'another thing to worry about' was quite frequent amongst potential key participants. Most potential key participants here had multiple and complex health needs that meant that although they may benefit most from using the smart healthcare devices, and their experiences would be of great value, they simply did not have the time (physically and mentally) or the energy to take part in the research. This finding was also experienced in many studies seeking the participation of people with disabilities in research occurring in the home (Bashir 2018). This finding is a lesson for future research around how best to engage with this group to gain some lessons over good practices for future developments of smart and assistive devices and homes. I was restricted, due to lack of research budget, to include any participants from remote rural locations. Although such key participants may have offered a different layer of findings, I could not afford to undertake a multi-visit approach to such remote locations. I also had access to variable numbers of wider caring network members per key participant. Having more consistent and comparable access across network members would also have been a helpful addition to the research.

In terms of reflections of the specific methods, I found that digital storytelling proved difficult to implement for several reasons. Appropriate equipment and training were hard to find given my tight fieldwork budget, so it was often difficult to know what or how to film. Thus, I erred on the side of caution and filmed as much as I could. However, in the end, I managed to create a film that I and my key participants were proud of. Furthermore, it created an additional layer of data, for use both within the thesis and to provoke further (and more open science focussed) conversations with wider audiences on the specificities of ageing with DIY HSH beyond what is potentially possible through a written thesis. Similarly, keeping a reflective diary and recording observations were at times difficult, particularly in the initial visits when I did not know my key participants very well. This got easier with time. Reflecting on the interviewing, it was effective to have a few 'stock questions' to get the ethnographic conversations started. It was tricky to ensure full consistency throughout the visits with all key participants as each had different experiences that they wanted to highlight, and as such, identical questions across all visits was not appropriate or helpful. The use of multiple ethnographic methods allowed me to create some interesting contributions to research around DIY HSH experiences and living with smart and assistive devices. It also enabled some participatory elements in terms of the key participants being involved in the final edit of the film and thus allowing them a greater sense of ownership of their voices in the final product (both thesis and film). Overall, I have developed

a robust qualitative methodology that can be used in future studies involving the multiple and competing experiences of technology and the home.

Given the intensive and long-term nature of this research, which was being conducted with older individuals with various health conditions, there was always a risk that some key participants may drop out. This could have been for numerous reasons such as the research becoming too time-consuming, the key participant becoming ill, or in the worst instance having passed away. One key participant (Angela) did drop off early on in the process, but luckily, I found another key participant (lain) soon after to replace them. After my second visit with Angela, I was unable to get in touch with her again (i.e., I left voicemails, but these were not returned). After a while, I had to assume that she was no longer interested in participating in my research. However, the observations at the dementia group and my autoethnographic reflections were additional forms of data. Two key participants had 'health events' in between my visits with them. Georgette had a bad fall in her house, and George had a heart attack in his home. Fortunately, they both recovered quickly and were happy to continue in the research, which may also highlight the extent to which my key participants were keen to be 'good research participants' in upholding their appointments with me even after these events.

Finally, given the specific rural issues of housing, healthcare and ageing introduced throughout Chapter 2, I expected my key participants to discuss rural issues in relation to home, identity and futures to a greater degree. However, even though they all lived in rural areas, they rarely spoke about rural issues. Thus while 'rural' provided the geographical focus, this thesis concentrated on other (more data) rich findings that emerged from this research (i.e., in relation to home, identity and futures). Furthermore, gaining participants from less remote locations meant that my findings were potentially more applicable across a large range of geographical areas.

3.7 Conclusions

In this chapter I presented the methodology underpinning this thesis. Initially, I explored the study design. Following a phenomenological theoretical approach to explore the phenomenon of DIY HSH, and recognising the existing literature and gaps, I used qualitative methods to understand the experiences of five older people and their wider caring networks of living with DIY HSH across Scotland between June 2019 and January 2020. Specifically, I utilised multiple ethnographic methods: visual ethnography (and digital storytelling), observations, (unstructured and semi-structured) interviews, and autoethnography. I analysed my data using interpretative phenomenological analysis, both throughout and after my fieldwork period, to generate findings according to my research objectives and questions. Finally, I concluded the chapter with some reflections regarding my positionality, my study design, data collection and analysis, and the steps I took to manage their potential impacts. Overall, through this methodology chapter I have established a multi-modal ethnographic methodology to understand the multiple experiences of DIY HSH living, both for residents and their wider caring networks. Such a methodology can contribute to the literature gaps on both the longer-term experiences of living in DIY HSH, and the gaps around the impacts on, and experiences of, multiple occupants and frequent home-visitors (i.e., wider caring networks). In Chapter 4 I now build on some of these reflections, drawing on autoethnographic data, to highlight some parallels between the experiences of my research participants and my own personal experiences which occurred during my PhD.

4 Autoethnography: Troubling the field boundaries

4.1 Introduction

As highlighted in Chapter 3 (section 3.3.4.3), the boundaries of 'the field' in ethnographic research are not always clear at the outset. Instead, they emerge and are moulded as the data is encountered. This was clear in my research. As my time 'in the field' continued, I began to see similarities between some of my own experiences and those of my research participants, and as such, boundaries of the field became increasingly unclear (Naess 2016). I have placed this account here as although the story (i.e., the death of my dad) originated before my data collection began, the connections between my own experiences and those of my key and wider caring network participants only became clear during my fieldwork. In section 4.2 of this autoethnography chapter, I offer a personal story on a missed opportunity for smart and assistive devices in rural areas, resulting in the death of my father at home in a rural area. In section 4.3 I link this story to ongoing impacts on myself and my mum regarding our changing roles in the home (4.3.1), her requirement to learn new digital skills (4.3.2) and how these roles and skills continue to evolve (4.3.3). Finally, in section 4.4, I offer some conclusions, linking these discussions to specific ROs and RQs, and the links with my wider research.

4.2 The death of my dad

In 2016 my parents both took early retirement and moved from an urban area, Belfast, to a much more rural area, within a small, but somewhat remote town 30 miles south of Belfast. They had dreamed for years of retiring to the countryside, and my dad had spent each day excitedly counting down the months until his retirement. In the year leading up to their move,

my mum spent her evenings trawling the property pages and google maps looking at potential new homes (at that time this was the limit of her digital engagement), and they spent their weekends going to view houses. They probably would have moved to Scotland if it hadn't had been for my dad's season ticket and an almost unhealthy obsession with Ulster rugby. I remember on one occasion talking to him on the phone and he sounded very unhappy at finding out there had been a miscalculation from HR and he would have to work one extra month until his retirement. My mum had worked in a care home and my dad was a social worker, so they were both very aware of the problems and burdens within the health and social care sector. But they settled on Newcastle, County Down, and moved there in the summer of 2016. Having previously lived in the same house for 26 years, this was a big deal for them. After moving they spent their time doing up the house and the garden and walking their dog. Newcastle lies at the foot of the Mourne Mountains and my dad had never climbed Slieve Donard, the highest mountain in Northern Ireland, and so he was determined to do so before his 60th birthday. After a failed attempt in which we nearly lost the dog for good, my dad and I successfully summitted it in September 2017, a few days before his 60th birthday. Shortly after this, things began to slowly change.

In Northern Ireland, when you reach 60 you are offered not a cake or a telegram from the Queen, but a routine bowel screening! So, my parents sent off their screening samples in late 2017 and then my dad's results came back in 2018 with a query, and so he was sent in for a colonoscopy. The consultant told him that they had found small polyps (stage one cancer) and so he referred him for an operation to remove them. There were multiple mix-ups with the type of procedure he was to be admitted for and a lack of information on pre-surgery requirements, for instance, he was required to not take his diabetes medication on the morning of the operation but was not informed due to no pre-operation assessment. Finally, he was readmitted for the operation on 6th April. The polyps were larger than the scan had shown, and the surgery was more complicated than initially expected, so a colostomy bag was fitted. After this, my dad spent a week in hospital recovering. He was shown how to use the colostomy bag (my mum was not, as the staff member had visited earlier than agreed when my mum was at home). He hated his time in hospital and was frequently texting me to let me know this. He was discharged on Friday 13th April, even though he had been very poorly whilst in hospital and had even tripped over his slippers and fallen on the day he was let home. He spent 11 days recovering at home. This was a time of ups and downs. He was glad to be home and was told in

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the first week that all the cancer had been removed via a call from the consultant. But at the same time, he and my mum had no visits from health care staff over the first weekend after his discharge and he struggled to keep any food down due to being intubated in hospital and the colostomy bag frequently leaked, causing his distress. He had to live downstairs, no doubt impacting his relationship with his home. During these 11 days, my parents had one visit from the colorectal nurse, but knowing how busy and overstretched they were my dad did not want to bother them with any concerns. At one point he even said to my mum, 'I don't think I'm going to survive this'. When my mum called up the colorectal nurse for advice on the difficulties with eating and changing the bags, messages were not returned until the next day and then she was told, 'this is all normal, it just takes time'. The surgeon also gave similar advice over the phone. But as he had diabetes this was extra worrying for my parents. My mum also sought advice from the hospital dietitian, but her call was never returned. Then on 24th April, he became weaker. My mum had called the GP first thing that morning to request a home visit, but the GP receptionist could not confirm a time for the visit, saying, 'he IS dealing with very ill patients you know'. My mum was keen to call an ambulance, but as they were due for this visit from the GP that day my dad wanted to wait for him to visit first. When the GP finally arrived, he arranged for a rapid response nurse to come with an IV drip. The nurse was lovely and kind (I met her the following day when she visited after her shift to check on my mum) and administered the IV, but it was of no help. Whilst she was working on him, my dad began to lose consciousness, at which point my mum was told to phone the ambulance. My dad then had a sudden heart attack, but it took 40 minutes for any ambulances to arrive (no doubt partly because of their more rural location), by which time there was nothing that could be done. My dad died that day at home, aged 60, and had his funeral two years to the day after his long-anticipated early retirement.

4.3 Changing and evolving impacts on my family

I share this reflection, not to invoke an emotional response, but to highlight how my personal experience of death and bereavement has impacted my research (Woodthorpe 2009; Letherby 2015). The story I laid out in section 4.2 represents an example of a missed opportunity whereby smart and assistive devices could have had a more positive impact. I had now experienced first-

hand the overburdened health services, concerning the lack of home-visits from health professionals and an unexpectedly long wait for the ambulance, particularly due to the rural location of my parents' home. With hindsight, I was able to see just how useful certain smart and assistive devices could have been in this situation, for instance, a heart rate monitor may have highlighted inconsistencies in the readings, and the ability to video-conference healthcare professionals would have allowed healthcare staff to see my father face-to-face and then, at least hopefully, realise that his experiences after leaving hospital were not 'normal'. I now had lived experience, through my dad, to counter notions of the home as a good place to be ill or recover from illness, as is also argued by Visser (2019) and Pollock (2015). In the following three sections, I highlight how my mum has coped with this loss, through a changing role at home, the need to learn new skills and how these have evolved over time and across new situations.

4.3.1 Changing role in the home

Ever since this experience, I have seen first-hand how my mum, brother and I have coped in the aftermath. I have observed my mum being somewhat forced to become more familiar with smart devices and activities such as internet banking and email - things that used to be my dad's responsibility. This distinction between roles in the home also links to Strengers and Nicholls (2018) notion of the smart home and use of smart devices as a space for creating and amplifying gendered work and roles within the home, in that the majority of 'technical' jobs were undertaken by my dad. The importance of attempting to learn how to use new technologies before you are forced to after the loss of a spouse was also highlighted by my interview with Evelyn Hickman of Geoff's network. In supporting my mum with this process, my role has often been to help her learn how to adopt and use new smart devices and activities (Hine 2019). I have

often been the one to teach her (and mainly remotely from Scotland where I live) how to use her smartphone and internet banking.

4.3.2 Learning new (digital) skills

Also, since 2018, I have witnessed my mum taking on ever-increasing informal carer duties for my uncle, her brother who lived with bi-polar disorder. As highlighted in Chapter 2 (section 2.2.1) informal care duties are multiple and wide-ranging (Broese van Groenou and De Boer 2016). Within this role, she had to learn new digital skills (e.g., contacting the housing officer via email) to provide better care and support for her brother. Similarly, as I also found from attending the dementia carers group, this new carer role that my mum undertook was not one which is confined to certain shifts or hours of the day and started to become a full-time role. Also, my mum experienced additional and unexpected stresses from this role including extra cleaning of his home to make it hospitable enough to 'entertain' visits from professional staff and helping with logistical things like pensions from a distance (i.e., virtually) as her brother still lived in Belfast. More recently, this brother also passed away and I have watched her also come to terms with this.

4.3.3 Evolving roles and skills

My reflections in sections 4.3.1 and 4.3.2 have highlighted that caring networks can often take on multiple roles in smart technology use, being both recipient and receiver of care and support (Mennicken and Huang 2012). Here my mum was both learning new digital skills from me, whilst at the same time, using these skills (i.e., internet banking, emailing) to provide better care for her brother. This was also demonstrated by my key participant George, as he received daily care in the form of support check-ins through his alarm system, but also offered technological and physical support to other older adults at his lunch club who were not as knowledgeable about technology as he was.

I have also seen the great support that having a dog has been when living alone (Gee et al. 2017). Fergus (my mum's dog) was very useful in terms of maintaining a routine, 'getting her out of the house' each day, as well as for just having something to care for and as company at home. This was similarly highlighted by both my dog-owning key participants (Georgette and Geoff) and reinforced by their wider caring networks. This importance was further emphasised after the loss of Fergus just before the COVID-19 lockdown, highlighting the potential for increased isolation and loneliness. Luckily, she has now rescued a new dog (Mabel), when lockdown temporarily eased in Northern Ireland in July 2020. Again, more positively, I have witnessed her build new routines and new social interactions, by joining a choir. This was similar to my key participants' experiences of joining lunch clubs, shopping trips and poetry groups. I have seen similarities between the experiences of my mum and my key participants, their wider caring networks and the dementia carers group.

4.4 Conclusions

In this reflective autoethnographic chapter I have highlighted how my own experiences have both informed my wider research in terms of my positionality, and how these experiences have enabled me to better relate to some of my key participants and their wider caring networks in terms of shared experiences of grief, changing identities and roles, and the impacts of rural living. I have highlighted the importance of exploring beyond the more traditional data and boundaries of the field in ethnography, though particularly within autoethnographic accounts. This lived experience has allowed me an insight into some of the experiences also highlighted by my wider caring networks in this thesis, for instance, since the death of my dad, I have played a perhaps increasingly important role in my mum's identity regarding helping her to learn new digital skills and devices to complete tasks once undertaken by my dad. These skills are necessary for her maintaining the identity of a capable rural-dwelling person. As such, this has meant that my relationship with my mum (i.e., as part of her wider caring network) is becoming increasingly important as she navigates her new and evolving identity with some DIY HSH devices, linking to RQ2c. Had my parents been able to utilise more smart and assistive devices, linking to RQ3a in terms of potential futures with DIY HSH devices, a different future may have been possible (i.e., there perhaps would have been better collection of my dad's health data in the weeks after leaving hospital and as such action could have been taken earlier). As Hine (2019) highlights, autoethnography is interested in what is left out of more traditional qualitative accounts - the texture of lived experience (Ellis et al. 2011; Lake 2015; Hine 2019), which this chapter reflects. I highlight further autoethnographic reflections throughout the thesis.

5 Results one: The home when living with smart and assistive devices

5.1 Introduction

My health deteriorated to the point that I couldn't manage my house. It was quite a big house with lots to do, huge garden. I thought, I really should look for, I could see the way it was going, you know. I knew that it's not going to get better. So, I thought I better look ahead for somewhere small, contained and with an element of support. I was lucky enough...I applied, and I was lucky enough to get this place. We'd sold the house and moved here. It was perfect you see because it's quite compact. I can come here, do my cleaning, do the hoovering, and every two months I hoover [laughs]. I don't ignore the dust. I'm glad you came because it meant I was tasked to do that. So, it means I can do that in ten minutes. It's perfect for my needs.

(Visit one with George, July 2019)

This quote from George offers an example of how and why decisions are made to maintain and regain a sense of home, and that these experiences can differ when compared to a previous home. Nevertheless, this sense of home and making a home in either a non-smart or smart home is a fluid and active process, rather than a static one. Even here, George does not make use of the term 'home', instead referring to 'my house' and 'this place'. In this empirical chapter, I explore the experiences of older DIY HSH residents and their wider caring networks concerning meanings of home (RO1) (Figure 19). This is the first of my three results chapters, each of which will deal with a single research objective. I also include a floor plan drawing of each key participant's home in this chapter to highlight the context of the home, including key furniture and smart and assistive devices. These drawings were completed by myself and I provide most
detail in each of the living rooms, as this was both where the resident spent the most time and the main settings for my visits.



Figure 19: RO1: Explore the experiences of older people living with DIY HSH concerning meanings of home

In section 5.2 I explore how my participants (both key and wider caring networks) considered and discussed home (connecting to RQ1a). In section 5.3 I explore how HSH technologies are changing the meaning of home (connecting to RQ1b). In section 5.4 I explore the emerging contradictions between these motivations for living in DIY HSH and the experiences concerning meanings of home (connecting to RQ1c). In the conclusion (section 5.5) I highlight that, firstly, my participants considered and discussed home in a multitude of ways, however all discussions connected to an emotional connection to the home, rather than a physical connection (i.e., a house that is physically safer may not translate to an emotional connection/ sense of home). Secondly, the motivations for DIY HSH living (i.e., independence) often differed from the motivations of their wider caring networks (i.e., safety and peace of mind) regarding the devices that were utilised and suggested, thus creating a diminishing sense of home. Finally, my participants demonstrated that they were creating DIY forms of HSH¹⁰, by relying on a range of smart and assistive devices to maintain a sense of home and the multiple motivations of safety, peace of mind and independence, however, this was not always achieved. Thus, living with DIY HSH (and the associated devices) could help or hinder the sense of home depending on the extent to which my key participants could feel in control of their own surroundings and that they existed as part of a wider community.

5.2 How do my key participants consider and discuss home?

Through my ethnographic fieldwork, I came to understand that my key participants experienced their homes in a multitude of different ways. Each experience was reliant on an emotional connection to the home and what this represented. Specifically, the home was experienced as a place of safety (5.2.1), social relationships (5.2.2) and forging identity and control (5.2.3). Finally, in section 5.2.4 I reflect on how these experiences related to feelings of empowerment, arguing that the absence of these feelings led to a reduced sense of home.

5.2.1 Home as safety and security

Home, as a site of safety and security, was important for both George and Georgette. These examples, followed by the importance Geoff and Anne placed on having their family nearby, are explored in this section. As I illustrated in both the quote at the start of section 5.1 and the fieldnote below, George moved to his new flat to improve his safety at home.

¹⁰ DIY HSH are HSH which are created through the accumulation (by the resident and/or their wider caring networks) of predominantly privately commissioned smart technology devices (i.e., Alexas, Fitbits, CCTV cameras) - to create a makeshift rather than more formal HSH which instead are designed and created by professionals before the resident moves in.

When I first went to meet George, he greeted me and showed me through to the living area [see Figure 20]. This was the main area of his flat, with both his small kitchen and bedroom leading off of here. George's living room was filled with books and DVDs, and there was a gas fire always purring along in the background which made it feel quite homely. He had pictures on the walls of his daughter, and framed photographs on the mantelpiece of himself from his army days. He also had printouts of his poems scattered around the room. His flat was always full but tidy. Old furniture, gathered in France and from his old house, was dotted around his home. There were also lots of smart healthcare devices around his house, including fall alarm cords, a Fitbit, an Alexa, a smart television and all its associated devices, and a laptop that his daughter Kate told me was 'essentially a gaming laptop for him to chat on his message-boards' [you can view George discussing all his smart and assistive devices here¹¹]. He had fall alarm help cords in his living room and bathroom, and an intercom buzzer system near his door which he had to answer each morning to alert the staff he was alive and well. He had moved here to have more security and somewhere that was more manageable to clean as he now lived alone. (Condensed fieldnote from my visits with George, 2019-20)

In this fieldnote and quote I highlight the combination of empowerment and disempowerment that George felt from his house. From the film clip you can also see George gesturing to where the smart technology devices were located around him, all of which were in easy access from his chair – so he had thought carefully about where to place them to enable frequent use (which increased his feelings of empowerment). You can also see that he had so many smart technology devices that it was quite hard for him to remember them all (i.e., *'oh yes, and an Alexa!'*). George experienced some disempowerment initially, as he had moved here to have more external support through his (telecare) intercom alarm and assistance cords, being no longer capable of managing all the tasks in his previous house due to deteriorations in his health. The home layout drawing (Figure 20) depicts some of this support.

¹¹ <u>https://www.youtube.com/watch?v=jx8Vpg22B8&feature=youtu.be</u>



Figure 20: George's flat

Through this drawing I highlight the compact nature of George's flat, and the range of built-in safety measures (i.e., telecare assistance cords and intercom system) that offered this additional security. More information on his flat was given in Chapter 3 (section 3.4.1). However, when discussing these anticipated feelings of increased safety and security he referred to his house, not his home. For George, this sense of home came later when he felt secure and familiar in his new house.

George: Now that I can walk about with my eyes closed and be sure that I know where everything is, apart from my Kindle which I've lost...it's great. It gives me a feeling of security and confidence, and I didn't have that for a long time. I didn't have that for about a year. It was all new. I think that's how it is with me. I needed that time to become, I suppose to realise that it's mine, and it's only by usage that you get to know that. So, I know where to put my hands and things, I know where my coffee pot is, I know where everything is, and that gives a feeling of security.

(Visit three with George, Sept 2019)

Thus, a sense of home was not achieved by the move, but instead developed over time. This developed further as his involvement in the community and his ability to reform his sense of identity and independence at home increased (after moving to Cupar after his marriage separation). Similar experiences were reflected by Georgette who moved to her current flat seven years ago as her previous home was considered a safety risk for her and her wheelchair in the event of a fire emergency. Her new ground-level housing association flat was specially adapted for her wheelchair, offering enhanced feelings of safety as there were now fewer risks of housing-related accidents. Figure 21 highlights the layout of her flat.



Figure 21: Georgette's flat

This drawing illustrates Georgette's designated 'safer house'. It included wider doorways (for wheelchair access) with a lot of open-plan style living. I have also highlighted the location of her key smart and assistive devices. Important also in the drawing is the indication of the glass doors that overlooked Georgette's patio garden. Access to her/ a garden was very important to Georgette. However, for Georgette, the physical move to a safer house did not automatically translate to a sense of home straight away as is now highlighted.

Rachel: Does it feel like home, living here?

Georgette: Ach aye, it does...now. I'd a terrible time when I first came in. The woman above, she was a drug addict and so we'd police raids every other night. So, Lynne [Georgette's daughter]...if it wasn't for Lynne, I think I'd be in Craig Dunain [Inverness mental health hospital] ...it was horrendous. One night they were there with dog...sniffer dogs, and everything. They were throwing their cigarettes out of the bedroom window...landed on my bin. But the police were in here at the time and they got her red-handed doing it, because she was blaming me, 'it wasn't her taking the drugs' she said.

Rachel: That sounds stressful.

Georgette: But the chap that's up there now, you'd never know he was there. Oh aye, he's excellent, he's very quiet.

(Visit one with Georgette, June 2019)

Thus, this increase in physical safety did not simultaneously translate into increased feelings of security for Georgette. This feeling of security took time to develop.

Meanwhile, Geoff and Anne had moved to St Monans to be closer to Anne's daughter (Tracey) and her young family. Their house (Figure 22) was nearby to Tracey's house, and this appeared to give comfort to Geoff and Anne, knowing that their family was close by if they needed anything.

Geoff: We were just getting desperate because we had sold ours and we were hoping to find something down in Anstruther or Pittenweem, but we looked in this one when we first looked at it. We told the estate agents that we were interested, and they said right. So, they are supposed to keep you informed, aren't they? When we came up again, we asked to look around again, and they said it's been sold, but we didn't know. So, we then had to look again. We were looking at a flat in Pittenweem, a big flat it was. But fortunately, we didn't take it because that must have been 25 concrete steps up to get to the back door. As we drove up to it, the estate agents phoned us and said, 'it's back on'. It's so handy with the kids just 350 paces away, and I know that [because he had counted the steps].

(Visit three with Geoff (and Anne), Sept 2019)

Thus, safety and security, in knowing their family were close by, was an important factor in their decision to move this house in St Monans.



Figure 22: Geoff's home

Within their house, the kitchen seemed to be very much 'Anne's space'. Each time I met with Geoff, we would sit at their dining room table whilst Anne would be in the kitchen baking cakes for church and community fayres (also linking to the home as a social and identity-forging place). You can often hear Anne baking in the kitchen in the background of Geoff's film clips too.

Both George and Georgette recognised the importance of the additional support and safety, but found that the feeling of security, and thus sense of home, came later and not immediately from the increased safety measures. Geoff and Anne felt safe and secure knowing their daughter was so nearby. However, both Kate (George's daughter) and Lynne (Georgette's daughter) lived much further away (e.g., 3 hours, and 45 minutes, away by car respectively), thus the attempt for added safety and security had to come from smart and assistive devices rather than the wider caring networks. As highlighted in Chapter 3 (section 3.4.3), Georgette had a fall at home. The impact this fall had on Georgette was fearful of interacting in her community, which was troublesome as this was a key aspect of her 'sense of home'. In this section I have highlighted that safety can be a key motivator for moving to their DIY HSH, but heightened safety does not automatically create a sense of home. This is based more on feeling secure, which can develop, but also diminish, over time.

5.2.2 Home as a space for socialisation: The importance of community and relationships

Important to several key participants was the role of the home as a site or enabler of socialising. I highlight this through the examples of Georgette reflecting on her housebound neighbour and her love of having a dog, in Angela playing an active role in her community and George and Kate's discussions of Cupar and George's neighbours. This is first illustrated by Georgette in the fieldnote below regarding her discussions of her housebound friend and neighbour.

On a couple of my visits with Georgette she spoke of her friend and neighbour who spent a significant period in hospital and since returning home had not left her house. Her friend's family were not that close to her and so she had not had many visitors. Georgette always seemed very sad when we spoke about this, as she didn't feel like this was much of 'a home' for her friend. Georgette's house was nicely decorated with photos of her family and dog, and she took great pride and enjoyment in her garden.

(Condensed fieldnotes from my visits with Georgette, 2019)

This emphasises the importance of home for Georgette in maintaining relationships and connections. This promotes the importance of wider social and caring networks for the home to be considered as a refuge and place of sanctuary which is undermined if the home environment becomes a place of social isolation or connected to loss. Georgette also spoke frequently about how grateful she was to have her dog Molly to force her to get out of the house and feel part of her community, as illustrated below.

It would be awful if I was stuck in a place on my own all day. I have to get out with the boss [Molly]. Then you meet people, and it makes you want to go out. Don't you Mol...cheeky chops!

(Visit three with Georgette, Nov 2019)

Having a dog gave Georgette the 'excuse' to get out of her house and into her community. This also signals the importance of the specific type of home or tenure, and a benefit of home-living, as keeping a pet would likely not be allowed within a residential care setting. Meanwhile, Angela associated her sense of home with her family and being able to interact in her community, as illustrated below. Angela: I'm pretty well serviced. I've lovely neighbours. Until last year Neighbour X and Y [anonymised for privacy], were magnificent neighbours. I mean just unbelievable, and they still are even though they've moved a bit further away. They're now at Barley Cottage. Barley Cottage used to be called the slaughterhouse, but it isn't anymore. There're so much barley fields there, so that's nice. I've known them since...When I came here at first, we had at first, we had a housewarming party and there was Neighbour X and her dad. Neighbour X's dad was Jimmy Shand's minder. So, we had Jimmy Shand here playing for our housewarming. Lady Alexander, a waltz tune that Jimmy Shand wrote was about me. That's really special. As I say she still looks after me, I still see her once a week.

(Visit one with Angela, July 2019)



Figure 23: Angela's home

Through Figure 23 I depict the layout of the ground floor of Angela's three-storey house. Angela's living room was filled with photographs, paintings and books. It also overlooked Pittenweem beach and harbour, and her large garden could be viewed from her kitchen. Although Angela experienced the death of her husband whilst living here, she was very happy in her home due to her involvement in her community, but also because she still felt capable and in control within her home. Relatedly, the sheer number of photographs on the walls of her living room of her extended family (i.e., at birthday parties, weddings, graduations), emphasised that her home was a place of identity - as a mother and grandmother - but also a sociable place. This is illustrated in the fieldnote below.

Angela told me the stories behind several of the photographs on her wall, and I could see how proud she was of her family. One was a picture of her daughter on the day of her PhD graduation. Another, a different daughter during a dance performance. She joked that she had so many photographs because of her large family and she had to represent everyone equally. We then sat in her kitchen and she proudly showed me her colourful wallpaper which seemed very important to her, because it has been put up by two of her children. She made us coffee and offered me some cakes from the recent Pittenweem community bake sale.

(Fieldnote from my second visit with Angela, Sept 2019)

Thus, for Angela, her home was both a place of pride and socialisation, but also identity (connecting to section 5.2.3). In all of these illustrations, having positive relationships and interactions within the wider community was key. George's attempt at feeling at home through achieving independence and security was connected to the idea of home as being more than a house. George was a very sociable person and liked to fill his time with social activities, and often creative activities. Specifically, since it had been harder for him to participate in and enjoy his more active hobbies such as long-distance cycling, he had become a keen poet and attended a lunch club daily to maintain and forge new connections and relationships within his community. He highlighted the importance he placed on neighbours and community here.

George: It's also helpful that I've got to know the neighbours. It's comforting to know that there are some people worse off than yourself. It's mostly the women because the women outlive the men. But it's nice to know them and know that somebody knows you. So, I made a point of trying to befriend my neighbours, and they're kind. There are some people in this block...it obviously used for...I wondered of the reluctance of the

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housing people, I couldn't understand, when I viewed it and said, 'this is absolutely great', they said 'really?', and then I realised they used some of these for placing men who had learning difficulties and needed a wee bit of protection. Above me, there's a canny guy, a nice black man, and there's a couple more in the buildings. That's fine because they're all very nice. One of them takes my bins out for me because I can't manage, in fact, he takes everybody's out, and that's nice and kind.

(Visit two with George, Aug 2019)

This reinforces the sense of empowerment he felt from feeling part of a community. Moreover, his daughter Kate was also appreciative of the location of his current house to enable him to feel at home and part of a wider community regarding its amenities and services.

Kate: It's interesting because when they first came back from France, he wouldn't even consider anything in Cupar...this he denies now though. My mum loved Cupar, but he said it was a hole of a place. But in the centre, it's a lovely wee place to live, and he's really thoroughly enjoying it. I'm so happy that he's happy in his place, because it's just there to the chippy and there to this, and there to that. And as painful as walking is, he can walk to places which is great.

(Interview with Kate, Nov 2019)

As such, Kate demonstrated the empowerment she felt from knowing her dad was living somewhere with good access to support and services, whilst George experienced this empowerment through the good relationships and connections the location of his house enabled.

Here I have demonstrated the importance of community, in terms of amenities and services, and the relationships that community can promote. These feelings were experienced to different degrees by each of my key and wider caring network participants, but all related to

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feelings of (dis)empowerment. Such (dis)empowerment was also closely considered within conceptions of the home as promoting identity and control.

5.2.3 Home as identity and control

The home was also a site of identity and control for my key participants. In this section I offer examples of the importance of identity through Iain's impending move to a home in which he would be more (cap)able, through George's connections to his former hobbies, Georgette's connections to her garden, and Geoff's tactics to feel capable in his home through touch. This importance of identity was initially highlighted in the following fieldnote describing Iain's impending move to a smart bungalow.

Iain, who lived with advancing MS, had the help of carers three times a day for cooking and showering, but he often remarked on his hopes of living in a house with more technology in order to have less reliance on carers and more independence in his routines. He designed his current house himself [see Figure 24] to overlook the fishery and take advantage of the spectacular views. It did not have as many photos dotted around as in George or Georgette's homes, but it still had a somewhat homely feel. It was however full of old wheelchairs and furniture that was no longer fit for purpose for someone in a wheelchair. He said his current house felt less like a home, and more restrictive, once he could no longer use the upstairs level and appreciate the views, and knowing he was going to be moving soon. This highlighted to me it was not a home that was fully fit for purpose anymore as it was not keeping up with the changing circumstances of its resident. Iain also attested to this.

(Condensed fieldnote from my visits with lain, 2019)

Given that lain designed his existing and future homes, this may explain why he felt quite emotional in terms of his relationship to his home. For lain, his upcoming house was a metaphorical mirror of himself, as he helped to design and then reconfigure his mirror as one of 'a capable person'. However, his existing house was no longer as fit for purpose, given his increasingly reduced abilities due to his MS. Through Figure 24 I illustrate Iain's existing home, highlighting the non-portable (privately commissioned) devices and some of his old wheelchairs. The drawing also focuses on the ground floor, as Iain could no longer reach the upper floor. More positively, it highlights the impressive view overlooking his fishery. However, overall, it depicts the limitations imposed by Iain's existing house as he could not access either the upper floor or the view by opening his curtains when he would like.



Figure 24: Iain's house

As is illustrated in the quote below, Iain felt that his existing home had lost its homely feeling. You can also listen to this conversation <u>here</u>¹². You can also hear the sadness in Iain's voice when he is talking about his lost opportunity to experience the view from upstairs.

Rachel: So, I wondered if this place feels like home and what steps you might take to make the new place feel like home?

Iain: This, to a certain extent, has lost a little bit of the feeling of home because when I started off, I lived upstairs. Have you been upstairs?

Rachel: No, no.

Iain: Aw you ought to pop up and have a look.

Rachel: Oh yes, you said it had a really nice view.

Iain: Yes. And it hurt having to make the move downstairs because I could no longer cope with going up and down the stairs. Then having to change the wet room. I had to get...this [the counter] originally came out at this level...I had to get somebody to come and drop it for me. I had to make changes to the house and its lost a little bit of its homeliness. You can see the way everything is, and the furniture is, it's a clutter. So, it doesn't have the original feeling that I got from it.

(Visit two with lain, Oct 2019)

The design of his new house may have been an attempt to portray a self-image of independence and capability once more, and also increase his sense of home. Meanwhile, George portrayed

¹² <u>https://www.youtube.com/watch?v=9vPPXKU8d7c</u>

this sense of capability at home by maintaining connections to his old more active lifestyle. As illustrated below, George, as a keen cyclist, tried to continue this hobby at home.

Between my fifth and final visits, George had bought a fold-up exercise bike and remarked how by just looking at it the 'pounds had dropped off him'. The bike was awarded a place by the wall beside the window, highlighting another aspect of his identity as a cycling-enthusiast. (Fieldnote from visit six with George, Jan 2020)

George considered his home as a safe space to continue this hobby, albeit in a less risky form (i.e., static indoor bike). George associated his sense of home with capability and independence, the 'goalposts' for which changed over time. Previously he lived in France and built much of his own house which he said was 'my dream house, the only house I'd ever loved, I had to leave it and come home' (Meeting one with George, July 2019) because his wife wanted to return to Scotland. In building the house in France, George felt capable and confident in his abilities. After returning from France, George and his wife lived in a large house in Auchtermuchty where he did all his own home repairs until it became too challenging for him.

I had a house with a huge garden and what really did it for me was, I went outside to sweep my drive in the front, and I found that I had to sit down. I lost a third of my heart, and I found I had to, in the middle of sweeping a drive for god's sake, I found I had to sit down and rest. I thought I can't really do this. I used to do all my own repairs, even change slates up on the high roof. I used to do everything, electrical, tiling. (Visit six with George, Jan 2020)

This frustration at not being able to do all the tasks in his house signalled a reduction in him feeling a connection to his home. This was also likely coupled with the breakdown of his marriage at this time which again led to reduced feelings of control at home. Thus, his move to his new house in Cupar was an act of empowerment and taking back control. However, he struggled with having to identify somewhat as someone in need of additional support, as is illustrated in the quote below.

When I find that I can't...you know it's hard for me to get down on my knees no matter mind anybody else. I do rely on the care people manning the intercom you know. If I...I don't sleep well...but if I don't put off the wee signal in the box, then a wee voice comes through the intercom, 'are you alright Mr White?'. It's reassuring and gives a sense of security that there's somebody there. But on the other hand, it chips away at the person.

(Visit three with George, Aug 2019)

George further expanded on the 'wee signal in the box', which I captured in the fieldnote below.

George spoke of having to make sure to remember to alert the staff if he was going to be away for a night (e.g., on holiday) so that they did not try to contact him through the intercom on those days, as if they did not hear from him when they were expecting, they would have to come into the flat or call an ambulance.

(Condensed fieldnote from my visits with George, 2019-20)

This move was both empowering and disempowering for George, rather than simply one or the other. Meanwhile, Georgette felt empowered and happy within her garden, as it was a place in which she was happy as she could still do some gardening activities herself. This is illustrated in the quote and fieldnote below.

Rachel: Does this place feel as homely as the last place you were?

Georgette: Yes...ahh...it does now. And I've a nice garden that I can sit out in the back when the weather's good. It's a sun trap ... when the weather's good.

(Visit one with Georgette, June 2019)

Her garden was secluded and very colourful, filled with an array of colourful potted plants that Lynne, Georgette's daughter, helped her to care for, along with a gardener once a month. We sat out in it on my second visit with Georgette and it appeared as though this is where she was happiest in her house.

(Fieldnote from visit one with Georgette, June 2019)

Although the garden was outside her house, it was important to Georgette's sense of identity. It was a space in which she felt fully in control. Meanwhile, for Geoff and Anne, they had made adaptations in their house to help Geoff feel more at home and in control, especially if things were always kept in the same place, as he illustrated to me during my fourth visit.

Rachel: I also wondered, all the different pieces of technology you have, does that make you feel more, or less, at home here? Or it doesn't make a difference.

Geoff: I think it makes it more because you're able to do things that you couldn't if you didn't have it. You've not been in the kitchen, have you?

Rachel: No.

Geoff: Because I have trouble reading small thing, the clock on the wall in the kitchen is this size [demonstrates large clock], which I can see quite easily, I don't have to walk up to it. Things like that that we've done does make a difference and make it easier. If things are in the same place all the time, it makes it easier.

(Visit four with Geoff (and Anne), Oct 2019)

Thus, for Geoff, knowing his way around his house by touch and by memory brought a positive connection to his home. In this section I have highlighted the importance of identity and being in control in how my key participants experienced their homes. However, identity and control were understood in slightly different ways for each key participant. For Iain, it was the ability to create a new smarter home for independence, for George, it was feeling comfortable to undertake his hobbies, and for Georgette, it was managing her garden. Whilst for Geoff, it was feeling comfortable in knowing his way around his house by memory and touch, rather than sight. All these motivations or activities related to feeling comfortable at home to do the tasks they enjoyed doing such as cooking, a form of cycling or gardening.

5.2.4 Summary

In summary, although my key participants understood home in various ways, but all were connected to an emotional sense of home, rather than any physical experience. As a key finding for RQ1a (What is home?), the feelings and considerations of home are somewhat dependent on the specific access that my key participants had to specific characteristics that enabled positive feelings of home, such as, homeownership, home being within a vibrant community or motivation and ability for ageing-in-place. For example, Iain's opportunities for creating his ideal DIY HSH was possible given he was designing and funding this new build himself which was not an option for George and Georgette who had smaller financial reserves, and thus, had to find other ways to feel capable and reinforce their identities in their home (i.e., George through his exercise bike and Georgette in looking after her garden). This section supports my conceptual framework (Chapter 2, section 2.4), concerning the importance of maintaining a sense of home within a DIY HSH. Through this section, I have gained some understanding of how this sense of home can be and is maintained by my key participants.

5.3 The multiple motivations for DIY HSH living

In section 5.2 I illustrated the various ways in which my key participants considered home. This section (5.3) explores the motivations for choosing to live in a DIY HSH. These motivations often

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differed within and across key participants and their wider caring networks. Through this section I offer findings for RQ1b (What are the motivations for those choosing to live in a DIY HSH?). Specifically, in section 5.3.1, I highlight that 'home' within a DIY HSH was also experienced by my key and wider caring network participants as a place of consumption of healthcare and capability data, in addition to (or sometimes in direct conflict with) a place of safety, social interaction or identity. Section 5.3.2 illustrates how my key participants were trying to navigate these multiple motivations of home within and through the creation of DIY HSH. Overall, through section 5.3, I argue that the multiple motivations for DIY HSH living can create feelings of (dis)empowerment which may differ depending on the specific access that a resident has to particular devices.

5.3.1 Home as consumption

Since the 1980s and 1990s, there has been an explosion of TV programmes on DIY processes of homemaking such as Changing Rooms and DIY SOS (Miller 2008). Such programmes promote the idea of home being something that can be bought and achieved through physical changes to a house, i.e., that the sense of home is waiting to be uncovered. In this section I highlight how the home is being potentially reaffirmed as a site of consumption through smart and assistive devices. I illustrate this through examples of Georgette consuming (or being consumed by) an increasing range of smart and assistive devices throughout the course of my fieldwork to keep her daughter Lynne happy, through Geoff and Anne getting somewhat addicted to consuming more devices through my visits after the recommendation from their daughter, and George consuming more devices to feel more 'at home'.

The paternalistic notions of smart and asstive healthcare technologies, in keeping with existing paternalistic models of healthcare, are offering longer-term ageing-in-place in exchange for

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additional consumption of one's data, and thus wants and desires, within the confines of the home. This is illustrated well via Georgette who utilised increasing amounts of privately commissioned devices throughout our meetings.

Georgette recently had a fall at home. Thankfully, she had the fall alarm. She wasn't wearing the bracelet at the time of her fall, but she was still able to pull herself along the floor to the alarm base unit and call for help. Nevertheless, the fall motivated Lynne to add more devices into her mum's house, specifically an Alexa and a pair of CCTV cameras. Lynne thought the Alexa would be helpful if her mum had another fall so she could call her using voice activation, and the cameras were to see if she had fallen, however on speaking with Georgette she thought the cameras were more to allow Lynne to doublecheck that she was wearing her fall alarm bracelet.

(Condensed fieldnote from my visits with Georgette, 2019)

As this fieldnote illustrates, the use of CCTV cameras in the home to observe residents, although providing peace of mind to the network members, has altered Georgette's behaviour. After the cameras were installed in Georgette's house, Georgette wore her community alarm bracelet more than she would have done previously as she could never be sure when she was being observed.

Georgette: Aye, I've got the bracelet on all the time. That's why Lynne put in the camera so that she could see.

(Visit three with Georgette, Oct 2019)

This highlights that Georgette was wearing her bracelet more to convince Lynne that she was safe within her home after her fall (view Georgette discussing this here¹³). In this clip you can see Georgette's wheelchair beside her armchair signalling that she cannot move about freely

¹³ <u>https://www.youtube.com/watch?v=EGgkL3reEAo&feature=youtu.be</u>

without her wheelchair. There was one camera placed on her TV stand (directly opposite Georgette's chair and to the right of where I would sit), so Lynne could see if Georgette fell when transferring between her wheelchair to armchair. The other camera was beside Georgette's front door so Lynne could see if Georgette left the house with/without her fall alarm bracelet. Thus, she was potentially 'being consumed' (through being viewed by Lynne) from many locations in her house. Georgette said she was reasonably happy with the cameras being in the house if it was only Lynne who was able to view the content. However, I am not sure that was true, as depending on the brand of camera other parties may also have been able to view the footage. Georgette appeared to place a lot of value on the fact that Lynne tended to suggest devices for Georgette that she used at home herself. This is illustrated below regarding her Alexa.

Rachel: Some people get worried about Alexas and things like that because they think that they're always listening. That's a big thing...

Georgette: There's no privacy, Big Brother's watching you.

Rachel: Exactly yeah. You don't know where the data goes.

Georgette: Well Lynne's got one herself right enough.

(Visit three with Georgette, Sept 2019)

Georgette put a lot of trust in Lynne's opinion. She was less worried about the impacts of using an Alexa knowing that Lynne already had one. Thus, perhaps the best way to encourage smart and assistive device use is through leading by example. Similarly, Geoff was given an Alexa as a present from Tracey (his stepdaughter) and thus seemed happy and excited to use it. Anne was also subsequently thinking about getting a second one for the dining room, as illustrated below. You can also view Geoff discussing his Alexa <u>here</u>¹⁴. From the clip you can hear the excitement in Geoff's voice whilst he talks about the potentials of his new Alexa. Geoff was also able to hear the Alexa even when it was in another room as he signals in the clip.

Rachel: But you're doing really well just taking an Alexa and being happy to use it. I go to see another lady [Georgette] and her daughter's trying to get her to take an Alexa and she's like, 'no I'm not having one, I'm not having it in the house'.

Geoff: Oh, Anne wants one out here [the dining room] too.

Rachel: You've got the bug now. You're addicted.

Geoff: Yeah.

(Visit three with Geoff (and Anne), Sept 2019)

For others, the lure of consuming new devices was hard to resist. George was aware of the ethical issues with Amazon and their products but, as shown below, was still tempted to use them.

Rachel: Do these concerns about technology and data put you off using anything, or put you off getting any pieces?

George: Well, it's a difficult one you know, because there's the allure of new technology. It's the same sort of problem you've got buying things from Amazon. Amazon, as we all know, do seem to exploit their workforce, and there's a moral issue about buying something from them. On the other hand, they are so slick, they are so

¹⁴ <u>https://www.youtube.com/watch?v=tha5KV2gKcM&feature=youtu.be</u>

slick at delivering, the logistics are so slick, and it's so well done, that you're tempted into buying from them because they make the buying experience so easy.

(Visit five with George, Nov 2019)

The ability to consume new devices and innovations within the comfort of one's home can be hard to resist. As such, for George, Geoff and Georgette, the home was a place to consume these devices, but in doing so, the benefits extended by this ageing-in-place solution can result in greater and greater control of one's home space by others (and in being consumed through surveillance by others). I discussed similar findings for Iain in section 5.2.3. These 'others' may be wider caring networks, technology companies, or non-technology companies such as online retailer Amazon. This rise of the DIY HSH needs greater interrogation.

5.3.2 The DIY HSH

The transformation of a home into a DIY HSH often (but not always) requires the existing home to be understood as risky in some form. Georgette's previous home was a fire-risk and George viewed his previous home as a risk because of the lack of additional support. Within this conceptualisation, these risks can be eased by smart and assistive devices. However, with fullyfledged, ready-made HSH rarely available, residents and their networks have turned to DIY versions of these homes, to ease these risks. In this section I explore some experiences of building DIY HSH through examples of Lynne utilising more privately commissioned smart and assistive devices to keep her mum safe, through George, Angela and Georgette reluctantly using fall alarm chords/ bracelets to improve their safety, and through lain being less restricted by home rental contracts thus having more freedom to tailor-make his ideal DIY HSH. Lynne always carefully considered the devices she suggested to Georgette. She was particularly concerned for her mum when she would leave her house alone (i.e., to walk her dog Molly). Georgette considered her ability to leave her house as empowering and enabling her independence, however, Lynne was a little more fearful. Lynne mentioned that, particularly as Georgette lived in a relatively rural area, she was worried that she may fall when she was out with Molly and have no way to contact anyone for help, as she often forgot her mobile when she leaves the house. Thus, Lynne even discussed putting a tracking device on Molly.

Lynne was thinking about putting a tracker on the dog as Molly goes most places with her. She thought of this because sometimes Georgette goes out and doesn't take her mobile phone with her, and she is worried that she may hit a pothole in the road.

(Fieldnote from interview one with Lynne, July 2019)

Lynne thought of innovative ways to reduce the potential risks to her mum. This highlights the potential use of a smart device (i.e., a GPS dog tracker) to reduce the risks of another assistance device (Georgette's wheelchair). This is an example of interoperability of smart health devices, whereby it is used for an unintended purpose, in this case, to act as a tracker for Georgette, rather than Molly, and reduce the risks from her wheelchair.

George used his intercom buzzer system and fall alarm cords, in case he needed assistance from the connected support worker whilst at home, however, he was reluctant to use the cords and intercom because he did not want to be a burden or bother to others. He also expressed some embarrassment over accidental fall cord pulls.

George: Then I've got the alarm system there, and that's a wee bit of added security.

Rachel: Yes, I was going to ask you about that ...

George: Except I keep setting the bloody thing off! The cord gets caught in my electric drill or something. Or I go through, and I pull the wrong cord in the bathroom trying to put the light on. And of course, the voice comes through the intercom, 'are you alright Mr White?' and I have to say aye. Or I could have been grilling a chop and the smoke alarm went off you see. So that's my life at the moment.

(Visit two with George, Aug 2019)

This consideration of fall alarms was shared by Angela and Georgette, who expressed to me their frustrations because the alarms represented restriction and disempowerment. Iain, meanwhile, did not even consider using a fall alarm because it could restrict his movements to only within his house.

Iain: There is, you can...The council will provide you with a wristband with a button on it to get help.

Rachel: Yeah, a call alarm thing.

Iain: Yeah, but it's not very successful because once you move away from the house, it won't work.

Rachel: Yeah, which sort of makes you more housebound than before in a way, which is not really what you want...

Iain: No, no.

(Visit one with lain, Sept 2019)

This highlights that although these publicly commissioned devices were designed to empower and offer freedom in a safe and controlled manner, they were not viewed or considered by residents in such ways. Any additional devices for George and Georgette were of a more portable privately commissioned nature (i.e., smartphones, Alexas, laptops), because of the restrictions on their potential to alter their homes, as they were renters rather than owners. Meanwhile, Geoff was able to acquire different pieces due to his career in the RAF, and he was also less in need of devices like fall alarms because he did not live alone.

Iain was also not constricted by housing rental laws (owning and building his own house) and so was planning to create the exact DIY HSH that he wanted (albeit within the confines of planning laws); and importantly leaving flexibility for when his MS worsened.

We talked at length about his new house, and the first time we met he excitedly showed me the architectural designs for his new DIY HSH. He was planning a multitude of technology to future-proof him somewhat for when he couldn't do certain tasks or use his kitchen. Within his new home, lain was planning to have a range of technologies including envelope doors, voiceactivated blinds, voice-activation for his garage door to drive his car in, Hive heating systems, a bed hoist and fall alarms, and a remote doorbell to see who is at the door from anywhere in the house. The interior walls would be hollow and movable (to allow for easier introduction of additional devices in the future). He always appeared excited at the potential benefits these devices could bring to his life and spoke with some frustration at having to rely on carers and their routines in terms of when he could eat and when the blinds would be closed at night. (Condensed fieldnote from my visits with lain, 2019)

lain's new house was also an attempt to feel more at home, by surrounding himself with things that were personalised to his circumstances and he was in control of, rather than things he could no longer do or spaces he could no longer make use of (i.e., reduce his risks, both physical and concerning empowerment). His existing house was becoming a space of compromise. As I mentioned in Chapter 3 (section 3.4.4), lain loved the view from the upper level of his existing house. He highlighted this on my second visit and encouraged me to see it for myself. Iain: I mean I was very pleased with this house when I had it built, and being upstairs, you didn't need to see the curtains upstairs because nobody could see in. It was nice waking up in the morning with the curtains open and seeing out. All that has sort of gone. It's not so much a home now.

(Visit two with lain, Oct 2019)

The view looked right over the fishing ponds, and lain told me it also had nice sunsets. In the last few years, lain has had to reimagine his existing home as a bungalow, moving his bedroom downstairs and creating a wet room on the ground floor. As his condition deteriorates, he will be faced with increasing difficulties in the kitchen and in completing once-simple tasks such as closing the curtains. When I first visited him, he demonstrated his difficulties carrying out activities in the kitchen because his existing kitchen was designed for a person living without disabilities. You can also listen to him simulate his new kitchen <u>here</u>¹⁵.

Iain: Yes, I think it'll [his new house] give me an awful lot more freedom.

Rachel: But yes, I suppose it's even simple things like being able to cook what you want, when you want it, and not having to wait for someone to come and do it.

Iain: Yes. And I mean I might be able to go back to doing a simple stir fry or something like that.

Rachel: So, the cooker and the hob are going to be much lower?

Iain: The cooker will have a space under it.

Rachel: oh yes, I remember you saying.

¹⁵ <u>https://www.youtube.com/watch?v=je_hWfJ_zJ4&feature=youtu.be</u>

Iain: The same with the sink. It will be a shallow sink. It won't be a deep sink. It will be a shallow one so I can go right underneath.

Rachel: So, you can reach in and still empty it easily?

Iain: Yes, and then there'll be spaces there for all my drawers that I can pull out. That means that I can get at everything in the drawer. Whereas with drawers, the only things I can get are at the front, you can't get to the back.

Rachel: I remember you saying that last time, I didn't even realise that, but of course it's obvious now.

Iain: Yes, I mean I've got drawers here [demonstrates] that I can just about get to whatever's at the back of the drawer. But I can't do that with a door.

Rachel: You need things that you can pull out.

Iain: So, it'll be even better if I've got a space that I can go in. This one's fine because... [*demonstrates*]

Rachel: Because you can fit underneath it still.

Iain: But if I could get to the side of it or being able to get to either side of it...So, things like that.

(Visit two with lain, Oct 2019)

This quote highlights lain's difficulties in his existing home, and his resulting desire to move. This desire is further emphasised in the following quote.

Iain: I had to make changes to the house, and it has lost a little bit of its homeliness. You can see the way everything is, and the furniture is, it's a clutter [gestures around the room]. So, it doesn't have the original feeling that I got from it. The new house, it's going to have plenty of space, and I'll have to try and create that home feeling in it. I think I will.

(Visit two with lain, Oct 2019)

lain was creating his own stage within his new DIY HSH to feel empowered through demonstrating his control and capabilities. In this section I have highlighted the DIY nature of how different devices are being used to create a DIY HSH. These DIY practices can differ, and result in differing feelings of empowerment, depending on the type of device and the limitations of access depending on the type of tenure. For Iain, this empowerment was clear through the potential of what his new home could do and would offer him. For the remaining key participants, empowerment was more of a compromise around what devices were available to them, dependent on access to various smart and assistive devices concerning specific financial, geographical, career and housing tenure characteristics.

5.3.3 Summary

Through section 5.3 I have discussed several ways in which smart technology has altered the meaning of home for my key participants and their networks, in terms of additional surveillance (and thus insecurity in feeling at home), but also more positively, as opportunities to leave the home (both physically and virtually) and enable impressions of capability and control. Ultimately through section 5.3 I have highlighted the multitude of ways the home can be experienced and consumed by my key participants and their wider caring networks, given that I am framing sense of home as a feeling rather than a specific place. These materialities can include peace of mind, safety, surveillance, (in)capability or evidence base. I have highlighted that the notion of the home is being reconstructed as a place to consume DIY healthcare, and the experiences of this can relate to feelings of (dis)empowerment which may differ, again depending on the specific access that a resident has to particular devices. From this section I offer findings for RQ1b (What

are the motivations for choosing to live in a DIY HSH?) concerning the specific types of smart and assistived devices that are available to different individuals (depending on specific financial, geographical, career and housing tenure characteristics). It also supports my conceptual framework (Chapter 2, section 2.4) which highlighted the potential importance of recognising individual characteristics when developing and promoting HSH for older people.

5.4 Contradictions of smart and assistive device use and meaning of home

In section 5.4 I highlight some of the contradictions that have emerged from my key participants' and their wider caring networks' experiences of DIY HSH regarding unintended impacts and interoperability of technology use and discussions of their aspirational home (i.e., one which is homely). This endeavour towards the aspirational home in the hope of achieving an emotional feeling of home can lead to the increased insecurity of my key participants and their wider caring networks in the quest for more security. Through section 5.4 I offer findings for RQ1c (How do those living in DIY HSH interact with the various technological devices?). Throughout section 5.4, to build on the notion of various DIY HSH, I will signify when I am discussing private, public or charity commissioned smart and assistive devices to highlight the variety of the interactions according to device-type. Examples of contradictions explored in this section are George's heightened insecurity, Georgette's frustrations in trying to use her devices (coupled with Lynne's view of Georgette's attempts as impressive), and Kate's continuing to live far away from her dad (George) and having to rely on smart and assistive devices for some semblance of peace of mind.

Firstly, there is a contradiction when there is a need to move to a DIY HSH for more security when the move itself can heighten feelings of insecurity, as experienced by George. George's move to a new house was partly motivated by the desire to have more technological support (e.g., publicly commissioned fall alarms) within his home, however, as highlighted earlier in this chapter (section 5.2.1), this move simultaneously created a feeling of insecurity and disempowerment because his prior feelings of familiarity with his surroundings, both in the home and the wider community, were lost. Thus, George was also experiencing some grief concerning his loss of familiarity in the quest for greater security through technology at home.

Smart and assistive devices were often utilised to give my key participants more control in their homes, however, if they were not familiar or confident with how to fix these devices when they would break then this sense of control could be lost. In the case of Georgette, for instance, all her privately commissioned devices (i.e., voice assistant (Alexa) and CCTV cameras) were installed and adopted after recommendation or persuasion (albeit well-intentioned) from Lynne. During my first interview with Lynne, she mentioned she was thinking about getting an Alexa for her mum, and by my third visit with Georgette, roughly three months later, she had bought one for Georgette, motivated by her mum's fall. This interaction can also be viewed here¹⁶. Through this clip I highlight Georgette's feeling of the process of getting an Alexa, and towards the Alexa and herself when she could not get it to work. This frustration appeared to cause her some amusement at least.

Lynne is keen to try and get her mum to use more technology in her home, for her own peace of mind, and to help her mum. She's looking at things like Alexa, as you can get an Alexa with a screen so you can sort of Skype call.

(Fieldnote from interview one with Lynne, July 2019)

Yet by my third visit, in reaction to her fall, Lynne had bought an Alexa for Georgette.

¹⁶ https://www.youtube.com/watch?v=kCELdV746Us&feature=youtu.be

Rachel: So, Lynne didn't convince you to get an Alexa yet?

Georgette: oh, be quiet, she bought one! She said that last night on the phone. I said, what you wasting your money for? She said it's not wasting money; I got an offer. Oh jeez! I had an Alexa on the Kindle, and I wouldn't have thought anything of it, but having it on the Kindle as well!

(Visit three with Georgette, Sept 2019)

By my fourth visit, Lynne had brought and installed the Alexa, but Georgette was having trouble with getting it to understand her accent (see Chapter 7). Georgette also highlighted the high levels of help she needed from Lynne to understand how to use her devices (i.e., laptop) or if anything went wrong.

Georgette: When I had the first computer and every now and again, I'd be phoning Lynne up because the screen had gone blank because I'd pressed the wrong button. I'm surprised she never got the sack from her job; she was the on the phone to me that much.

(Visit three with Georgette, Sept 2019)

Or on another occasion, when she faced problems with her Kindle, she asked Lynne for help. This can also be viewed <u>here</u>¹⁷. Through this clip you can also see that Georgette massages her legs a lot because of restlessness that she experiences due to her Charcot-Marie-Tooth disease, and thus perhaps is more easily frustrated with her devices as already has 'a lot to deal with'. It also shows that she gestures a lot whilst telling stories.

Georgette: I don't know what was wrong with my Kindle last week, but the Facebook and messenger icons disappeared from it. Then this safe mode came up on it, so it

¹⁷ <u>https://www.youtube.com/watch?v=SG1VynyHL2A&feature=youtu.be</u>

must have been updating something. But as soon as they update something, I lose the Facebook and the Messenger. So, I was saying to Lynne and she can't understand that. So, she said try your phone, and that was working fine, it was just the Kindle. So, I don't know what that was about.

Rachel: Even me, and I'm meant to be of a generation that understands these things. Sometimes something happens and I don't have a clue.

Georgette: No, she [Lynne] hasn't either!

(Visit three with Georgette, Sept 2019)

Whenever I met with Lynne, she would also say how pleasantly surprised she has been with her mum in trying out and often adopting new smart or assistive devices at home.

She just kept saying that she was really surprised at what her mum could manage. Lynne didn't think her mum would manage Facebook, or her Kindle or her fall alarm, but she's usually pretty good with all these things, so she's keen for her to get more.

(Fieldnote from interview one with Lynne, July 2019)

This difference of opinion highlights that the same situation can be experienced in vastly different ways. The same situation offered security, and empowerment, for Lynne in that her mum could use her devices and she could offer help when needed. However, it also offered insecurity, and disempowerment for Georgette, who lacked some confidence in fixing her devices if something unanticipated happened. This offers another potential contradiction and example of the multiple ways in which the home (and its materialities) can be experienced through DIY HSH in terms of offering both security and insecurity at the same time.
My data highlighted a contradiction of living with DIY HSH through a reimagining of space. By aiming to enhance resident independence and (virtual) social interactions through smart and assistive devices such as voice-assistants, remote cameras and social media, this has meant that children can live at some distance from their parent, however, this is a stress during a health emergency. Although George now felt more at home in his house, Kate lived quite far away, which she found stressful.

Kate: Of course, my mum and dad are of an age now that I really feel that I should be much closer. I mean, my dad, it takes me about three and a half hours to get to my dad; and about three and three quarters to get to my mum. Which is just madness! So, on the occasion that I get a horrifying phone call, even if I get in the car straight away, half a day has passed by the time I get anywhere.

(Interview with Kate, Nov 2019)

For Kate, her dad's devices (i.e., privately commissioned laptop, smartphone, Alexa) meant that she could easily offer support to her dad from a distance (i.e., phone calls, interacting on social media), however, not in the way she would ideally like to if she lived closer. Yet, lack of job opportunities in Fife meant that she could not easily move, and so virtual support was the only option for now.

Kate: I don't think there's any chance of my moving. So now I'm just thinking...retire! Retire as soon as you can, and I'll move at that point. Then it'll be back to Fife because that's where my friends, and what little family I have, that's where they are.

(Interview with Kate, Nov 2019)

Kate's desire for the future was to move back to Fife to be closer to her friends and family. She especially felt this recently, as George had had quite a few heart attacks, after which she would get a phone call from George stating this fact and saying how he was waiting for the ambulance

or he was already in the hospital. Then she had to make this journey down not knowing what she would be met with. Thus, there was a mismatch both between the expectations and realities of smart and assistive devices in terms of improving the sense of security, and as a result the sense of home, for some of my key participants.

The interactions with smart and assistive devices highlight that often new and additional insecurities are bred through this quest for additional security from smart and assistive devices, for instance, key participants may no longer easily know the way around their home, not knowing how to use their new smart and assistive devices, or wider caring networks may see a health emergency occur but not being able to prevent it. There was no clear division here of common experiences relating to specific commissioning sources, instead the division tended to relate more to the levels of empowerment experienced by a device. These experiences of empowerment tended to differ between key participant and wider caring network. George felt disempowerment over his accidental fall cord pulls, whilst Kate felt empowered to an extent knowing that the cords where there.

5.5 Conclusions

Through this chapter I have demonstrated some of the experiences that smart and assistive devices can have in connection with the meanings of home. In response to my research questions for RO1, I offer the following three key findings.

In response to RQ1a (What does home mean?), my first key finding is that for my key participants, the sense of home was something more than having the physical space of a house (i.e., more than the bricks and mortar). For these key participants, the home was a place to forge

an identity, to enable and develop social connections and a place to feel secure, in and above living in a safer house. The emergence of this sense of home depended upon: the ability for homeownership; access to a local and vibrant community (to enable social connections); and a desire to live at home for as long as possible. This may include the motivation to use smart and assistive devices to encourage this ageing-in-place. For example, lain's opportunities for creating his ideal DIY HSH was possible given he was designing and funding this new build himself, which was not an option for George and Georgette, who were not homeowners and had smaller financial reserves, and thus, had to find other ways to feel capable and reinforce their identities in their home. The multiple layout drawings also highlight these attempts to create a sense of home through the inclusion of mementoes and the range of smart and assistive devices. Relatedly, the home, within DIY HSH living is becoming a site of consumption but also a place to once again undertake DIY practices in DIY versions of the healthcare smart home.

In response to RQ1b (What are the motivations for choosing to live in a DIY HSH?), my second key finding is that such motivations are intertwined with the notions of maintaining a sense of home (i.e., RQ1a), the accumulation of smart and assistive devices or a move into a more healthcare smart home are signifiers (by my key participants) to both maintain this sense of home. The necessary moves to the home as a site of consumption and the rise of the DIY HSH are attempts to recreate this sense of home in a setting that the wider caring networks will approve of. Furthermore, the degree to which this sense of home may be reaffirmed within DIY versions of HSH is somewhat dependent on the specific types of smart and assistive devices that are available to different individuals, depending on specific financial, geographical, career and housing tenure characteristics.

In response to RQ1c (How do those living in a DIY HSH interact with the various technological devices?), my third key finding of this chapter is that these interactions offer new forms of insecurities through the quest for additional security, for instance, in key participants no longer easily knowing the way around their home, not knowing how to use their new smart and assistive devices, or wider caring networks seeing a health emergency occur but not being able to prevent it. All of my participants could see some benefit (or need) for certain smart and assistive devices; however, they also identified several unexpected impacts of interacting with these devices.

Thus, in response to RO1 (Explore the experiences of meaning of home for older people living with DIY HSH), this chapter has highlighted that although the ability to maintain a sense of home can be heightened through smart and assistive devices, such interactions come with some potential unexpected consequences (i.e., heightened insecurity or witnessing but not preventing a fall). Over the longer-term may negatively impact on the sense of home in terms of reducing the ability of the resident to feel safe and secure, for the home to act as a base for social interaction or to forge the identity that the older person would live to portray. Furthermore, the specific DIY HSH and smart and assistive devices that can be envisaged and accessed by each of my key participants varied from person to person depending on financial standing, geographical location, career history, housing tenure style and existing device knowledge and exposure, which have an impact on the type of experience that is even possible.

My key findings have so far supported my conceptual framework (Chapter 2, section 2.4) for developing DIY HSH which offer more optimal experiences for their older residents, concerning the importance of maintaining a sense of home, and in being mindful of spatial inequalities. However, this chapter's results highlight that spatial inequalities may not be the only important inequalities (i.e., differing levels and forms of access), thus I include this in the reconceptualisation of framework the framework towards the end of this thesis. Maintaining a sense of home will need to be frequently evaluated to account for the longer term and potentially changing experiences of DIY HSH living. My multi-modal and networked ethnographic methodological approach allowed the capture of these changing experiences of home over time to an extent, but my data still presents a snapshot of my key and wider caring network participants' feelings, meanings and materialities of home, which will no doubt continue to change in the future as health capabilities and social connections and relationships evolve.

Furthermore, the importance of place over and above home also emerged, in that the home is formed by more than simply a connection to the house. The sense of home also extends to the wider community and its suitability for a place in which to age well. Existing homes can be prohibitive to creating a sense of home as some of my key participants realised due to their evolving health and social care needs (i.e., relying on care workers to draw their curtains, or no longer being able to carry out their own DIY jobs at home). Thus, the importance of 'the right place' may also need a greater role in my conceptual framework. Next, I present my second results chapter, which explores how the identities of my key and wider caring network participants change through DIY HSH living.

6 Results two: Changing identities when living with smart and assistive devices

6.1 Introduction

In this second results chapter I explore the range of roles (and thus identities) that my participants appeared to play whilst living in and with DIY HSH. Similar experiences and findings were also emphasised in my autoethnography chapter (Chapter 4). This chapter offers contributions to my second research objective and all the related research questions (Figure 25).

RO2: Explore the extent to which living with DIV HSH impact		RQ2a: How do DIY HSH shape identities of older residents?
the identities of, and relationships between,	$\left\{ - \right\}$	RQ2b: How do DIY HSH shape identities of wider caring networks?
their wider caring networks.		RQ2c: To what extent are wider caring networks important for the identities of DIY HSH residents?

Figure 25: Explore the extent to which living with DIY HSH impact the identities of, and relationships between, the older residents and their wider caring networks

In section 6.2, I reflect on the seemingly empowering roles performed by my key participants and their wider caring networks within DIY HSH living. In section 6.3, I reflect on the seemingly disempowering roles that are hidden/ performed by my key participants.

6.2 The empowering roles

In this section, I highlight the range of roles that my key participants and their wider caring networks played that could be potentially empowering to these key participants, in terms of building and maintaining identities as more than simply stereotypically burdensome older people. These are the good older person (6.2.1), the good parent and child relationship (6.2.2) and the good partner/ carer (6.2.3). Ultimately through section 6.2 I highlight that DIY HSH living may signal more positive and productive identities for older people as they are awarded more opportunities to perform these roles. These roles are adopted and utilised to cover up and act as a buffer to more disempowering roles, such as, social and emotional isolation, burdensome older people, or as undertaking risky activities, which will be discussed in section 6.3. Thus, multiple roles are played at once, a performance that is perhaps even more necessary with the increased surveillance and the lack of privacy created by many smart and assistive devices. These potentially empowering roles are now discussed.

6.2.1 The good older person

'Good older person' relates to my key participants' attempts to highlight themselves as assets to their families and communities, rather than burdens on society. As such, my key participants, as 'good older people' at least in part utilised smart and assistive devices to reduce their potential burden on their wider caring networks and society. However, through such attempts, my key participants were also reinforcing the burden stereotypes by signalling their need for additional support. First, I give some examples of the good person via a reduction on state support (i.e., lain and Angela). Then I give examples of being societal assets via highlighting abilities to care for others (i.e., George) and to happily adopt smart and assistive devices to improve their independence (i.e., Geoff). From my meetings with Iain, it was clear he was keen to be considered a 'good older person' by reducing his burden on the local health and care services, through building his DIY HSH.

Given his MS, Iain was reliant on carers several times a day to help him with daily living tasks such as cooking and cleaning. As such he was reluctant to rely on more visits from carers to assist him in the future. Iain appeared to have been a good member of society in his younger days, working as a local solicitor in various locations around Scotland. Although he accepted his MS, Iain was always clear that he did not want it to define him; his MS was simply one aspect of his life. As such, and because he had the financial means to do so, he attempted to reduce his burden on wider society (i.e., carers) by building his DIY HSH.

(Condensed fieldnote from my visits with lain, 2019)

For lain, although his motivation for his home-build was to improve his capabilities, this was intertwined with his desire to reduce his dependence on the State. Having spent most of his life working for himself as a self-employed solicitor this no doubt also connected to his desire not to rely on the State through health and social care provision. Iain was keen to use his skills in law to 'right some wrongs' in his local area, such as better laws for monitoring disabled blue badge use. This again highlights his portrayal of himself as a 'good older person'.

lain: Asda employ a firm to check the blue badges and twice I have collared the wee man that's doing the job when I've seen him and I've said, 'go and check that man there, he's sitting in the car, he's probably the blue badge holder but his partner is in doing the shopping'. Anyone with a grain of sense can see that that's not what a blue badge is for. The blue badge is to let the disabled person get closer. And he said, 'oh no, that's okay'.

Rachel: So, you can just take the disabled person along too...no.

lain: Yes! So, that's a battle that I haven't won yet. I was in touch with the MSP Richard Lochhead, and he got in touch with the council on a number of caring issues which they've sort of addressed. Whether they'll ever do anything about it, I don't know, but they did come back to me. They were prompted by his letter. I'm not sure whether he raised the issue of blue badges or not, and I'll have to try and get in touch with them. But he'll be pretty busy with the election nearing now. He'll not be interested in blue badges for a while. My view is that the council, at no expense to themselves, could designate one or two blue badge holders as enforcements officers. They would be quite happy to do it voluntarily to protect their rights, and it would just be a question of picking the right sort of people. People like me!

(Visit two with lain, Nov 2019)

For lain, he viewed relying on the State through the receipt of extensive health and social care as being in direct conflict with being a good older person. His reliance on the State was akin to being a burden. Similarly, Angela was contented in that by having a large family she would never be a burden on one specific family member.

Rachel: Obviously technology is good for certain things, but you need your family and stuff around too.

Angela: Well yes, I would say that was more important than any of the others. Again, I'm extremely lucky having five children, 10 grandchildren, and four greatgrandchildren. So, I'm over 30...and with their significant others about 35 or so. On my birthday we usually get together, especially significant birthdays like 90, or when 95 comes up. I went to somewhere, where you have the baths that you jump into...hot tubs. So, we all go there on significant birthdays. Then, my granddaughter, Rachel is getting married on the 1st of November, and my birthday is the 28th of October. So, we'll have a get-together. That'll be nice. I'm really so well placed that I'm no good to you. Rachel: It's good to see the differences. You're very lucky to have so many in Scotland and close by too.

Angela: It started off that I was lucky to have five children. That was planned because as I was telling you, I was one of three and virtually an only child. So, I needed to have five and that's how I've been so lucky. I'm not a burden on anyone because there's so many.

(Visit two with Angela, Aug 2019)

This example also feeds into Angela's interconnected portrayals of a good parent through allowing her children to be 'good children' and offer care support to Angela if required. Both Angela and Iain spoke of their reluctance to be a burden and tried to be good older people by not taking too much from wider society (through health and social care support) by relying more on their large family and smart and assistive devices respectively.

This was also the case for Geoff and George somewhat, however, they focussed their portrayals of good older people on the other side of the coin – on being societal assets through their former careers in the armed forces and the public sector.

Geoff spent decades serving in the RAF and participated in many tours of duty around the world. Often my visits would digress to Geoff reminiscing about his time in the RAF, the places that he saw and friends that he had made. He even met his wife Anne through the forces. He spoke with me about his tours in the forces, and the friends that he met. It was clearly an important time in his life.

(Condensed fieldnote from my visits with Geoff, 2019)

Geoff always seemed nostalgic when he spoke about his time in the RAF, perhaps because he had a clearer sense of purpose then, as well as much better eyesight. As he acquired different

charity commissioned devices from Scottish War Blinded (e.g., a tabletop magnifier and his Synaptic tablet), he maintained a link to this time through reading the organisation's newsletter and attending Scottish War Blinded events. On several occasions, he remarked on how lucky he was to receive this support. This was especially true as such devices were not available at a similar cost to my other key participants. He spoke about this <u>here</u>¹⁸, and you can see how he appeared to feel somewhat guilty when he accidentally recommended these charitycommissioned devices to his fellow lunch club members (who were not eligible for this support).

George also talked at length about his careers as a social worker and teacher and regaled me with many stories of his experiences, some of which appeared to have been very tough given the specific clients that he worked with (children at 'the pointy end' as he put it). His performance, although in most ways extremely genuine, allowed his wider caring network to identify him as a once 'good and caring member of society', and to come to terms and cope with the more challenging aspects of ageing. For example, George also spent eight years in the Army's Parachute regiment.

George: So, what I do is, I keep a photograph of how I was when I was in the Army up there [on the mantlepiece], just to remind myself when I get up, 'you weren't always like this, you were quite a fit person, so it's not the end of the world'... It helps a wee bit.

(Visit six with George, Jan 2020)

Kate remarked he had only recently (i.e., since moving to Cupar) put these photographs on display and spoken at length about his time in the army.

¹⁸ https://youtu.be/P4oDguMbvD0

Rachel: It's quite interesting you are saying that you go on holiday and that's to help you and him. Everyone else I go speak to it's quite obvious that these are your support network, and these are the people that help you...but he was always talking about, 'no, no, I help people and I find it hard to grow old and becoming someone who receives rather than provides help'.

Kate: He has resisted so much, every stage of it. In some ways, I wish that was different. It makes him disappointed, and I wish it was easier for him to accept but he just can't, and I'm not sure I'm going to be able to accept it any easier than he could. He's even put photographs up in the house of him in the army, I'm not sure if you noticed them around the fireplace. Now they never were on show, and he never spoke about that time much at all. But he wrote about it on one occasion at least one occasion, about everything he's lost. I used to be able to do this and now I can't and this. I'm thinking, oh dear god, find some positives. He doesn't go easy with it at all. It's not...I find it really hard...I know other old people kind of, but I suppose they are more akin to my parents and they're not just accepting of age, him less so. I don't really know what that looks like in an old person, just sitting there.

Rachel: I guess it might feel like he's given up if he accepts help.

Kate: I know.

(Interview with Kate, Nov 2019)

Thus, Kate was fully aware, and a little frustrated, of her dad's resistance to ageing. But she did understand that it was especially hard because of his particularly active lifestyle in his younger days. One way in which George maintained this connection and resistance to ageing was through poetry. After my second meeting with George, he sent me a poem which he wrote about his time in the army, signalling another attempt to maintain his links with his past as well as a way of silencing his current less active and able identity. I include this poem here, with the relevant lines emphasised in bold.

The Nudge

I keep this photo by me... it hangs on the wall beside my chair and every time I rise, I look at it.... a young man is kneeling on some tropical white beach looking at the camera and smiling from sixty years past I recognise him as from some long-past dream a bronzed familiar stranger... no longer relevant to the life I now lead and so unknowing....so unsuspecting of what's to come... I need him there to remind me...over and over day in and day out...of how it used to be so that each time I slowly rise he can say... now remember...it was not always like this.

Poem by George White, written July 2019

Relatedly, in attempting to be a good member of society, George used these opportunities to continue the roles he held during his career and younger days. He spent much of his career caring for others, so liked to maintain and take on tasks that allowed him to fulfil this role of 'caring individual'. He used some DIY privately commissioned technologies (e.g., voice assistants) to perform this role to the best of his ability. Alexa helped him remember his upcoming appointments and events, further strengthening his identity as a good older person capable of fulfilling his commitments.

George: That's why I got Alexa because it was getting to the point that...for instance, when you phoned, I immediately said, 'Alexa, make a reminder'.

Alexa: What's the reminder for?

George: There you go. That's quite good for ...

Alexa: When should I remind you?

George: [to Alexa] Stop! ... It helps me. We don't sit and have conversations, but it helps me order my day. So, I put it in the diary but that's not enough, because I forget

to look at the diary. So, I tell Alexa and I get her to remind me when I'm sitting here and having my coffee, ten o'clock ish, doctors' appointment, or whatever. Because it's really bad. I once was about to step out onto the street without my trousers on, not here, but in my old house. I remember getting to the front door and I remember putting my hand out on the door and I looked down. I was about to step out and I realised I was wearing navy blue long johns and not trousers. So, I went back and put my trousers on. It's dreadful!

(Visit one with George, June 2019)

George performed this role of 'good older person' through how he cared for others at the lunch club. Although he acknowledged it was nice to get a homemade meal every day, he said he resisted attending the lunch club for months after moving to Cupar because of the negative connections he had to ageing. He finally went along and accepted this aspect of ageing by using the lunch club as a means to strengthen his performance as a good older person. From this he has been able to help other attendees with their computer issues.

George: A guy I met in the lunch club, he's 93, and he was going on about how he couldn't understand Windows 10, so I said I'll come up. So, I said I'll come up and Jesus, he was using Windows 7. Now Windows 7 leaves you vulnerable to all sorts of scams and malware because they've stopped supporting it. So, I set it all up and showed him how to use Windows 10. I said to him, his email was Windows 7, stop using Windows 7 because you're incredibly vulnerable to being ripped off. It was only then that he told me that previously he had lost thousands being ripped off on his laptop, through using Windows 7. He didn't even know enough to associate it to Windows 7, because Windows 10 is much more secure. So, I told him how he should be downloading a decent security, malware, and he's lost thousands of pounds, poor man.

(Visit two with George, July 2019)

Meanwhile, although Geoff spoke with some sadness of things he could no longer do (i.e., driving), he often emphasised how appreciative he was of his support in Fife via Scottish War

Blinded and Seescape to try not to be a burden on others or to make a fuss. His wife Anne also spoke a lot about this support.

Anne: If we'd still have been in England, I don't think we would have the same support we have here. We wouldn't have Scottish War Blinded for a start. We wouldn't have that support. We would probably have had support from our friends considering that when we came here, we didn't really have any friends. But it's surprising now that the people out there, we've been here for three and a half years, nearly four, that the people out there who would turn their hand and help us. That proved... we were talking about it last night. Charlie got attacked by a dog that used to live just over the fence here, and the man across the road just came across. Somebody came into the vets to see if I was alright. We would have had support from friends and neighbours, but we wouldn't have had that type of support. We probably wouldn't have had the support from the Blind Society [SeeScape] that we have here. Apparently, Fife is meant to be one of the best areas for the Blind Society.

(Interview one with Anne, July 2019)

I believe Geoff was always performing to some degree when I visited, as he was simultaneously trying to identify as a good older person and good partner, and perhaps good research participant. Partly this could have been because he lived with his wife rather than living alone. After all, he had an additional role/identity (i.e., good partner) to perform at the same time. Also, perhaps because of his sight-loss, Geoff had to work harder to convince others of his identity beyond being burdened by sight loss. Possibly because many of his devices were charity-commissioned devices, Geoff desired to emphasise the positives of these devices. Much of Geoff's backstage presentation was illustrated to me by Anne, concerning some frustrations and difficulties that Geoff experienced with his condition and devices. When talking to me alone however, Geoff was generally quite positive about his experiences of his devices. This positivity

can be viewed <u>here¹⁹</u> in Geoff's demonstration of his Synaptic Tablet and in the quote below. The clip shows that the specialised tablet allows Geoff to do a whole range of activities that he would otherwise struggle with, being sight-impaired (e.g., shopping, navigating around new areas). It also shows that he is quite experienced with using this tablet, but that he still got frustrated on occasions, as shown 60 seconds into the clip. However in general he was appreciative and happy to use his devices as illustrated below.

Geoff: I had, my first tablet was a fire, which I've still got, an Amazon Fire. On that one, and I did it several times when I first got it. You could press a button and get the help desk up in the top-right hand corner, and it was an actual person you were talking to. The calendar wasn't working so I asked the helpdesk and, it was a bloke then, he said, 'sorry about that, I think somebody's put the wrong one on, I'll change it for you, is there any particular one you would like'. I said, 'no, just give me one which is nice and easy to use' Two seconds later, there it was. It was an incredible machine, and it still works and that must be six or seven years down the line.

(Visit four with Geoff, Oct 2019)

Although my key participants highlighted a variety of aspects to their 'good older people' roles, they all were keen to emphasise their desire to not be an increasing burden on society, either by accepting their devices, by highlighting what they add (or once added) to society or in how they are choosing a different path for their future that reduced this potential future societal burden. Yet, simultaneously, most of my key participants were also keen to highlight their potential as an asset by maintaining important roles within their wider families.

¹⁹ <u>https://www.youtube.com/watch?v=AA1qtDg0N2I&feature=youtu.be</u>

6.2.2 The good parent / child relationship

For my key participants who had children (i.e., all but lain), there was understandably the desire to continue to be a good parent to their children. Even though my key participants were all aged over 73 and their children were fully grown adults, some with children of their own, they still had a desire to protect their children. This was protection from either from the full extent of their (potentially risky, as viewed by the child) activities, their everyday difficulties with their devices or their health concerns. Maintaining this 'protective shield' was important for my key participants to retain some control of their identity as a good parent providing care to, rather than receiving care from, their children. My key participants appeared to occasionally diminish their own identities as good parents and good older people by allowing their children the opportunity to perform the role of a good child in helping their parents with healthcare needs and daily activities. Thus, the relationship between parent and child appeared to be a fine balance between retaining some, but not all, power. My key participants agreed to adopt certain (mainly privately commissioned) devices in their homes, such as remote cameras and voice assistants, to transfer some power to their children and reduce their children's guilt in not being able to more effectively solve some of the inevitable impacts of ageing or health conditions. In this section, first I highlight the use of smart and assistive devices through suggestions and gifts from family members (i.e., Geoff and Georgette), and then the expression of the 'good parent' role through caring for pets (i.e., again Geoff and Georgette, plus George). Finally, I discuss the complexities of the good parent-child relationship due to potential for disagreement over the capabilities the parent (i.e., George and Kate).

On my third visit to Geoff and Anne, I parked up around the corner and knocked on their door. Geoff excitedly answered the door, 'have you got an Electra?', he exclaimed. Realising he

meant 'Alexa' I said 'no, but Callum [my partner] has a Siri which is similar'. He led me into their living room to show me his new Alexa. I hadn't been in here before, as I always spoke with Geoff and Anne in their dining room. It was cosy with pictures on the wall and cushions on the matching sofas. 'What's your favourite song? Ask Electra and she'll play it?' Struggling to think on the spot, I ask for, 'Respect by Aretha Franklin', and sure enough Alexa bursts into song. Later in this visit he told me how he used his Alexa to find rare Ted Heath Orchestra recordings. (Fieldnote from visit three with Geoff, Aug 2019)

This fieldnote highlights Geoff's excitement at his new Electra [Alexa], which was a birthday present from his stepdaughter the week before my visit. In this case, Geoff was happy with the technology gifted to him by his stepdaughter, to the point that Anne wanted another one (as mentioned in Chapter 5, section 5.3) to use whilst cooking (i.e., to read out recipes) or to use call her daughter.

Georgette also tried to convince the audience (her daughter in this case) of her role as a good parent and enable and promote Lynne's good child role by adopting the devices suggested to her by Lynne. Specifically, Georgette associated patience as a good and virtuous characteristic. As in recognising her limited technical abilities, she appreciated the level of patience that Lynne gave her when teaching Georgette how to use her devices such as her computer, tablet and Alexa.

Rachel: Do you think you would use more technology than other people because of Lynne?

Georgette: Yes probably

Rachel: Because she is proactive

Georgette: Oh aye, Lynne has got patience, a lot of patience

Rachel: When I was talking to her, she was saying that she didn't think she had much patience. So, it's good that you think she does.

Georgette: Oh, aye she does.

(Visit three with Georgette, Sept 2019)

This example highlights that the performances can be both two-way (i.e., the relationship between a good parent and good child), but also that the audiences are two-way and can reinforce and assess the quality of the performance. This may also be a means of performing a strong mother-daughter relationship to an outsider. Whilst Geoff was excited and saw the benefits of using the Alexa suggested by his family, for Georgette, it appeared this performance was undertaken to give peace of mind to Lynne and her wider family, rather than pure excitement and desire to use her devices, especially the privately commissioned devices.

Rachel: When I went to see Lynne, she was joking that she'd have you all tagged and stuff. At least she hasn't done that. The camera isn't as obtrusive as that.

Georgette: Oh yeah, she'd be in jail. Oh aye, she's got one in the lobby and one here.

Rachel: It gives her peace of mind.

Georgette: Oh aye, that's it. If it wasn't for Lynne, I would never have half that stuff at all. I would never think about it.

Rachel: Yeah, often it's not if you want it or not, but if you know about it.

Georgette: That's a certain thing too, right enough.

(Visit four with Georgette, Nov 2019)

As such, the role of a good parent can be performed in different ways to different audiences. As Geoff lived with his wife Anne, whilst Georgette lived alone, there was perhaps a greater need for Georgette to be a good parent and accept the devices to give her family peace of mind - she was capable of living alone and was not a risk to herself.

This role of the good parent can be considered more broadly to include the caring for pets. Geoff and Georgette extended their good parent roles in looking after their dogs. As well as offering companionship and routine, the performance of caring for, walking and feeding their dogs was strengthening their performances as good parents, as they were emphasising that they could still care for others.

Geoff: He [Charlie, the dog] might get another walk?

Rachel: So, you've been already this morning?

Geoff: Yeah. It was just a little damp. Hopefully, it'll be dry for a couple of days now because the grass'll be soaked. When it's dry we just go across the field. He loves walking around the field. I was all around the edge and then across the diagonal and back round. He loves it.

Rachel: Do you keep him on the lead, or does he go off...

Geoff: I've got a long lead. I daren't let him off the lead because if he goes too far, I can't see him.

(Visit three with Geoff (and Anne), Sept 2019)

George also spoke frequently about wanting a dog. This was the first time in his life that he had lived without a dog. He often spoke with sadness about not currently owning a dog, longing for the company and something to look after. However, he was also realistic about his health condition and house size and as such always hesitated about getting a dog in case he was to 'pop his clogs soon'. Such careful consideration also demonstrated his maturity and protectiveness. It also offered me a glimpse of his truer self.

Rachel: Sometimes the TV is just good sort of company too, more than a book because it's easy.

George: I think you'll find, with people of my age, that television is kept for company more than anything else. It's a voice you know. I miss my dog. I'd love a wee dog. I meet people with their dogs down by the river when I'm out walking, and I'm jealous as hell. That wouldn't be very fair on a dog.

Rachel: Maybe you could get an older dog that doesn't need so much walking?

George: It's not that Rachel. I don't mind that. It would be a wee one. It's just that at any time if I get a heart attack and it's a paramedic job and I'm whisked away and I've got a dog, I'd have no one to leave it with.

(Visit five with George, Nov 2019)

George, to protect and shield his daughter from additional anxiety, did not always tell her the full extent of his health conditions. However, it was clear across the course of my visits with George and Kate that this was slowly changing, with George now opening up to Kate more. This change allowed Kate further into the private spaces of George's DIY HSH so she could more effectively be a 'good child'. He even wrote a poem entitled *'The visit'*, about his relationship, both with Kate and with ageing in general. You can listen to it <u>here</u>²⁰. This poem also allowed Kate further into another private space (i.e., his thoughts and feelings).

²⁰ <u>https://www.youtube.com/watch?v=XB09wnRBo58&feature=youtu.be</u>

Within the 'good child' role, my key participants' children tried to satisfy two aims through introducing devices into their parents' home; firstly, to satisfy their parents' desires to age at home independently, and secondly, to reduce their guilt concerning their ageing parent's health deteriorations. However, as my wider caring networks realised, this role also often included learning how to use, maintain and fix the devices for their parents when problems arose. Thus, in the case of DIY HSH living, to be a good child the children also needed to be 'technical gurus', as highlighted by the examples between Georgette and Lynne in Chapter 5 (section 5.4).

Often the children of my key participants, keen to reduce the risks (from within their homes and wider communities) on their ageing parents, increased the prominence of surveillance and monitoring technologies. Thus, the wider caring networks can experience pressures from several fronts, to accept, promote and understand the devices to best (or most acceptably) care for their ageing parents. The key participants and their children did not necessarily agree on the capabilities and abilities of the older DIY HSH resident, as already illustrated by Kate discussing her dad's difficulties in accepting or coping with the negative impacts of ageing. Kate was encouraging him to get out and about more and take trips in Scotland, whilst George had in some ways accepted (albeit begrudgingly) his fate of a smaller social and environmental circle.

George: My world has shrunk to this small little circle, and they're saying, and they're quite right, but they're a pain in the arse. They say you should get on and you should be going to Edinburgh, and they're right I should be. You should be going to the festival and the book festival and the station's just down the road, and they're right. I've just got lazy, I guess. I probably would go if there was somebody to go with me, somebody with similar interests. Kate will say to me, you should go for a nice lunch in Perth or Dundee or whatever and get out and do something and I do occasionally. But meals out are not as enjoyable if you're not sharing it with somebody. It's like viewing a picture in an art gallery, you need somebody there to share your thoughts and bounce

against because you can't savour it as much if there's not somebody there. So yeah, it puts you off a bit. But she's right, I should be going to Edinburgh.

(Visit three with George, Aug 2019)

Thus, there are multiple facets to the good parent and child relationship. Wider caring networks also portrayed certain roles concerning the care of my key participants, both to enhance this care, but also, I believe, to ease their guilt of the inevitable negatives of ageing that their older relatives and care recipients were experiencing. This sense of guilt will only be reduced if the network members believe the roles to be genuine.

6.2.3 The good partner/ carer

For Anne and some members of the dementia carers group, there was the 'good partner' role. This also overlapped with the good carer role. In this section, I highlight this good partner role and relationship via Geoff and Anne's relationship and consideration of their roles, followed by an example (from Georgette) of the technological capabilities required by carers (to be good carers), and finally the anger expressed by some members of the dementia carers group in becoming identified solely as their partner's carer (and be both a good partner and good carer). Such roles and identities could be understood as potentially disempowering (especially) for the wider caring networks.

Although similar to the role of a good parent and good child as they want to offer support to their partner and encourage their independence, the good partner role differs because they live within the same house. When the home would in other cases be the setting of the backstage, the private space in which the older person can be themselves, the existence of a partner or carer in the home changes the extent and location of this normally backstage space. This is illustrated below with Anne and Geoff's slightly conflicting experiences of Geoff's sight loss in terms of how they both try to be good partners. Specifically, with Geoff being capable of pushing the shopping trolley, and Anne capable of looking after her husband and undertaking activities on her own.

Anne: The only thing he's not allowed to do is use the shower when I'm not here, which he has done once because I was late getting back. 'Could you not have waited?' 'No'. That's it you see, if he wants to do it, he will, he's a bit stubborn. He does it when he wants to, not when I do. That's the bit I get a little uptight about because I think to myself, you're putting me under pressure. If I go out shopping, he'll ask how long I'll be and I'll say about two and a half hours. If I'm back before then that's fine, but if I'm not...That's why, when he goes out on a Thursday for his lunch club, if I want to go into St Andrews, or even to Morrisons, just so I can walk around the shop without him pushing the trolley asking, 'where are you?'.

(Interview two with Anne, July 2019)

Similarly, to the good child, the good partner or good carer may need to take on the role of 'technical guru' in knowing how to fix and maintain the technological devices in the home. This can also allow for a wider spread of support, and thus potentially less-intensive feelings of burden, as the support is now shared amongst children and carers or partners, rather than solely the children. For example, Georgette recalled to me the multiple family members on her fall alarm contact sheet.

Rachel: If you had a problem with anything like your alarm, who or where would you go to?

Georgette: Lynne! Well, my brother, he's my first point of contact if I set the alarm off. But he's 95! He's 18 years older than I am. But him and his son, they're...and my niece, she's the second point of contact. But she's in her sixties now, and she's another...she'd

had a double mastectomy, and now she's got kidney problems. So, I've got to change it over a bit, I think. I'll leave Paul on it right enough...my nephew.

(Visit one with Georgette, June 2019)

After her fall Georgette also discussed with me about adding Danielle, her home help, onto the contact sheet because she lived close by and was especially helpful.

Yet for the children and partners at the dementia carers group, although there was a huge degree of love for their family members, there was also often a sense of anger and sadness (and potential disempowerment) expressed. The carers group was viewed as a safe place and many members spoke candidly and openly about their experiences. They spoke about how they often had to hide these feelings when around other friends and family members. This was to simultaneously not be a burden on their friends and family and because of fear that others would not understand these struggles as caring for a parent or partner was viewed by society as a form of moral obligation. Thus, the performance of these good carer and partner roles can be simultaneously empowering for the older residents (i.e., Geoff in relation to Anne), and disempowering for the wider caring networks who have to adapt their behaviours, role and identities to fit in with the needs and schedules of the older person and wider society. Thus, this section (section 6.2.3) perhaps highlights that the same relationship can result in feelings of both empowerment for one party (i.e., the older residents) and disempowerment for the other (the older residents' caring network).

6.2.4 Summary

In section 6.2 I have highlighted the range of potentially empowering roles that my key participants and their wider caring networks have played whilst living with DIY HSH. These roles

are potentially empowering because they could offer purpose and satisfaction to one's life. Also, the enaction of these roles meant that other more disempowering roles could be hidden from view more easily. For example, by assuming the identity of a good parent or a good partner, the key participants were less likely to also be stereotyped as burdensome older people. The potentially empowering roles enacted by my key participants and their wider caring networks connect to RQ2a and RQ2b, illustrating that DIY HSH living may signal more positive and productive identities for older DIY HSH residents as they are awarded more opportunities to perform these roles (i.e., by living at home for longer and playing an active role in their wider families). However, a closer examination of the simultaneously more disempowering roles is required to offer fuller findings for these research questions.

6.3 The disempowering roles

In section 6.3 I focus on the potentially disempowering roles played by my key participants and their wider caring networks. Specifically, in section 6.3.1 I reflect on the potential social and emotional isolation experienced by my key participants. In section 6.3.2 I illustrate my key participants' experiences as burdensome older people. In section 6.3.3 I highlight some of the activities undertaken by my key participants deemed as potentially risky by their wider caring networks (e.g., cycling (George) and dog walking with sight-loss (Geoff). However, the undertaking of these 'risky' activities likely brought feelings of empowerment to my key participants and some disempowerment to their wider caring networks. Ultimately through section 6.3 I highlight that DIY HSH living can reduce the potential for social interaction and increase the potential burden on wider caring networks who need to act as technical gurus and introduce additional levels of support to counter a lack of smart and assistive device-use.

6.3.1 Socially and emotionally isolated identities

My key participants all spoke about the importance of social connections and interactions in their lives. This section highlights the experiences of my key participants of social and emotional isolation, some of which have been heightened through living in or moving to a DIY HSH. Specifically, in section 6.3.1 I highlight Geoff's experiences of losing his ability to drive and the importance of his lunch club and George's experience of isolation after moving to his assistive flat.

For Geoff, even though he attended a lunch club once a week, he seemed to struggle with how his social life had changed since he and Anne moved to St Monans. While they moved to Fife to be closer to family, and Anne was well engaged in the local community, they both admitted it was not the same as when they lived in the South of England. Geoff was happy to receive the extensive charity support in Fife, but they did not have the same long-term group of friends here as when they lived in England. Since his sight-loss, coinciding with his move to Scotland, Geoff was no longer able to drive and as such he was glad of his lunch club as they provided transport, but this was uncommon.

Rachel: When you go to the lunch club, does Anne bring you, or is there a bus?

Geoff: No, no, there's a bus that picks me up outside the door and runs me back. When I go to the one at Kirkcaldy, she's got to take me. I mean I could catch a bus, but I'd have to leave about six o'clock in the morning to get it.

(Visit one with Geoff, June 2019)

Angela also attended this same lunch club. She spoke of maintaining her weekly routines, such as walking up to the main street in Pittenweem to pay her newspaper bill as a means of resistance to feelings of isolation.

Angela: I go to a coffee morning every Wednesday. Then the council puts on the lunch club on a Thursday. I have lunch, it's normally provided by the Waid Academy but if it's exams or something we'll get taken out. Normally the cost is just £4.50 for a threecourse lunch. Well, mains, sweet and coffee or maybe soup. Really three courses because you always have biscuits or cake with your coffee. Monday, we go to Morrisons, they take us to Morrisons. So, it's Monday, Wednesday and Thursday. I might walk up the street because I have to walk up the street once a week to keep going up the street because it's a steep street. I usually go up on a Friday and order and pay my paper and bread, because I get sourdough, you know, nice bread.

(Visit one with Angela, July 2019)

Angela appeared to be very involved in her community and thus not at risk of social isolation in her current circumstances, however this social life was very dependent on her maintaining her mobility (i.e., her ability to walk up the street and board a bus to take her to events). This social life was interlinked to her identity and her home, and so also relied on any health declines being able to be managed within her current home.

In other instances, my key participants used technology devices (i.e., smartphones, laptops) to improve their social interactions by joining new online groups or rediscovering old hobbies. However, these performances were more closely tied to that of a 'good older person'. My key participants were simultaneously navigating the health declines of older age, the pressures from wider caring networks and society to behave in a particular way, and living in a new house, new area or new form of house. This was illustrated by George below. George: But obviously, the problem [of moving to Cupar] was isolation.

Rachel: Yeah.

George: So, that was a problem for me mentally because I lost. I had a network, support network, with my cycling buddies, but I would have to be on a meet a couple of times a week. So, I might drive to where they are meeting to get some company. But, otherwise, it would be very little [social and emotional interaction].

(Visit one with George, June 2019)

After his series of heart attacks, these 'brushes with death' made him reflect more fully and often about death and dying, including through his poetry. George often spoke candidly to me about death and the conservations he had with Kate about his death. However, he also expressed some fear and feelings of disempowerment about death as it was not something he could really control. In the quote below he discussed the fear of dying in the same way as his father.

George: We talk about it freely which is good, because I dare say some folks are very sensitive about discussing death. But to me, that's very foolish because it's going to happen. I can't understand why they can't seem to be honest with people, but my god come on, you're old, you're old and it's going to happen. You've got to do your best to shape the happening so it's as good as it can be, and everybody feels they have contributed to that and have peace with how it happened. My dad died in an ambulance and he choked on his own vomit while he was having a heart attack, with nobody there but my mother, and knowing my mother she wouldn't want to have stopped it happening. I mean how unsatisfactory that it, it would be nice...I want nice crisp linen on my bed...and I want some woman sitting at the side with a harp strumming gently, and Kate on the other side stroking my hand and saying, 'you've been a great dad, we're going to miss you'. That would be nice. I wish I could be at my own funeral. I really have a hankering to see who's there and say all the things I want to say to them.

(Visit three with George, Sept 2019)

Thus, George felt disempowered in thinking about his lack of control over his own death and funeral. Meanwhile, Georgette expressed disempowering concerns at not having the same carers visit each day or at least frequently. As is illustrated below, the carers would change frequently and without warning.

Georgette: Well, it's just the carers, the Highland Home Carers. They're very short staffed just now.

Rachel: Do you always get the same people coming?

Georgette: Well, this week it's alright, but some weeks it's terrible. You never know who's coming in. Yesterday they were meant to send somebody and somebody else came, and somebody else showed up at 5 o'clock. They don't keep regular...This week it's fine but that's unusual. They never tell you in advance. They never tell you in advance. They never phone you and say such and such is coming today.

(Visit four with Georgette, Nov 2019)

This could trigger social isolation in the future as Georgette could not build up the same rapport with the frequently changing carers, at least not to the same degree as her home help Danielle. Georgette was extremely fond of Danielle as I noted in the following fieldnote.

She's very fond of her home help, her carers also do a good job, but she doesn't have the same relationship with them. But even Lynne was saying that she thinks Georgette wants Danielle to be her daughter. She even recently painted Georgette's bedroom.

(Fieldnote from visit two with Georgette and interview one with Lynne, Aug 2019)

Thus, Danielle was key for Georgette in staving off potential social and emotional isolation, particularly now that her carers changed so often. This was particularly true for Georgette as she lived alone and did not get out of her house much.

Most of my key participants were performing versions of good parents or good members of society without the support of their partner for the first time due to separation, bereavement or dementia-onset (in the case of my dementia carers group). While once they could share the performance of certain roles, they now had to take on the roles fully and individually, which may be emotionally isolating. This also connects to my autoethnographic reflections related to my parents (Chapter 4), with my mum attempting to adopt new tasks that my dad once did so as not to be a burden on me or my brother. These desires to not be a burden are illustrated below.

6.3.2 Burdensome older person

My key participants did not wish to be associated with the stereotyped notion of the burdensome older person. As such, they tried to present themselves as assets to their families, communities and wider society. However, there were some instances when this burdensome older person identity was still recognised by the wider caring network. This section highlights these interactions around the notion of burden, specifically the competing interpretations of George's involvement in his lunch club and the dementia carers group and Anne feeling the burden of their partner's diagnoses (i.e., with dementia, and George's sight loss respectively). George was keen to forge his asset identity through his provision of support at his lunch club.

George: Then I kept putting off going along to Age Concern because, I suppose, at root I didn't want to be considered an older person. That's what it was too. In my head, I'm just entering puberty. But that's what it was, I didn't want to be identified with that could if you see what I mean. But it was a good thing to do because I get fed. I don't

mind cooking, but I get no pleasure out of eating alone. I like company. I'm quite gregarious and I like a laugh. Going along there, once you get to know people, is smashing. I liked to feel useful so it was nice to be able to help folk that couldn't manage. That was nice. That's really been a lifesaver.

(Visit one with George, June 2019)

Thus, for George, the lunch club was both an opportunity to gain some social interaction and also give back to his community. However, Kate discussed his lunch club visits in a different manner (although likely joking) in that he may have been a burden to the other attendees.

Kate: There was a period of time when he lived in France, and we had a lot to do with France when I was growing up, and I've always said to him, 'when you're older you'll feel like an old French man and should go out and find yourself a really good lunch, so you don't have to worry about cooking'. You can just have cheese and bits and bobs at supper. He did it, but he did it via Age Concern. Not what I would choose, but it meets lots of his needs. I have warned him, I've said, 'I really do hope you move yourself around the room because my god you're in danger of making people really sick of you telling them how to do things'.

(Interview with Kate, Nov 2019)

Thus, George and Kate's understandings of the lunch club differed, calling into question the level of burden that the club created. Even when they experienced ill health, some of my key participants (i.e., George) tried to conceal these experiences or at least the extent of them from their families. This was so their families would not worry. However, in reality, the concealment just worried the wider caring networks more leading them to put extra supports into place, either in the form of additional smart and assistive devices or arming themselves with extra knowledge. This is illustrated here by Kate.

Kate: But he has heart attacks, and he could quite easily have another heart attack. But what can you do? We were due to go away to...Eyemouth or something, within the week of that last event happening, but we went anyway. Unbeknownst to him, I did locate on my Satnav where the closest hospital was.

(Interview with Kate, Nov 2019)

Kate explained that her dad did not use his intercom system as he should. Instead, he phoned the emergency service directly. As such, she is reliant on him giving her the right information about his health over the phone.

Kate: The last time at Easter, he thought he was having a heart attack, I'm not sure he actually used the box, I've got he probably didn't and probably just phoned 999. I'm sure they would have expected them to maybe have done that but I'm not sure if he did. All I get is a phone call, very matter of fact, 'I think I'm having a heart attack, yeah but I've phoned them they're on their way'. I'm like 'okay....'

(Interview with Kate, Nov 2019)

This created a sense of burden for Kate, as she could not necessarily rely on the intercom system. Instead, Kate had to rely on the activity log on Facebook to achieve some peace of mind in knowing he was okay in addition to the 'intercom system', as is illustrated below.

Kate: Certainly, I am hugely grateful for the things that are assisting him to live how he does. For me to feel a little bit of security in the fact that if, for instance, he doesn't do what he should when that green light goes in the morning, somebody's on the case, because we can go a few days not having much conversation. I know he's active because I can see he's been on Messenger, and on Facebook. God knows I know he's been on Facebook! George White shared, George White shared, George White comments. So generally, I know he's alive, but I'm really grateful knowing that he has that tech and people on call essentially. That's great!

(Interview with Kate, Nov 2019)

So, Kate is relying on Facebook via a privately commissioned laptop to check that her father is safe – a purpose it (Facebook) was not designed for, highlighting further interoperability of devices and feelings of burden on Kate as she had to actively log on and check Facebook for updates. George tried to hide his feelings of burden and embarrassment over accidental use of his fall cords with humour. I illustrate this in the quote below and it can also be viewed <u>here²¹</u>. From this clip you can see how excited that George becomes when telling stories, reinforcing his identity as capable and non-burdensome (i.e., *I've only used it by mistake*).

Rachel: Yeah, and you see the way you've got the cord for the alarm. Does that worry you in any way...not worry, but in that someone is always sort of listening?

George: Awk it does give me a sense of security. I have used it before, not that I meant to. But I remember, it got tangled up in my electric drill when I was doing something, and they were immediately on the intercom saying, 'are you alright Mr White?' And I had to say, yeah, stupid tradesman got it tangled up in his tools.

(Visit four with George, Oct 2019)

Thus, George and Kate's experiences with his smart and assistive devices differed in several ways. They could each see the benefit of the devices, but also recognised some downfalls which connected to feelings of burden. Furthermore, George was most concerned with this form of surveillance (i.e., via the intercom) and seemingly was unaware that Kate was simultaneously keep an eye on him via Facebook. For members of the other caring networks (e.g., the dementia group and Anne), feelings of burden were expressed in having to come to terms with the new carer identity.

²¹ <u>https://www.youtube.com/watch?v=qmRxHBEM5LU&feature=youtu.be</u>

The mismatch of the carers' desired identities pre- and post- dementia diagnosis was clear from my observations at the dementia group reflected below.

From attending the dementia carers group meetings, I was struck by just how supportive and kind the group members and facilitators were to each other. It was clear they were a community. They spoke of their difficulties, and in struggling to take on new roles that their partner used to do for the family such as the cooking or cleaning. They all clearly struggled. However, they would also tell jokes and make light of their situations as a means of coping. Nevertheless, they had to simultaneously create a new present and a new anticipated, reconfigured future, which was not filled with the same hopes and dreams they once had for themselves and their families before the diagnosis.

(Condensed fieldnotes from the dementia carers group, 2019)

Many group members spoke with a sense of loss over their now pipedream pre-dementiadiagnosis potential identities. One woman at the group spoke of previously looking forward to retiring from nursing so she could grow old and travel the world with her husband. Since his diagnosis she had to reconstruct her identity back to once again being 'a carer', although now this was twenty-four hours a day, seven days a week. She also had to reimagine herself as simply the wife of someone with dementia. Dementia had become a part of her identity too, in terms of how she believed she was now viewed by others. This was also something that Anne, Geoff's wife, highlighted, in terms of her association with Geoff's sight-loss.

Anne: There's nothing you can do about it, it's life.

Rachel: It [the sight loss] affects both of you.

Anne: It does. Sometimes people don't always see that. They just expect you to be you, and you get on with it. I sometimes think my daughter thinks that 'oh well, mum you have to get on with it', although she always says how am I. I never tell her if things are not quite as they should be as I don't want her to worry.

(Visit four with Geoff (and Anne), Nov 2019)

Anne highlighted that other people often do not realise that when your partner gets ill it has an impact on you too, but you just have 'to be okay with it'. It also reinforced her desire to be a good parent (i.e., in not telling her daughter if things were tough). Anne also spoke of fears of not being able to leave Geoff alone for long, because he would insist on doing certain activities even if she was not at home, such as having a shower. Such a situation was likely disempowering for both Geoff and Anne. As such, to feel more empowered (understandably) Anne was regulating Geoff's routines to better fit with hers. This is now illustrated.

Anne: Yeah, because I go out on a guild trip every year, but I only go if I know it's alright with my daughter. It's normally the first Monday in June when the kids are off, and most people are off work. I don't know why but it's just something they do in Scotland. But he always goes there for tea, and I leave him something for his lunch, and the kids pop in. It works fine. But I know people say do you worry about him today, and no I don't worry about him today. It's always there because I know he'll have walked the dog when I left and then he'll come back and he'll potter around, and put the telly on, probably have a sleep, have a bit of lunch and walk Charlie and come back. It's fine.

(Visit two with Geoff (and Anne), July 2019)

Although Geoff did not speak at length of his fears, Anne on the other hand did. Anne said it was reassuring to know that her daughter was just around the corner if they needed anything. It also allowed her to have a little freedom to occasionally go out without Geoff to help at bake sales or have coffee with friends.
These changes to and loss of identities are intertwined with prominent stereotypes of retirement and old age (i.e., Chapter 2, Table 1). Ultimately, my key participants did not want to be identified by such stereotypes, their increasing age, or disabilities, and so they tried to emphasise other more accepted aspects of their identity, highlighting their contributions to their families and wider society. However, this concealment of burden did not always mean the burden disappeared, as was evidenced by Kate in relying on her dad (or Facebook) directly to tell her about his health concerns or locating the nearest hospital as a precaution during their trips together.

6.3.3 'Risky' activities

The roles and activities that were likely to be perceived as risky by the wider caring networks were hidden away in the background, masked by numerous less risky and potentially more empowering performances (e.g., those from Section 6.2). Often these hidden and risky activities were of great importance to my key participants' identities. In some cases, these activities were stopped or reworked so the older person can be considered as less of a risk, and in others were tied to the wider accepted performance of capability and independence. The examples of risky activities I give in this section are cycling (for George) and dog-walking (for Geoff).

George had been a keen cyclist, cycling all around Europe in his younger days. More recently, with his health deterioration, he was forced to give up cycling and instead now contributed to online cycling forums and attends local cycling club social meetings. On my final visit with George, he had bought an exercise bike which could be considered an acceptable way to continue his hobby because the risks were lowered. The static bike could also (acceptably) contribute to his wellbeing and improve his health. Kate remarked that George considered a death during cycling as admirable.

Kate: But he was much more active than I have ever been, with his cycling and stuff. He was perfectly prepared to keep going till he died you know. He always said he would be really perfectly happy if one Saturday he just tipped over into the ditch and that was it. I'm like, 'That's a great picture Dad, thanks'. I understood where he was coming from, and many a person that he went out with on a Saturday just tipped over into the ditch and everybody concerned saw that as a fine end. They were doing what they enjoyed doing, with people that they enjoyed spending time with, so doesn't get much better. It was a better life than what he's got now. I think everybody can see that and he certainly feels it quite keenly. I don't think technology can do anything much about that.

(Interview with Kate, Nov 2019)

His move to less-risky associations with his hobby was also a means to promote his good parent identity, by putting his daughter's mind at ease. But he found this difficult, as illustrated below, as he felt a loss of identity through his inability to continue these hobbies.

George: I miss walking, I miss hillwalking. I used to love that. I used to hill walk in the spring to the youth hostels. I used to sail on the Tay, and I used to sea kayak around the west coast. I cross-country skied in the winter. When you can't do that, it's depressing when you can't do these that you want to do. But I suppose everybody... I often wish... I speak to people that don't do much, and they sit, but they've never done much, they haven't been active in that way. I think old age for them won't be as hard as it would be for somebody who's always been doing things.

(Visit one with George, July 2019)

George discussed his identity in terms of a sense of loss - of things he could no longer do. He believed the negative effects of ageing were more difficult for him because he had previously

led such an active life. In other words, if he had a less active younger life, then this more sedentary older age would have been less of an adjustment. Meanwhile, Geoff was forced to give up driving due to his sight-loss, but he attempted to regain some sense of independence and capability through walking their dog Charlie several times a day. This was highlighted by Stephen, an outreach worker with Scottish War Blinded.

Stephen: I mean Geoff's got his wife and they get out, and he's got his dog. I mean I was up there the other week visiting someone else and I saw him out walking around the village with his dog, which is really good for his own wellbeing and mental health and things like that.

Rachel: Yeah, he's said to me that if he didn't have that and didn't have that opportunity to get out that it'd be a big hole.

Stephen: Yeah, it's a big part of his routine, his morning routine, is that he goes out and walks the dog. One of the biggest things for almost everybody that I go to see is if you have to give up driving. That's one of our criteria as well, because obviously if you're driving, probably your eyesight's good enough. But so many people say they don't know what to do because they lose their independence and they become reliant on other people or public transport to get places.

(Interview with Stephen, Scottish War Blinded, Sept 2019)

However, Charlie was not specifically an assistance dog (i.e., for sight-loss), and Geoff was not able to simultaneously walk Charlie and take his assistance stick (i.e., for people with sight loss), thus the activity was considered a risk by Anne. Although Anne worried when he was out walking Charlie as he had fallen several times before, she was reassured that Geoff was well-known in their village, so this popularity acted like an extra layer of surveillance and peace of mind for Anne. Anne: There's always somebody willing to help. The church is very good here, I've got a lot of friends from church and they all know him. Yesterday I was saying, we have a big sale here for three weeks, it starts next week, and I was helping put things out yesterday. Another friend said Geoff this, and Anne [a different Anne] looked up and said, 'you leave my Geoff alone, he's lovely and he's my friend'. I said to her, 'you want him?'. So, there's always somebody. She's an ex-minister's wife as well so you know. So, it's okay, there are people there.

Rachel: I think it's partly small communities as well, they look out for each other more.

Anne: They do, we're very lucky here. I've got an Australian friend and she always says to him, 'G'Day', so he knows who it is. They've been told to say who they are because he doesn't know. He'll come home and say, 'I've met so and so', 'right, where do they live?', 'down Invery Street, by the fire station', 'that's Anne', 'she had a man with her, 'that's her husband' I say, 'that's Philip Somebody', I don't have a clue and I'll go out and someone'll say, 'I haven't a clue', 'Ahh, that answers that question'. So, we're very lucky. You always say you're lucky? There are people worse off.

(Interview two with Anne, July 2019)

By masking his risky hobby in his good parent (to their dog) performance, it was more easily accepted by his wider caring network. As such, often the risky hobbies, or at least reworked versions of these hobbies, could be continued if they could fit into the pre-accepted performances of a good older person or a good parent. Their wider caring networks could ensure greater monitoring and surveillance (or peace of mind) by framing certain technology devices within the guise of helping to promote independence and freedom in the home.

6.3.4 Summary

Through section 6.3 I have highlighted the potentially disempowering roles that my key participants and their wider caring networks enacted through living with DIY HSH. These roles

are potentially disempowering as they painted my key participants as isolated, burdensome or as posing a risk to their safety. Thus, my key participants needed to perform their empowering roles, as introduced in section 6.2, to reduce the prominence of these disempowering roles. Concerning my research questions (RQ2a, RQ2b), the findings in this section highlight that although DIY HSH may increase the prevalence of empowering roles, they can also increase the prevalence of disempowering roles. DIY HSH living can require a house move, which can reduce the potential for social interaction and increase the potential burden on wider caring networks who need to act as technical gurus and introduce additional levels of support to counter the older resident's lack of knowledge of smart and assistive devices. So-called 'risky activities', can be both made safer through smart and assistive devices (i.e., cycling at home surrounded by fall alarms), but also increase risks (i.e., falling whilst dog-walking) to the older person in a bid to convince wider caring networks of their good parent roles. Finally, in response to RQ2c, wider caring networks are clearly very important to DIY HSH residents as they are the main audience for my key participant's range of roles and performances, and thus they are the main group that they have to convince (i.e., of their capability and independence) so they may continue to agein-place. In addition, the identities of the wider caring networks are also shaped by their relationships with DIY HSH residents in terms of moderating their behaviours (i.e., Anne for Geoff and Kate for George) to fit with their partner or parent. Thus, these identities are codependent and co-produced.

6.4 Conclusions

In this chapter I have focussed on how the identities of older people and their wider caring networks can be altered through living with DIY HSH. Due to the stereotypes of older people that are accepted in our current society, they perform several roles including good older person, parent and partner to enable them to highlight their worth to society, and as such, increase their opportunities to also perform their riskier and less empowering identities.

From this chapter, I offer three key findings for RQ2a (How do DIY HSH shape identities of older residents?). DIY HSH and their devices are increasing the visibility of the residents. Thus, my key participants had to carefully perform an increasing number of roles at once and for an increasing range of audiences (i.e., family members, technology companies, health professionals), to convince these audiences of their capability and non-burdensome nature. However, there were limits to the roles that my key participants could convincingly perform. Such limits were related to existing stereotypes of older people; the financial, career or health-specific access to smart and assistive devices and the quality of the relationship with the wider caring networks (i.e., the extent to which they could and would be 'technical gurus').

Regarding RQ2b (How do DIY HSH shape identities of wider caring networks?), the wider caring networks were grateful for many of the smart and assistive devices to allow the key participants more independence, capabilities and opportunities in their homes and lives. However, the use and uptake of these smart and assistive devices also necessitated the wider caring network members play certain roles (i.e., good carer/ child/ partner), which had an impact on their identities and everyday lives, for example, taking on new carer roles, becoming technical gurus, or having to observe their parents through Facebook.

For RQ2c (To what extent are wider caring networks important for the identities of DIY HSH residents?), wider caring networks were very influential in shaping the identities of my key participants. With a reduction in privacy within a DIY HSH, my key participants often had to work harder to convince their audience (i.e., their wider caring networks) of their roles and ultimately

their identities. These networks were important in helping to decide which type of DIY HSH resident identity is accepted by both as wider caring network members and by the DIY HSH resident themselves. Such networks also helped establish the level of (dis)empowerment that the residents experience from living in a DIY HSH.

Finally, I return once again to my conceptual framework (Chapter 2, section 2.4). The findings of this chapter support aspects of my conceptual framework. Specifically, the importance of relational living (i.e., concerning wider caring networks and wider society and the potentially conflicting or competing views of DIY HSH experiences) is critical for DIY HSH living, and the quality of this relational living can have an impact on desires to consider future DIY HSH living. Spatial inequalities did not emerge in this chapter as important. However, other inequalities have emerged as potentially important for considerations of DIY HSH living such as financial or health or career-specific access to smart and assistive devices (and thus ultimately varying DIY HSH experiences). Next, I introduce my third results chapter which relates to discussions of 'the future'.

7 Results three: Planning for the future when living with smart and assistive devices

7.1 Introduction

My empirical research found there is often a mismatch between the hopes and envisioned futures of my key participants, their network members and the wider societal vision of the potentials for smart healthcare technology in the home. In section 7.2 I highlight the role of smart and assistive devices in futureproofing healthcare in the home in terms of improving capabilities, in creating multiple anticipated futures, and some fears of their use and misuse. In section 7.3 I offer my contributions to RO3 (Figure 26) in highlighting that DIY HSH enable a greater potential range of possible futures for residents and their wider caring networks, but simultaneously these futures may require additional unexpected labour and heighten some fears of older people (i.e., my key participants).

RO3: Explore the extent to which DIY HSH enable older people and their wider caring networks to plan for the future RQ3a: What types of futures are possible with various HSH devices?

RQ3b: How do these futures differ between older people and their wider caring networks?

Figure 26: RO3: Explore the extent to which DIY HSH enable older people and their wider caring networks to plan for the future

7.2 The role of DIY HSH in creating new potential futures

In section 7.2 I highlight the role of DIY HSH devices in creating new potential futures for my key participants and their wider caring networks. These futures can differ depending on the types of devices and the various levels and types of access to these devices. Specifically, in section 7.2.1 I explore the potential for a more capable future through living with smart and assistive devices. In section 7.2.2 I illustrate how different devices were creating different futures. Finally, in section 7.2.3 I illustrate the key participant and wider caring network's fears of a potential future reliant on smart and assistive devices. Overall, through section 7.2 I highlight that DIY HSH have the potential to create additional (and somewhat hopeful) futures for my key participants, but simultaneously some fears accompany these potential futures. Often these more capable and less burdensome futures create additional labour and consequences of the wider caring networks.

7.2.1 A more capable future

Some DIY HSH have created or are envisaged to create a more capable future for my key participants. In this section (7.2.1) I offer some examples in terms of increasing capability in the home. Specifically, I use examples of Iain's DIY HSH build to feel more capable at home, and Angela adopting HSH to enable her to continue living at home and in her community for longer as this is where she felt most capable (i.e., she had a purpose).

Although lain accepted that his health would deteriorate, he was looking forward to a future in which, due to the use of smart technology he would be able to be more capable in his home. Iain seemed to have accepted his emerging new future (as a person with MS) more easily than

say George or some of the dementia carers group, perhaps because he was in a better financial position to adapt to his new circumstances. George discussed Iain's DIY HSH build with me once, as now illustrated.

I told him about the new participant Iain and his smart home. He said he was amazed that people could be so innovative and proactive and wished he had the financial means to do something like that.

(Fieldnote from visit four with George, Oct 2019)

lain considered the future through the lens of resistance – as something to both prevent and improve. He hoped to prevent the otherwise inevitable reduction in his capabilities with the support of smart and assistive devices. In building his new DIY HSH, lain was taking back control and independence that he felt he had lost, both to his illness and his carers. Here he discussed the benefits of having voice-activated devices to pre-empt his condition worsening.

Iain: As soon as I saw what it could do, I thought, yep, that's a way forward. It seems to be able to do more and more and more. I'm not using it to its full capacity but hey, who's ever using a computer to its full capacity. If you're using a percentage of it, you're doing well. You can do so many other things. But then when I was thinking about this house, I was thinking about getting as much technology in as possible, so that when my hands cease to function, I can do so many more things by just voice control.

(Visit one with lain, Oct 2019)

His vision of the future was one which he was more in control. This was empowering for lain, as otherwise he feared that doing nothing would make him a prisoner in his own home. If he did not make these changes, he feared that he would continue to be at the whim of his carers' routines and schedules, rather than his own. For lain, the building of his new home was very

significant in offering him hope for his future which otherwise could be bleaker due to the seriousness of his MS diagnosis. Thus, having the control (and the financial and knowledge access) to create his own smart home was a way to (hopefully) improve his capability in the future. The specifics of this new build are highlighted below, and you can also listen to this conservation <u>here²²</u>. From this conversation it is clear just how much time and effort lain has put into planning his DIY HSH build.

Rachel: Yeah. So, you haven't fully decided what things are, all the technology, that's going to go in your house yet?

Iain: Yeah, pretty well. Windows and curtains and blinds will be voice-activated. Doors will be voice-activated. I'll have a telecom sort of system so that when I'm sitting here if somebody's at the door, I can speak to them through a voice thing, I can get a picture on my screen of who it is, and I can open the door for them. Just sitting here. That's the next bit of technology I've got to get. The garage door is going to be electrically operated. I think there is a bit you can get and you can put in the car, you don't even have to press a button, the system will recognise your car as it drives in the driveway and will automatically open the garage door for you. These are the sorts of things that I'll be looking at. Also regulating the central heating by voice. That's planned for through there as well.

(Visit two with lain, Nov 2019)

As he did not have much family around, he was faced with a decision of placing a burden on additional carers or technology. To give himself the opportunity for more independence he chose the technology. To futureproof against his fears of not being able to do anything for himself he built his DIY HSH. However, his hopes and fears (of a future without technology) were also compounded by the experiences of his friend Lynn, who also had MS.

²² <u>https://www.youtube.com/watch?v=iu5oxyRSjNI&feature=youtu.be</u>

Iain: Well, it's Hanover housing that we have here. My friend Lynn was offered a place in one and quite reluctantly she's turned it down because it's in the middle of a brand-new housing estate and there is absolutely nothing there and it's miles out of town. She can't...there's not a shop or a community hall or anything...or even a garden area...nothing.

Rachel: I don't understand planning now. They just make everything into commuter villages. For a home for someone with a disability, they really need to think about that.

Iain: Oh, I think Elgin has some of the nicest concentration camps outside of Germany. (Visit two with Iain, Nov 2019)

lain was motivated to build his own house in the location of his choice, rather than having to move to an isolated house such as the one that was offered to his friend Lynn. Relatedly, Angela was also motivated to live in her existing location and home for as long as possible, which enabled her to spend time with her family. Angela spoke of her desire to live at home for as long as possible and to even die at home if possible.

Rachel: Do you think if, hopefully not, but if your health deteriorated, would you be happy to use more technology to help with that or would you...

Angela: I'd stay here as long as I could, however that might happen. As I say, I'd be desperately unlucky not to be carried out of here in a box. But not just yet. (Visit one with Angela, July 2019)

Being a part of her community was a key aspect of Angela's feelings of capability. For Angela, her home enabled her to remain a part of her community and retain some independence, thus she was happy to utilise technologies that would maintain this for longer. One key role of DIY HSH in future proofing for my key participants relates to allowing them more control and even improving their anticipated futures (which links strongly to feelings and experiences of capability). In the case of Iain, one reason for his optimism is that his vision was not yet realised (i.e., he had not moved into this new home during my visits). Although he already lived with some smart and assistive devices, this future DIY HSH was more tailormade for his lifestyle and condition rather than making do with portable privately commissioned devices not created to specifically assist someone with MS. As such, his future DIY HSH represented his ideal (and perhaps utopian) future and home. It was full of hope of what his new HSH could offer him in terms of increased control and capability, especially given the tailormade nature of his new home. However, his lived experience of this new DIY HSH was (at least then) yet to be encountered. Meanwhile, Angela said she would be happy to use smart and assistive devices to stay at home for as long as possible, but again, apart from her experience of her few existing devices (e.g., her fall alarm and laptop use), this was largely through anticipation rather than lived experience (i.e., the smart and assistive devices having the potential to solve multiple problems of ageing). The realities of these futures were yet to be encountered, but during my fieldwork, such views were signifiers of hope and control for Angela and Iain. Through this section I have highlighted that a future in which my key participants have greater capability is possible through DIY HSH living. This finding contributes to RQ3a. Specific desires and expectations for the future were also anticipated differently by my key participants and wider caring networks (linking to RQ3b) as I discuss in the next section.

7.2.2 Different devices create different futures

The commissioning source of the devices (i.e., public, private, charity) also offered different potential and anticipated futures. However, these anticipations for the future were often opposing for the key participants and their wider caring networks. In this section (7.2.2) I highlight these commissioning-source dependent futures. I first explore the competing futures anticipated through publicly commissioned devices, and then those anticipated through privately commissioned devices and charity commissioned devices. I argue, in response to RQ3b, that different and competing futures are anticipated by the key participants and their wider caring networks. Such differences are made apparent through a consideration of smart and assistive devices according to commissioning source.

My empirical results found that the publicly commissioned devices were often accepted by my key participants to reduce their sense of future burden and guilt towards their wider caring networks. These publicly commissioned devices were more clearly identifiable specifically as pieces of healthcare technology (i.e., they had a single purpose) and as such did not so easily fit with the empowered utopian visions of living in a DIY HSH or ageing-in-place. These devices were also often more simplistic, sometimes not even digital. They were more common in society and often came from a trusted source (i.e., housing association, social worker) with more accessible support and maintenance systems. However, fears in these instances related to their appearance and what this signalled to society. Thus, there was resistance to wearing and using some of the publicly commissioned devices because of their appearance. In other words, they were not aesthetically pleasing as they are symbolising burden and decrepitude to the wider world. Perhaps smart and assistive devices that were less obtrusive or had a dual-purpose would have been better accepted by some of my key participants. This fieldnote illustrates Georgette's experiences.

Georgette didn't really like or always see the point of her fall alarm. I think Georgette could see the benefits of a tracker device if it was contained within a wristwatch, so it's not in the way so much, doesn't move around, or get stuck. So that might be a way forward for her and Lynne.

The future fears of becoming a burden were not always directed towards the wider familial support network, but also, for example in lain's case, the fear of being a burden on wider society and professional care providers, as discussed in section 7.2.1.

Meanwhile, the wider caring networks often considered these publicly commissioned devices as having the potential to enable the key participants to live more empowering futures through fulfilling desires to live at home for longer. Kate remarked how grateful she was for George's built-in publicly commissioned devices (e.g., fall cords and intercom system).

I don't know how he sees the kind of in-house, built-in, technology. He sees it for what it is. He knows it is an aid, shall we say. I'm not sure he cares in the same way if he actually ends up dead on the floor. For him, it's just the end, and for me, it's like my god, please somebody find him. He doesn't feel the same way about that. He's quite practical and realistic. Also, he gives it serious consideration as to quality of life, whereas I'm just scared to shit about losing him. So, although he recognises it, and he probably gives it some degree of importance. He certainly doesn't see it in the same way as I do. I'm just hugely relieved it is there. I wish we didn't need to have it quite so much; I wish I lived next-door, but not in that building...up the road a wee bit. (Interview with Kate, Nov 2019)

Here, Kate recognised that she and her dad had differing views over the publicly commissioned devices and what they could mean for the future. For Kate, she desired a future with her dad in it, whilst George only desired this future if he could maintain a good quality of life.

Whereas, privately commissioned devices were often utilised by my key participants with the anticipation of developing a more empowered future, as well as out of sheer curiosity. The range

of privately commissioned devices such as virtual assistants and doorbells offers additional choices that are not always available from publicly commissioned devices. Such choice was only available to those who could afford or were aware of these privately commissioned devices. Also, there are again links between empowerment and the physical appearance of the device. My key participants felt more empowered and excited by devices that were not immediately identifiable as, or whose sole purpose was not as a smart and assistive device.

There was excitement from my key participants over certain privately commissioned devices because they did not so obviously identify key participants as receiving some form of remote care. The privately commissioned devices such as voice assistants, as well as helping residents with appointment reminders and socialisation, could provide entertainment and information. For instance, Geoff used his Alexa to make calls, give him reminders and play music.

Rachel: Did you just get your Alexa the other day too?

Geoff: On my birthday yeah. She said I didn't know what to buy you. It's brilliant. It's on most days for a couple of hours, two or three hours, doing something. I just pick a band, like Ted Heath Orchestra, if you've ever heard of them?

Rachel: Yeah, yeah, yeah.

Geoff: I just ask it to play music from Ted Heath Orchestra and it just goes on and on. Or Ella Fitzgerald. She shuffles them. She tells you she's shuffling music from, and just goes on with it.

(Visit three with Geoff (and Anne), Sept 2019)

Thus, devices such as voice assistants often had a dual purpose for the key participants in promoting wellbeing (i.e., through entertainment and fulfilment) and attempting to counter the

negatives of declining health in the future by helping with reminders for appointments and for taking medication, but also enabling the key participants to adopt devices that are not clearly associated with the stigma of old age.

For the wider caring networks members and dementia carers group, a future with privately commissioned devices signalled an opportunity to reduce their guilt around the declines of the older person (i.e., key participant) due to health or age, and their guilt at often living far away. However, to create such a future, these privately commissioned devices often entailed additional unanticipated labour by the wider caring networks in the form of technical support and research into appropriate technologies. Such a finding is illustrated by this fieldnote about Lynne and Georgette.

Lynne is keen to try and get her mum to use more technology in her home, for her peace of mind, and to help her mum. She's looking at things like Alexa, you can get an Alexa with a screen so you can sort of Skype call. She was also thinking of tracking and a camera, so was also thinking about putting a tracker on the dog as the dog goes most places with her. She thought of this because sometimes Georgette goes out and doesn't take her mobile phone with her, and she is worried that she may hit a pothole in the road. She just kept saying that she was really surprised at what her mum could manage. Lynne didn't think her mum would manage Facebook, or her Kindle, or her fall alarm, but she's usually pretty good with all these things, so she's keen for her to get more. Although Lynne was positive about her mum's attempts to use the devices suggested by Lynne it did seem to me that Lynne was having to do a lot of this additional and unexpected labour (i.e., the research into and installing of smart technology devices) herself, rather than there being a dedicated service for this. Lynne works vaguely in this industry already (e-health facilitator), and still needs to do additional research to find out which devices are most appropriate, so it must be exceptionally difficult for others without such existing knowledge. Apart from her fall alarm Georgette mainly utilised privately commissioned devices which were suggested and maintained by Lynne.

(Fieldnote from interview two with Lynne, Aug 2019)

Thus, Lynne was able to use her existing skills and knowledge to help Georgette, although even with such knowledge there was still unintended labour from these privately commissioned devices. For these privately commissioned devices there tended to be more background support needed by the wider caring networks, in terms of upkeep and support when things went wrong. The publicly commissioned devices, although they required less technological support, did often require more support in terms of needing reminding from their wider caring networks to use these devices such as fall alarm bracelets. Often, if the levels of choice and control (in other words empowerment) were increased for the resident, they appeared to be reduced in some ways for the wider caring network. For example, Geoff found great benefit from his talking tablet as it enabled him to listen to the news, browse the web and listen to emails. However, whenever a problem occurred with a tablet, his wife Anne would have to call the helpline (as Geoff could not see the buttons on the phone or tablet very well) and sort the problem. As I illustrate below, Anne had to help Geoff if there were problems with his devices, even though her technical skills and knowledge were, in her words, probably lower than those of Geoff.

Geoff: You can manage most things.

Anne: Yeah, I manage most things, it's just sometimes silly little things like...

Geoff: I was saying about the Synaptic thing when you phoned...

Anne: Oh yeah, when I phoned when he had a problem with his Synaptic and I phoned. I did say to the man, 'You've been very patient'. He said, 'It's alright, I have all the time in the world'. I said to him 'What's wrong' and he said, 'You need to tap it three times quickly', and I didn't do quite quickly enough. He said, 'Try again, don't stress over it, just take your time'. Anyway, we got there. He said do this and do that and we sorted it. I went around to my son-in-law because he couldn't get into it and it said, 'Ahh, I didn't tap it quick enough'. If he'd have tapped it, we'd have been okay. Sometimes

there's a couple of little things that go on with it and I think please, please, and cross my fingers and click it and nine times out of 10 it works.

(Visit two with Geoff (and Anne), July 2019)

Ultimately, the level of burden is not necessarily reduced, but just transferred between individual, familial carer, professional care-provider, and technology company depending on the device and the initial motivation for use. When my key participants could see the benefits of their devices, be these voice assistant, liquid levels, talking tablets or fall alarms, they were more willing and likely to maintain their usage. Furthermore, many of the devices that Geoff utilised, and as such anticipated using in the future, were only open to those older people who met the remit of the charities.

Each type of device (either publicly or privately commissioned) has a distinct role to play in the care of older people, but also the type of future that they can anticipate. Such anticipated futures rely on a range of motivations and the pursuit of empowerment. These motivations and experiences of empowerment may differ in a post-COVID world. Thus, it is increasingly important to understand existing connections between empowerment and the use of HSH devices in the present day and in planning for the future.

In contributing to RQ3a I argue that there are multiple potential futures created through DIY HSH living, which can be distinguished according to the commissioning source of the smart and assistive devices to create a continuum of (dis)empowering (or more or less utopian) futures for the key participants and wider caring networks. For RQ3b, these futures often differ according to the commissioning source. Specifically, publicly commissioned devices were often utilised by key participants out of fear (e.g., of having to move to a care home) or guilt of being a being a potential future burden to their wider caring networks, whereas privately commissioned devices were utilised by key participants mainly out of curiosity at their potential to increase empowerment in the future. Simultaneously, wider caring networks were keen for the key participants to utilise publicly commissioned devices to encourage empowerment (i.e., they could live at home due to the fall cords and alarms), whilst contradictorily, privately commissioned devices were promoted by the wider caring networks out of a sense of guilt (i.e., installing cameras and voice assistants out of guilt for living further away from their parents). Also, it is important to understand the fears that exist around smart healthcare technology, both in terms of use and non-use. Some of these fears will now be discussed.

7.2.3 Fears of a future with smart and assistive devices

Many discussions, both within my empirical research and the recruitment stages, revolved around general fears of technology. These fears were related to both anxieties from technology use and also from non-use. These fears were often grounded in extreme portrayals from the media, either from news stories, or even television shows and movies where 'man is taken over by machine' or from extreme stories from friends and families of scams. My key participants spoke at length about these fears. In this section I illustrate these fears in terms of general disinterest (as highlighted by George), fears of smart meters, digital scams, and in being left behind in an increasingly digitalised society (e.g., due to skill level in the case of Anne, or rural living or thick accent, in the case of Georgette).

As mentioned before, when I first spoke to George, he said 'I think I will be an anomaly in your research', because of his high level of interest in technology'. On one of our meetings, he expanded on this view about other older people's thoughts on smart technology. You can also

view this discussion <u>here²³</u>. Within this clip you can also see, through George's tone, that he did not consider himself to be one of these 'old people'. Interesting too was George's proliferation of smart devices (i.e., laptop, Alexa, printer) in this clip in contrast to the lack of interest and abilities of other older people.

They [the majority of older people, according to George] don't have that [desire to use smart technology or the internet] and means they don't Wi-Fi, they're not on the net, and that means that everything is more expensive for them. They don't have an advantage of cheap power deals and energy deals, because it's all through...So they're stuck in a world where you draw out of the bank, you don't benefit from anything like that, you believe what the BBC tells you because that's what they've been brought up with. They read the Daily Mail and the Courier, and they believe what it tells them. They think in a different way from me. They're happy in their world and their world consists of their grandchildren and their children, their friends, do you know what I mean, that's it. They're not interested in politics unless it's they can hate something because the newspaper tells them. But they're not really interested in it because they don't see it affecting them, really. At least that realisation is not felt, and they don't question anything. They'll moan, but they don't look for solutions if you see what I mean.

(Visit six with George, Jan 2020)

Similarly, Georgette highlighted that she considered the fears of technology from her friends to be based on a lack of knowledge and support for use. Georgette also spoke of her fears of using a smart energy meter, basing her view on the opinion of one of her carers.

Georgette: I'm always getting adverts for the card, for that smartphone, you know for paying the gas and that [Georgette is discussing smart energy meters here]. One lassie, one the carers said don't, when you're on your own, don't bother with it at all, she wouldn't advise it because it gets such a mix-up.

²³ <u>https://www.youtube.com/watch?v=_zwACYUaBSI</u>

Rachel: As in because it doesn't know what to read?

Georgette: Aye, that's it. That's what she just advised, not to get one.

Rachel: I think it's handy in that you know exactly what you are using, but it's not...

Georgette: It'd be different for a family or a couple. But that's what she was saying, on your own don't because you're not using that much really. Everything will be card soon. (Visit four with Georgette, Nov 2019)

Thus, Georgette was wary of the increasing moves to a digital-by-default world, as she lacked some confidence in using her existing devices and did not always see the point of them. Angela's fears, however, related to the increased risk of being scammed made possible through using more devices.

Angela: Other technologies? What other technologies I don't know. I'm not really skilled in it but I can manage the things I need to manage.

Rachel: Yes, you can use for the things you want to use it for.

Angela: As I say I wouldn't like to pay for it because I wouldn't feel secure. And I do know that people have been had with scams, so I'm well aware of that and don't take any outside calls and that sort of thing.

Rachel: It's the worst thing isn't it, because it's technology that you are perhaps completely familiar with and taking complete advantage of people.

Angela: It's really bad.

(Visit one with Angela, July 2019)

Interestingly, these two instances highlight that both Georgette and Angela place a lot of trust in feelings about technology in the recommendations and experiences of their wider caring networks and friends. However, there were other fears of ageing which could not be staved off or prevented through smart and assistive devices. George illustrated this to me through a discussion about his friend who had developed cancer. For George, the fears compounded when he saw the impacts firsthand.

George: I don't want to be a burden. I don't want to be a drag. I want to retain a bit of human dignity and that's what I...I think too, I watch my friend, he's got cancer you know...younger than me...it just precedes. They find it. They diagnose it. They take away a large part of his liver and part of his colon. He goes on chemotherapy. It's dreadful. Then they scan again and find more, and so it goes on. If I was put in that position, I would never let that... I would say that's fine.

(Visit five with George, Nov 2019)

Thus, as well as fears of misuse, there is perhaps fear of the things that smart and assistive devices could not solve. In other words, there is a fear that it cannot be the innovative one-size-fits-all solution that has often been envisioned by policymakers and marketing sectors.

Additionally, for all of my key participants and the wider caring networks, some of the motivations and benefits of smart and assistive device use were clear, and instead their fears related to 'being left behind'. Some key participants and their networks feared not being able to keep up, or not being able to use the devices to their full capabilities. Multiple key participants had developed their own routines and specific knowledge of how to use their devices (i.e., their mobile phones or laptops), and if they had to change these routines there was a worry that they would not be able to re-learn how to use new devices.

Many of my caring network members, including Anne, were having to learn how to use devices for the first time along with their family members, whilst at the same time providing informal technical support if something went wrong, or in setting up a device. In the case of Geoff, and particularly Anne, their wider caring network was very important as they often called on their family to provide further informal technical support if they could not manage. Thus, wider caring network members also have their own networks. An individual is never simply a member of a single caring network, or at the centre of a caring network – everyone plays a dual-role. This was highlighted especially well in the case of Anne who was both the support network member for Geoff but also relied on additional (technical) support from her son-in-law and grandchildren.

Finally, there were fears because of the geographic location of some of my key participants. Some expressed fears that because of their rural locations about being left behind because of poorer internet speeds. On the other hand, some have adopted devices in anticipation of closures of rural services.

Georgette: Aye.... well, our problem just now is losing the post office. There's no banks here, well the mobile bank comes, but the post office, well the shop that it's in is closing on the 4th of October so I don't know what's going to happen.

Rachel: So, you'd have to go to Alness?

Georgette: Well, that's the nearest. You can get the money out of the hole in the wall right enough, but it's the paying the bills. I pay them in the post office.

Rachel: Would you pay for your alarm in the post office?

Georgette: Aye, the alarm, and the light and the gas. You might be able to pay it at the co-op because you can get electric pay in there. But I don't know how it's going to work.

Rachel: Usually you can get prepaid top-up ones there so surely you could. But it is hard.

Georgette: Aye maybe you could, but I just usually take it off my pension every week. I suppose I could do it direct debit, it's just the same more or less. I'll have to get Lynne to look into it for me. They've not given anybody much time; I mean it's only a fortnight away.

(Visit three with Georgette, Sept 2019)

This vignette highlighted Georgette's reliance on Lynne once again, in this instance to set up her direct debits given the closure of her post office. Georgette lived in an accessible small town, but given her mobility issues (i.e., wheelchair-bound and no local wheelchair taxi), she was very much constrained to the services in Invergordon. Thus, closures to services there had a big impact on Georgette's future and increased her reliance on Lynne.

Another example involving Georgette was her difficulty using her new voice assistant (e.g., her Alexa). Due to her thick rural Scottish accent, Georgette was unable to easily communicate with her Alexa. This interaction can also be viewed <u>here</u>²⁴ illustrating her reluctance to use an Alexa, followed by her communication difficulties once Lynne had bought and installed it. This frustration was apparent across every visit and seemed to increase once Georgette actually tried to use her Alexa. This also highlights the usefulness of my method in capturing these experiences, both over time and across wider networks, as without multiple visits I would not have captured Georgette's evolving experiences with her Alexa.

Rachel: Did you get your Alexa in the end?

²⁴ <u>https://www.youtube.com/watch?v=kCELdV746Us&feature=youtu.be</u>

Georgette: [points to it] Yeah, and I can't get in touch on when I'm trying to get in touch with Lynne on her mobile. I don't know what on earth went wrong. Alexa, phone Lynne for me...

Alexa: I don't know that one.

Georgette: You see what I mean...Lynne Clarke mobile

Alexa: ...

Georgette: What's the weather in Invergordon, Highlands?

Alexa: ...

Georgette: Alexa, what's the weather in Invergordon, Highlands?

Alexa: Sorry, I don't know that location.

Rachel: Helpful...

Georgette: So, a lot of good that's going to do. I must get Lynne to look at it next time she's up. It hasn't moved from there since she plugged it in.

Rachel: I guess it takes a while to understand people's accents and thing.

Georgette: I think so aye.

Rachel: But I don't understand how you start if it doesn't understand you to start with. (Visit four with Georgette, Nov 2019)

As such, even if the device was working as expected there were still unintended and unexpected difficulties for Georgette, and these difficulties (i.e., her accent) could not easily be solved by

Lynne, especially from afar. Similar experiences were also expressed by Lynne regarding Georgette's difficulties using her smartphone.

Lynne was also thinking about getting a new mobile for Georgette, a better touchscreen one with bigger icons. Lynne said her mum finds it quite hard to use the buttons because she can't put a lot of pressure down on them because of her conditions.

(Fieldnote from interview one with Lynne, July 2019)

Anne and Geoff experienced similar difficulties in using their landline phone because of Geoff's sight-loss. Anne did not like Geoff using the house phone anymore because previously he would answer and not be able to properly carry out the phone calls (i.e., if they required him to press any buttons). This also led Anne to worry about how to let Geoff know if she was going to be later than planned home (e.g., from church or a bake sale). Hence Geoff was very happy with his new Alexa as it enabled him to 'use the phone' again.

I met with Geoff again today. He had learnt he could also use his new Alexa to call his family (who live close by), to find out the time, to listen to audiobooks and to alert him to when an Amazon parcel was about to be delivered. He then spoke about the potentials of his 'new toy' excitedly throughout this visit. His family, who lived around the corner, had got it for him for his birthday, and since this time Anne had also ordered another two to be placed at other points around their home.

(Fieldnote from visit three with Geoff (and Anne), Sept 2019)

From my visits with Geoff and his wider caring network, I always found Geoff to be particularly optimistic about his situation. However, it is clear that having Anne around was a big part of this, and more fears for the future may emerge for Geoff if he had to face a future without Anne. On speaking with Evelyn, team leader for the sight support team from Seescape (previously Fife Blind Society), she highlighted that individuals developing sight-loss who have partners often find the transition easier, as they can still rely on their partners to some extent (i.e., share the burden of the impacts).

Evelyn: The one thing about people being on their own is they're sort of forced to do things on their own and for themselves. So, for people who do have a partner, they might stop doing stuff, and then if something happens to that partner, they'll have to start doing things. So sometimes it's actually better if people are forced to do them [...] We often find, you deal with the initial shock of the sight loss and we work with them and they get on and they tap into the service when they need us. But if there's a death or a partner split, you're then back at square once again, dealing with the shock of the...and coming to terms with all of it again. So where possible we say keep trying to do the banking and make sure your bills are okay, so you don't have all of that on top of grief and loss and things like that. It's difficult if you've got somebody to rely on, you'll just think, oh I'll let them do it.

(Interview with Evelyn, SeeScape, Sept 2019)

Geoff even joked about this, saying if something was too hard, he would just get Anne to do it -'If I need something, I just tell Anne and she looks it up. It's easy!' (Visit two with Geoff (and Anne), July 2019). As I highlighted above, Seescape aimed to prepare their members for this potential future by trying to ensure that members learn how to use both technological and nontechnological aids themselves, such as smart banking, rather than waiting until they are forced to learn how to use them whilst simultaneously dealing with bereavement. This situation with my mum was also similar. As I highlighted in Chapter 4, my mum did not previously feel the need (and feared) to use various smart devices, such as emailing and smart banking, because these were roles undertaken by my dad. Although learning these things has been challenging for her, she has adopted the devices and skills out of necessity and can now see some benefits. As with my experiences with my mum, and as reinforced by Evelyn above, the impacts of the shock of a death can be compounded by a need to also (re)learn how to use smart devices which were previously their partner's domain.

Finally, although not explicitly a fear, there is a concern of being left behind due to not having the financial or career-history access to certain devices. As I mentioned in Chapter 6 (section 6.2.1), Geoff accessed many devices for low to no cost because of his career history. However, this was a concern for those who did not have this background, as illustrated by Stephen, an outreach worker with Scottish War Blinded (a member of Geoff's wider caring network).

Rachel: So, would you work a lot with Seescape then?

Stephen: I would. When we are looking for members a lot of our referrals come from Seescape. They might be going out to see somebody, and what the ladies will ask here if they're going out is, 'have you ever been in the armed forces', and if they say yes, they'll refer them onto me. We're in the fortunate position that we can provide these pieces of equipment free of charge, and many of them are quite expensive. That's the downside in that there's a lot of people in need out there but they've not been in the armed forces or the services.

(Interview with Stephen, Scottish War Blinded, Sept 2019)

Thus, the fears of being left behind are potentially not only because of confidence or knowledge with the smart and assistive devices, but also the access and exposure to the devices. Additionally, there are fears over the situations that smart and assistive devices cannot prevent or solve (e.g., cancer). In section 7.3 I have highlighted, in response to RQ3a, that as well as the opportunities for increased capability and potential for empowerment, a future in which society is becoming increasingly reliant on technology was feared by some of my key participants and their wider caring networks. These fears of the future relate to: 'feeling left behind'; potential misuse, overuse and of non-use or technology; or due to not perceiving a need to use smart and assistive devices given this was 'their partner's domain'. These findings also link to RQ3b in highlighting that some wider caring networks (e.g., Anne) can experience a more disempowering

future as they are forced to learn about new (often privately commissioned) devices to support their partners or parents, or else ask for help from other sources (e.g., Anne's daughter and grandchildren) if they get stuck, which again may be debilitating for the wider caring networks.

7.3 Conclusions

In this chapter I have highlighted the role of DIY HSH in creating new potential futures for my key participants and wider caring networks. Smart and assistive devices are becoming increasingly normalised in our society as a potential solution to the impacts of global ageing, and simultaneously may be influencing the visions that my key participants had for their futures. The potential futures made possible through smart and assistive devices gave some additional hopes and possibilities for their futures. In other cases, extreme examples from the media could highlight some new fears regarding a lack of control or fears of being left behind. In this chapter I have illustrated how my key participants and their wider caring networks discussed the future. This future can be made easier by using smart and assistive devices to address the expectations of ageing, rather than as attempts to reinvigorate oneself as somehow younger.

From this chapter I offer the following key findings. For RQ3a (What types of futures are possible through living with various smart and assistive devices?), there are multiple potential futures created through DIY HSH living, including the creation of 'a more capable future' in which older people have more control. This range of futures can be differentiated according to the commissioning source of the smart and assistive devices to create a continuum of (dis)empowering (or more or less utopian) futures for the key participants and wider caring networks. The range of futures possible through DIY HSH living are not always positive and utopian and can include the fears resulting from an increasingly digital-by-default future. These

fears relate to: 'feeling left behind'; potential misuse, overuse or non-use or technology; or due to no perceived need to use smart and assistive devices given this was 'their partner's domain'.

For RQ3b (How do these futures alter between older people and their wider caring networks?), these futures often differ according to the commissioning source. Specifically, publicly commissioned devices were often utilised by key participants out of fear (e.g., of having to move to a care home) or guilt over being a potential future burden to their wider caring networks, whereas privately commissioned devices were utilised by key participants mainly out of curiosity at their potential to increase empowerment in the future. Simultaneously, wider caring networks were keen for the key participants to utilise publicly commissioned devices to encourage empowerment (i.e., they could live at home due to the fall cords and alarms), whilst contradictorily, privately commissioned devices were promoted by the wider caring networks out of a sense of guilt (i.e., installing cameras and voice assistants out of guilt for living further away from their parents).

Additionally, for RQ3b, privately commissioned devices often necessitated additional unexpected labour from both the key participants and the (mostly informal) wider caring networks. Often my key participants found that they required more labour (i.e., even digital labour) than they first thought, and although they often saw many benefits after this point, it was sometimes difficult to get to this stage, as the vision that had been portrayed to them did not highlight this additional labour (i.e., Georgette's difficulties with her Alexa and her accent). Also, often this additional labour was taken on by the wider caring networks in researching products, dealing with helplines and maintenance. Thus, the levels of empowerment can often be a double-edged sword - what is considered empowering for the resident can be considered disempowering for the wider caring network member, and vice versa. These levels may also

change over time. These levels and impacts on (dis)empowerment may also change in a post-COVID world.

Finally, this results chapter has reaffirmed the importance of relational living within my conceptual framework (Chapter 2, section 2.4). This relational living was important here in identifying that the potential futures that are anticipated by key participants and wider caring networks often differed. As such, to create potentially more optimal experiences of DIY HSH living an understanding of the wider connections of the older resident is key. This chapter has also identified the importance of considering the commissioning source of the device when looking to creating optimal experiences for older DIY HSH resident. This consideration should also be added to the conceptual framework.

8 Discussion: Simulating experiences of HSH living

8.1 Introduction

In this discussion chapter I link my literature (Chapter 2), autoethnographic (Chapter 4) and

empirical findings (Chapters 5 to 7) to contribute to all my research objectives (Figure 27),

offering new contributions to the literature on the experiences of older people who are living in

DIY HSH.



Figure 27: Research aim, objectives and questions

In section 8.2 I discuss the meanings of home. I draw on notions of bricolage, ontological security and situated objectivity to argue that a DIY HSH can create multiple experiences of the home. This reflects conflicting experiences of security and contested realities of knowledge. It offers further contributions to RO1.

In section 8.3 I discuss the experiences of DIY HSH concerning the impacts on the identities of older people and their wider caring networks. I draw on notions of dramaturgy and the panopticon to argue that there is no longer a backstage private space within DIY HSH, and as such, older residents and their wider caring networks have to work harder to reinforce their identities as capable older people who are assets rather than burdens. It offers further contributions to RO2.

In section 8.4 I explore the extent to which DIY HSH enable older people and their wider caring networks to plan for the future. I draw on futures and speculative fiction literature to emphasise that the range of futures made possible through smart and assistive devices depend on varying levels and types of access (i.e., vertical noir hierarchies). This is perpetuated further through DIY HSH and in considering future-planning between older residents and their wider caring networks. It offers further contributions to RO3.

In section 8.5 I revisit my conceptual framework, updating it in recognition of my empirical findings. My framework now recognises the power of language and media stereotypes, the specificity of experiences within more DIY versions of these homes, and the importance of wider caring network's experiences.

The contribution of my ethnographic film is intwined in all these sections. Finally, I bring all these discussions and updated conceptual framework together in section 8.6 to offer several key contributions to the literature and existing research around ageing in DIY HSH.

8.2 The meaning of home within DIY HSH

8.2.1 Introduction



Figure 28: RO1: Explore the experiences of older people living with DIY HSH concerning meanings of home

In Chapter 5 I illustrated that sense of home was connected to feeling safe, secure, sociable and/ or capable. In other words, home was a mirror of the self (Marcus 2006). From Chapter 5 I identified three key findings for my research questions related to RO1:

For RQ1a, obtaining a sense of home was more than the physical space of a house. Sense
of home was dependent on the ability for homeownership, access to a local and vibrant
community, and a desire to live at home for as long as possible.

- 2. For RQ1b, the motivation(s) for DIY HSH living related to maintaining a sense of home in settings which were more acceptable to the wider caring networks. The degree to which the sense of home may be reaffirmed depended on the specific devices available to different individuals.
- 3. For RQ1c, living with smart and assistive devices can create new ways of understanding the home, and new forms of insecurities in the home, for instance, feeling unsure in one's home, wider caring networks not being able to prevent a health emergency from occurring, and in the multiple experiences of empowerment possible in a DIY HSH.

RO1 therefore explored the experiences of older people living with DIY HSH, and their meanings of home. Overall, I found that DIY versions of HSH have been created in an attempt to regain a sense of home. In these attempts, experiences of (dis)empowerment were felt by my key participants and their wider caring networks. Delving deeper, in section 8.2.2 I explore the RQ1a and RQ1b findings through discussion of the motivations for DIY HSH, drawing on ideas of bricolage and ontological security. In section 8.2.3 I explore the RQ1c findings, drawing on and advancing the use of 'situated objectivity', and finally, in section 8.2.4, I conclude by highlighting the key contributions to RO1 and my conceptual framework.

8.2.2 Bricolaged attempts at security within DIY HSH

Drawing on the findings of RQ1a and R1b, in this section I argue that a process of bricolage can help to understand the desire to create DIY forms of HSH (see glossary for definition). Subsequently, I argue that motivations for DIY HSH living can be understood as the quest for ontological security (introduced in Chapter 2, section 2.3.1.3) through this process of bricolage,
especially in DIY versions of HSH. Through this discussion, I highlight potential extensions of these concepts, whereby ontological security can be reduced in (especially DIY) HSH living settings given the negative way in which sense of home can be produced through DIY HSH living. All of my key participants were living within DIY HSH.

According to Marcus (2006: 9), 'our home and its contents are very potent statements about who we are'. It signifies our identity to others. Thus, the home is also a mirror of the self (Marcus 2006), as it projects the identity that the resident wishes to convey to others, to varying degrees of success. Moves to DIY HSH are attempts to renegotiate the mirror image as someone more capable once again. Within my research, these attempts were carried out through DIY versions of HSH. As mentioned in Chapter 2 (section 2.3.1.2), Miller (2001, 2010) considers the home to be a site of consumption and a place to undertake and consume DIY projects. Relatedly, Strengers and Nicholls (2018) conceptualised the smart home as a place in which to tinker with technology devices. The current trend towards the increased use of smart healthcare devices in the home is perhaps a reworking of such an idea, with the home a place of consumption through smart devices and healthcare. Given the lack of fully-fledged and purpose-built HSH in Scotland²⁵, there have been attempts to realise the vision of living with smart and assistive devices through makeshift and DIY approaches to HSH. This has meant an accumulation of an increasing range of smart and assistive devices being used for unintended purposes (e.g., CCTV cameras).

Such accumulations can be understood through Levi-Strauss's (1962) idea of bricolage (Chapter 2, section 2.3.1.3), whereby people make do with the tools they have available to them to address an immediate problem or need, using these tools for a new purpose. In my research,

²⁵ see (TEC 2019) for some exceptions

this process of bricolage was one in which older residents and their networks used any available technologies (often a mixed economy approach of both publicly- and privately- commissioned devices) to assist them in achieving a sense of home. For example, Georgette and Lynne used the CCTV cameras to increase independence and decrease risks in the home. Furthermore, the range of devices and potential achievement of a sense of home differed according to my key participants. As such, this process of bricolage needs to be considered as a continuous process given the evolving health conditions, levels of curiosity, knowledge and quality of smart and assistive devices. Multiple and competing processes of bricolage were simultaneously being conducted by my key participants and their wider caring networks, leading to the creation of multiple experiences of the home (linking to RQ1c). Indeed, key participants gathered more devices throughout my fieldwork as their motivations for use evolved due to increasing negative health events and increasing comfort with other devices, as evidenced through my film. This can be observed again <u>here²⁶</u> in Georgette's evolving relationship with her Alexa.

Home is often considered a refuge and retreat from the outside world (Cristoforetti et al. 2011) but also the potential site of reduced privacy (Chapman and Hockey 1999) and increased harm (Sacco et al. 2020). Thus, sense of home can be constantly in flux (Imrie 2004), as for my key participants, due to changes to their capabilities, their sense of home had waned. More positively, Leder (1990) has argued that attention to the body only reappears in times of pain, disease or impairment. Thus, fully-fledged HSH living, and the vision for living with smart and assistive devices, have the potential to create a place in which all residents feel empowered and capable irrespective of health condition. DIY HSH may make residents feel more at home and secure (i.e., safer and more capable) and thus increase the feeling of ontological security (Giddens 1991). Ontological security is a stable mental state derived from a sense of continuity

²⁶ <u>https://www.youtube.com/watch?v=kCELdV746Us&feature=youtu.be</u>

regarding the events in one's life. Chapter 2 (section 2.3.1.3) critiqued the lack of consideration of relationality within ontological security discussions. My findings highlighted that attempting to improve the sense of home through smart and assistive devices also increased insecurity for my key participants. For the wider caring networks, a privately commissioned smart and assistive device could help to alert them when a health emergency had happened, but it could not prevent an emergency from happening. In other words, the damage may have already been done and the necessary wait for the ambulance would remain. Thus, a wider consideration of the impacts of striving for ontological security within the wider relationships and networks is an important consideration for the concept going forward. This links to work by Ball et al. (2016), who found that call operators within telecare centres can experience a need for counselling in response to the traumatic events that they witness through surveillance but cannot prevent. Thus, the potential impacts, on wider formal and informal caring networks, of witnessing but not preventing health events cannot be understated. This also highlights the importance of inperson care and support in addition to smart and assistive devices, which are only as good as the people that are supporting them. Relatedly then, there needs to be greater consideration of the intended and actual use of smart and assistive devices (i.e., via a bricolage approach) as heightened feelings of insecurity often emerge when smart and assistive devices are not used for their intended purpose. For example, the purpose of a CCTV camera is not to prevent a fall but to monitor a location.

Many smart and assistive devices advertise regaining and maintaining control as a key benefit (Hargreaves et al. 2018). Ringo and other smart security devices (e.g., cameras) highlight that they give the resident control over the security of their home but were used by my wider caring networks to maintain a caring role over their family members in some way. Also, many privately commissioned devices such as smart doorbells offer control over something that cannot be

controlled (Bergroth 2019) i.e. the risk of an intruder. Related to my research, these smart and assistive devices may not reduce the risk of a fall event happening for instance, but they may allow for quicker responses after an event or encourage modification of behaviours, such as always wearing fall alarms and being mindful of undertaking risky behaviours in the home. Thus, in some ways, these privately commissioned devices can reduce, or displace, the stress burden felt by the wider caring networks. This too may change in the future if wider caring networks start to rely solely on the cameras for reassurance rather than physically visiting or speaking with their family members.

In this section (8.2.2) I have built on findings for RQ1a and RQ1b to argue that creating mainly privately commissioned devices has relied on a process of bricolage where the best available tools (i.e., devices) are used to create the DIY HSH. However, this bricolage approach has meant that feelings of ontological security are not always created or maintained, as the smart and assistive devices mean that what is created is simply a greater awareness (and feelings of disempowerment and insecurity) of potential emergency events, rather than proactive ways to prevent these events from occurring. In other words, these devices monitor individuals rather than their health per se. Such monitoring can also create multiple realities of the home and the potential for modified behaviours through DIY HSH living which are now explored.

8.2.3 The creation of multiple realities of DIY HSH living

DIY HSH have created additional ways to view and understand the reality of the home, for instance, by viewing the residents through their data rather than simply asking and believing them. In this section (8.2.3) I build on my key finding for RQ1c, arguing that multiple realities can be understood through the notion of situated objectivity.

Goulden (2019) and Hine (2019) consider the smart home as a form of 'capture of the home' whereby the data that is captured can be used to better understand habits, and then by virtue, the public. However, guestions and contradictions remain over the issue of resident-control in the home. As Strengers (2013b) infers, smart technology devices may not change the meaning of home in and of itself, and instead, any changes will depend on how people use these devices, and not simply in how they are used by residents, but also how others outside of the home use these devices, for peace of mind, or as a way to verify and check the resident's activities. Difficulties emerge when devices are used to meet the needs of others, for instance to gain 'peace of mind', creating a tension between what they do and what they or others think they ought to do in their home. There are also links with what Pink (2017) refers to as the multiple realities of digital life, whereby smart technologies can engender multiple realities at the same time, as they can be both a means of overt surveillance and overt care and consideration. Thus, homes are made from multiple materialities (Pink 2017). Furthermore, this builds on the work of Barad's (2014) notion of diffraction in which the same situation or object can be experienced differently depending on the position from which you view the prism. In this case the older person's experience of their smart and assistive devices (wanting to be considered a capable older person) often differed to that of the perspective of the wider caring network member wishing to care for the older person.

This links to the notion of 'situated objectivity' (Pantzar and Ruckenstein 2017), which I introduced in Chapter 2 (sections 2.1.1 and 2.2.2) whereby surveillance devices are used to establish the reality, which according to Pantzar and Ruckinstein is often based on partial data and vantagepoints. However, Pantzar and Ruckinstein's work considered self-monitoring and self-surveillance, rather than using smart and assistive devices to establish the reality of a

situation about an older parent/ care recipient, both from a remote location and from a partial vantagepoint. Within my research, the use of CCTV and Facebook by wider caring networks to check their parents (DIY HSH residents) safety at home was one example of 'situated objectivity'. It raises questions about whose experience is accepted (Hine 2019) - the resident's lived experience, or the wider caring network's experience gained virtually through cameras and Facebook. Virtual viewings only offer partial insights, as for example being logged off Facebook did not necessarily mean my key participant was unsafe. Coupled with the stigma and negative stereotypes of ageing (Chapter 2, Table 1), my key participants sometimes found it especially difficult to convince their wider caring networks of their own lived realities, rather than those viewed through smart and assistive devices. More broadly, situated objectivity helps to show a range of realities can be created through smart and assistive devices, but it could be developed further to take greater account of the pre-existing stereotypes and power relations that exist in relationships that involve an older person. Given the reduced power that older people often already hold (Wanka and Gallistl 2018), their lived realities and those considered by others can be in opposition, and the addition of supposedly 'objective' realities viewed through smart and assistive devices can further increase feelings of disempowerment for the older resident. This links to dataveillance discussions. Dataveillance (Chapter 2, section 2.3.1.1) is the monitoring of digital data relating to personal details and online activities (van Dijck 2014). Although there are many benefits to dataveillance, a major drawback is the assumption that our online activities, presence and behaviour are a true reflection of the individual (Clarke 1988), which may not be accurate. Thus, there are perhaps greater reasons to understand the home within the DIY HSH as a performance or an act, as residents may feel they need to perform certain roles and moderate their behaviours in the home as they may be constantly under surveillance from smart and assistive devices and their associated audiences. This links to my Chapter 6 findings.

My participants were moderating their behaviours with the best of intentions, such as to offer peace of mind to their wider caring networks or ensure the safety of the key participants. However, a moderation of behaviours (Pink et al. 2018) could become worrisome in the future if it becomes more related to distributing health and social care to deserving or undeserving older DIY HSH residents. Willem (2020) argues that rather than these devices becoming domesticated (Pantzar and Ruckenstein 2017), they may become mundane, whereby, due to the formation of routines and patterns of everyday life, the background activities (e.g. the hidden wiring, controls) are obscured until they stop working. When technology works it becomes woven into the background like epistemic wallpaper (Thrift 2004) until the point it is no longer noticeable. In other words, a creep effect could occur with smart and assistive devices where the surveillance element becomes increasingly mundane. At this point, the surveillance of older people through smart and assistive devices could be used to decide their quality of care (i.e., older users having to prove that they are 'good patients' to justify their receipt of care).

In section 8.2.3 I built on my findings for RQ1c. I highlighted that the multiple experiences of 'the reality of DIY HSH living' can be partially explained through the notion of situated objectivity. However, this concept needs to also account for the power imbalance that already often existed in the relationship between key participant and wider caring network member, or between key participant and HSH device with 'objective reality'. My key participants already had reduced power in their relationship with their wider caring networks through their smart and assistive devices. This supports the notion of the DIY HSH being a place of, and space for, performance as behaviours are moderated to fit with the devices' realities and the expectations of wider caring networks. Such findings would not have emerged without the utilisation of a networked and longer-term approach to my data collection. I now highlight my key contributions to RO1 and my evolving conceptual framework.

8.2.4 Summary: connections to RO1 and conceptual framework

RO1 aimed to explore the experiences of older people living with DIY HSH concerning meanings of home. In response, in section 8.2 I argued that DIY versions of HSH have been created in an attempt to regain a sense of home (and improved ontological security). These DIY HSH have been created through a process of bricolage in which a mixture of smart and assistive devices have often been used for unintended purposes to improve ontological security.

Feelings of ontological insecurity are perpetuated through DIY HSH living. The pre-existing power imbalance between older people and their, often younger and more technologically adept, wider caring networks can be perpetuated through the inclusion of smart and assistive devices which supposedly offer objective views of situations (i.e., how the older resident behaves at home). Given the supposed objectiveness of the realities created through virtually monitoring the older resident through smart and assistive devices, they may feel the need to moderate their behaviours to appease their wider caring networks (i.e., wear their fall alarms more often). Although such moderating behaviours may improve their safety, they simultaneously diminish their feelings of ontological security and sense of home. Whilst it may be that key participants moderated their behaviours because of my presence (both with and without a camera), my networked and visual ethnographic methodological approach identified these multiple realities.

Given the importance of ontological insecurity, sense of home remains key to my conceptual framework (Chapter 2, section 2.4). Next, I build on this further by examining identity.

8.3 The identities perpetuated through DIY HSH

8.3.1 Introduction



Figure 29: Explore the extent to which living with DIY HSH impact the identities of, and relationships between, the older residents and their wider caring networks

In Chapter 6 I depicted the changing identities of older people and their wider caring networks through DIY HSH living. Through Chapter 6 I developed three key findings for my research questions related to RO2:

- 1. For RQ2a, DIY HSH are increasing the visibility of their residents. My key participants had to carefully and simultaneously perform an increasing number of roles for an increasing range of audiences to convince others that they are capable and not a burden.
- 2. For RQ2b, the wider caring networks were grateful for many of the smart and assistive devices which allowed the key participants more independence, capabilities and opportunities in their homes and lives. However, the use and uptake of these smart and assistive devices also necessitated the wider caring network members to play certain roles which had an impact on their identities and everyday lives, such as taking on new carer roles, becoming technical gurus, or having to observe their parents through Facebook.

3. For RQ2c, my key participants often had to work harder to convince their audience (i.e., their wider caring networks) of their roles and ultimately their identities in DIY HSH living. These networks were important in helping to decide which type of DIY HSH resident identity is accepted by both themselves as and by the DIY HSH residents. Such networks also helped establish the level of (dis)empowerment that the DIY HSH residents experience from DIY HSH living. Within Chapter 4, I highlighted how my mum had to perform the role of capable device user, and I the role of 'technical guru', as an aspect of our evolving relationship after the death of my dad.

In section 8.3 I utilise the concepts of dramaturgy and the panopticon to better understand how DIY HSH are changing the identities of and relationships between older residents and their wider caring networks. The roles (introduced in Chapter 6) are those that traditionally filled the front and back-stage spaces of an older person's identity. However, within the DIY HSH, there is less (or no) space devoted to the backstage and more emphasis on the frontstage.

Specifically, in section 8.3.2 I explore the potential for dramaturgy and the panopticon to explain how older residents' identities are changing through a reconfiguration of space within DIY HSH. In section 8.3.3 I highlight the impacts of increased surveillance within DIY HSH. In section 8.3.4 I explore the changing relationships between older residents and their wider caring networks from DIY HSH living. Finally, in section 8.3.5 I conclude with the specific contributions to RO2 and my conceptual framework.

8.3.2 Increased frontstage and reduced backstage

The roles I highlighted in Chapter 6 may partially be understood through Goffman's (1971) dramaturgy concept (see Chapter 2, section 2.1.1 and 2.2.2). Dramaturgy conceptualises life as a play in which actors perform roles whilst on the frontstage and drop these performances within the backstage. Performers only reveal their true self when they believe they are not being observed by others. Within my research, my key participants and their wider caring networks sought to fulfil various roles to cement their desired roles and identities. Often multiple roles were portrayed simultaneously, given that multiple audiences were often present. These audiences may have different expectations from the performances, which may conflict with the expectations of another audience (i.e., Geoff expecting Anne to help him with devices, but simultaneously Anne would often need help and training to offer such help). Smart and assistive devices are percolating into the backstage space, making it a space of increased surveillance and decreased privacy, a change that is (at least initially) accepted by the residents due to the increased opportunities for independence. In this section I build on my key finding for RQ2a and discuss this increased frontstage and reduced backstage by way of highlighting the context for such a change (i.e., 'it's in their best interests') and the various types of stages and audiences, according to specific age or smart/ assistive device. I link discussions to Goffman's dramaturgy concept, arguing that it is not just a useful frame for understanding the context of these various roles, but that with DIY HSH living such a concept needs to evolve to better consider the impacts of the reduced or absent backstage. If a performer has nowhere 'safe' to drop their mask, are they then always performing?

My key participants were navigating the health declines of older age (Fausset et al. 2011), pressures from wider caring networks and society to behave in a particular way (Peine and Neven 2020) and from living in a new (form of) house or community. With rising concerns of the desirability and high costs of not ageing at home (i.e., in a care home), my key participants were

increasingly being monitored through smart and assistive devices as an alternative to care home living. My key participants were often willing to 'put up with' more smart and assistive devices at home to prevent a move to a care home. However, with so much monitoring and surveillance, one may ask what the real difference is between a fully monitored home and a residential care home. As society becomes more risk-averse (Batteux et al. 2019), the settings in which my key participants had to perform the role of a capable and independent older person were increasing. Linking to my findings for RQ2a, in Goffman's terms, the space for the stage and the performance was increasing. Thus, my key participants, to give a convincing performance, must let others (e.g., children, care workers, tech companies) into their backstage (i.e., their homes and bodies) to offer a capable frontstage performance. For example, Georgette allowing Lynne to place CCTV cameras in her home so that Georgette can continue to live at home. Or lain using his new DIY HSH so he can do more things at home (i.e., cooking) and appear more capable to himself and his formal carers.

The stage and type of audience can also differ depending on the specific smart/ assistive device. As Neven and Peine (2017) highlight, there is not simply a divide between older and younger people, but a divide between how technologies are pitched to and for people of various degrees of ageing. The motivations for the uptake and the expectations over the use of various smart/ assistive devices can differ between DIY HSH resident and their wider caring network, for instance George using Facebook to maintain social connections, and Kate using it to monitor her dad's activity levels. The differentiation of devices for self-fulfilment and monitoring and surveillance should not be considered as a binarism, as older people can and do use a mix of devices in shaping their identities. Binaries of older age of normal versus pathological, or functional versus dysfunctional (Katz and Marshall 2003; Wanka and Gallistl 2018) are outdated when considering smart and assistive devices. The increasing proliferation of smart and assistive

devices have transformed previous ageing binaries into a continuum of more and less acceptable older identities. Now multiple roles and identities are performed at once, and these can be a mix of active and inactive roles (i.e. caregiver and care-recipient) which may create new issues for maintaining and navigating identity in older age (Fealy et al. 2012). On the other hand, the children, partners and carers of my key participants were also wary about burdening their other friends and family with their concerns, either around their parent's situation or the pressure they felt. As such, a caring network is not self-contained. Individuals can play a key or supporting role in multiple networks, simultaneously highlighting and hiding multiple performances, a circumstance that DIY HSH can further complicate.

Linking again to dramaturgy, these monitoring and surveillance devices allow for little existence of a backstage. These devices necessitate the sacrifice of a backstage space to enable continued ageing-in-place. In other words, DIY HSH residents such as my key participants have little or no space that is private. This research offers a way to progress the dramaturgy approach within internet-connected and smart living situations, as it questions the space given to the backstage.

8.3.3 Changing degree of surveillance

With rises in smart technology and social media, our lifeworld is becoming more panoptic, and this is likely felt to a greater extreme for older DIY HSH residents. Additionally, drawing on Goffman (1971), for these older residents the audience is not simply one group (e.g. prison guards) but all of society. As the surveillance of smart and assistive devices are now virtually allencompassing, it (i.e. surveillance) becomes conspicuous (Sadowski 2020). In this section, I further build on my findings for RQ2a and discuss this changing degree of surveillance by focussing on the difficulties in producing a convincing performance within smart living

situations, including the ability to obtain a convincing personal front, the increased potential for mystification and a convincing manner. All of these were denoted by Goffman as important elements for a convincing front-stage performance.

Previously disempowering events were hidden away in the backstage i.e., not telling a carer or family member if you had had a fall; this becomes less possible within a DIY HSH, as residents are more often 'on show'. If, as occurred on several instances for my key participants, they are only utilising smart and assistive devices to offer their family peace of mind, the impacts of performing may be even more emotionally draining and negatively impact their relationships.

A performance also needs a personal front (Goffman 1971). This is the equipment necessary for the performance and can be identified by the audience as a continuous representation of both the performance and the actor. The personal front comprises appearance and manners. I first discuss how DIY HSH living is changing the appearance, followed by manners. The appearance is the equipment that reflects the social status of the actor. This links to my findings for RQ2a concerning the degree to which a performance can be convincing is dependent on their access to a range of criteria (i.e., financial, knowledge, interest, geography). Before the increases in smart and assistive devices, older people were often associated with frailty and degradation (Courtney et al. 2008). However, now there is often a simultaneous association that this frailty can be somewhat managed through DIY HSH. According to Katz and Marshall (2018: 63), these "new technologies around aging and quantifiable fitness create an ambiguous image of the aging body and brain as both improvable and 'plastic', but also inevitably in decline". As these devices are becoming more ubiquitous, the social status or appearance of an actor is no longer so easily identified. The specific device can highlight a great deal about the appearance of an older person, but it can also hide a great deal (Katz and Marshall 2018). In some instances, these

hidden aspects are negative, such as masking memory loss or even early signs of dementia, but in other instances, they can hide more positive and empowering aspects of the older resident's character, such as undertaking hobbies and retaining independence. My key participants were motivated to use smart and assistive devices to reduce their dependence and enable ageing-inplace, but they also by-proxy enabled opportunities to continue or restart hobbies online (e.g., George's cycling forums) and to reignite music passions. Thus, DIY HSH living can lower the prevalence of disempowering roles and increase empowering roles for older residents. For Iain, this was encapsulated in his increased potential feelings of capability in his new home, such as being able to poach an egg for himself and have control over his own actions at home. However, to do so, older residents have to identify themselves as somewhat frail, at-risk and in need of smart and assistive devices. This performance needs to be carefully constructed so that the wider caring networks will acquiesce to the desired outcome (Aceros et al. 2015). Relevant to all of these discussions and examples so far is the role of the good patient (McCreaddie and Wiggins 2009; Campbell et al. 2015) or perhaps good DIY HSH resident. As all my key participants had some form of existing health condition, they also had to perform the role of the good patient regarding adhering to medical advice, looking after themselves and trying to control their conditions as much as possible. Furthermore, they fulfilled the role of good research participant, with my older residents happy to take part in my film, eager to (I assume) please me and share their stories with wider audiences.

Meanwhile, manner is the way the actors conduct themselves, and it highlights what an audience should expect from the performance (Goffman 1971). Many smart and assistive devices have been developed around the optimal body, to either allow young people to monitor their own health and care data or a 'docile body in need of extensive management by others' (Neff and Nafus 2016: 124). Lupton and Maslen (2018) highlighted how much of the existing

research and literature on the use of smart technology in the home has held a bias towards people who live without disabilities and with full autonomy and self-awareness. Society tends to recognise a singular desire for independent living, rather than this being (at most) one of several desires older people may have for their daily and future activities. As Marshall (2018) highlights, with a sole focus on independent living, older people are treated as only in need of surveillance, and other human needs are ignored. Linking to Goffman's understanding of mystification (i.e., the concealment of specific information from the audience), such a process becomes more difficult within DIY HSH living. With this focus on surveillance, older residents may feel pressured to focus on their more conventional rather than risky performances, never sure of when they are being watched. For Katz (2003), risky behaviours, such as falls, are not simply accidents but are indicators of wider decline. Others (Boholm and Corvellec 2011; Lupton 2016b) have highlighted that risky behaviours may also be symptomatic of the wider policies. Thus, a focus of wider caring networks and wider society on risky and disempowering behaviours can enable transfers of power and identities. Yet, as I discussed in section 8.2.3, older DIY HSH residents are often already starting these experiences and performances from a position of diminished power.

In this section I have highlighted that, for older residents to take advantage of the opportunities that DIY HSH can provide in terms of independent living and enabling a reconnection to old hobbies, they are forced to 'play the game' through the performances that they focus on and those that they hide. This game playing also likely occurred in pre-HSH times, however these devices have increased the intensity of, and need for, such performances. Also, older residents may have to accept some further loss of control (i.e., a diminishing backstage space) to reap the benefits of DIY HSH living. To participate, older residents need to mould their bodies into not simply 'busier, smarter bodies' (Katz and Marshall 2018), but also create busier and smarter

performances using those bodies. Drawing again on Goffman, they may need to moderate their behaviours so that their performances are convincing through creating a convincing personal front, little potential for mystification and maintaining a convincing manner. However, this moderation of behaviours can be disempowering if the older residents are constantly having to play moderated versions of themselves, which can have knock-on impacts on their sense of home (i.e., no longer a private backstage space) or their relationships with their wider caring networks who are monitoring them at home under the auspices of care.

8.3.4 Changing relationships between older DIY HSH residents and their wider caring networks

Older people are increasingly being categorised according to their abilities to undertake particular activities (e.g., work, cook, clean, or dress themselves). As Katz (2000: 142) states, 'activity is not just something people do, but ... is a measurable behaviour whose significance connects the worlds of elderly people to the largesse of expertise'. Inactivity is also becoming increasingly measured (Lupton 2016c) (e.g., lack of movement). Thus, smart and assistive devices can highlight this inactivity to wider caring networks which can impact their relationship, in terms of trust and dictating the activities and routines of the older person. In this section, I build on my RQ2b and RQ2c findings to argue that DIY HSH living is changing the lifestyles of older residents, both in what they perceive is possible, and what others perceive to be possible for an older person. Crucially these perceptions are not always aligned, hence the need for the performance of various roles. In this section I explore these changing relationships and lifestyles, through my key participants utilising smart and assistive devices to offer peace of mind to wider caring networks, and the new roles required of my wider caring networks within DIY HSH living.

Drawing on an ethics of care perspective (Kim 2010), the relational aspect of this caring activity is of utmost importance here. In many ways, living with DIY HSH is a selfless act, but also a powerless act as residents in many ways have been forced to take up devices to appease their families even if they do not feel they require such devices. Additionally, the actions of wider caring networks in encouraging the use of smart and assistive devices, also comes from a place of care. Both are different forms of caring actions.

Many smart and assistive devices promoted for independence highlight a negative view of older people (e.g., fall alarms), as burdensome and in need of care, but other devices (e.g., smartphones and virtual assistants) require the older users to able to fix them if something goes wrong. Thus, in highlighting lower physical ability they necessitate higher cognitive ability. Linking to my findings for RQ2b, the technical guru role is learnt over time and taken on by wider caring network members, reinforcing this idea of burden (Hine 2019). Thus, the relationship between parent and child appeared to be a fine balance between retaining some, but not all, control (Hine 2019). It also highlighted pressure for wider caring networks to adopt these new roles and performances, especially for familial connections. Such a role may also be fulfilled by a formal carer, however the emotional bond, and hence sense of obligation, may not be as strong (Kim 2010). The motivation for device introduction may be, at least in some cases, to reduce the guilt felt by the child that they cannot provide more in-person support due to working patterns or living far away (Hine 2019).

In this section I have highlighted how DIY HSH living could alter the relationships between older residents and wider caring networks to one of misplaced burden. To put this in the context of dramaturgy and the panopticon, many smart and assistive devices simultaneously require constant monitoring from the wider caring networks to see if (a) such roles are constantly being

performed, and (b) if any such health emergency has occurred. Thus, the panopticon and dramaturgy concepts are useful to explain the moderating behaviours of the older DIY HSH residents, but not necessarily the wider caring networks. Without constant real-time surveillance, the wider caring networks will not know if their older DIY HSH resident is safe, and even with constant surveillance they may not be able to know this. This then offers a potential extension of these two theories in which an exploration of the wider networks, i.e., the audience as well as the performer, or the prison guard as well as the prisoner, is needed to see the real-world impacts of such performances or moderated behaviours.

8.3.5 Summary: Connections to RO2 and conceptual framework

RO2 aimed to explore the extent to which living with DIY HSH impacted the identities of, and relationships between, the older residents and their wider caring networks. In response, in section 8.3 I have utilised Goffman's dramaturgy approach to explain how and why older DIY HSH residents utilise multiple roles within DIY HSH living, to simultaneously award themselves more independence to age in place for longer but also identify themselves as needing to depend on smart and assistive devices to enable such extended home living. Such performances are a careful balancing act which may be especially difficult given that older residents often already have a diminished level of power in decisions about their futures, coupled with a reduced backstage or offline space. Exploring the simultaneous experiences of the wider caring networks has highlighted that they have to perform certain roles and act as one of several audience(s) for/ of older DIY HSH residents. Thus, they too have to undertake a careful balancing act. Finally, given my focus on a bricolage approach of smart and assistive devices that are adopted often not for their intended purpose, such empirical findings extend the dramaturgy and panopticon concepts. By simultaneously exploring the experiences of the older DIY HSH residents and their

wider caring networks I found that these concepts lacked consideration of the impacts on the audiences or those conducting the monitoring. In the case of some privately commissioned devices, constant monitoring is still required by the wider caring networks to create a sense of ontological security, as without this monitoring the health emergency may still occur.

My finding for RO2 emphasises the importance of my film in terms of gathering the more-thanspoken aspects of DIY HSH living. From undertaking a visual ethnographic approach, I could see additional aspects of their performances, i.e., smart and assistive devices visible in their room or photographs from when they were young and 'more capable', or instances when the backstage may 'slip out', i.e., difficulties using devices. Returning to my conceptual framework (Chapter 2, section 2.4), section 8.3 has emphasised the importance of a consideration of relational living in terms of exploring the multiple perspectives of DIY HSH experiences, and perhaps the importance of a longer-term study to gather the fluid and potentially evolving nature of experiences as health, financial or other aspects of access may change.

8.4 Creating the future within DIY HSH

8.4.1 Introduction

RO3: Explore the extent to which DIY HSH enable older people and their wider caring networks to plan for the future

RQ3a: What types of futures are possible with various smart and assistive devices?

RQ3b: How do these futures differ between older people and their wider caring networks?

Figure 30: RO3: Explore the extent to which DIY HSH enable older people and their wider caring networks to plan for the future

In Chapter 7 I illustrated how my key participants and their wider caring networks discussed the future. It produced three key findings for my research questions connected to RO3:

- For RQ3a, there are multiple potential futures created through DIY HSH living, including the creation of 'more capable future' in which older residents have more control, or fears from an increasingly digital-by-default future. This range of futures can be considered a continuum of (dis)empowering futures for the key participants and wider caring networks.
- 2. For RQ3b, these futures varied according to the commissioning source. Specifically, publicly commissioned devices were often utilised by key participants out of fear or guilt of being a potential future burden, whereas privately commissioned devices were utilised by key participants mainly out of curiosity at their potential to increase empowerment in the future. Wider caring networks wanted key participants to utilise publicly commissioned devices to encourage empowerment, whilst contradictorily, they promoted privately commissioned devices out of a sense of guilt.
- 3. For RQ3b, privately commissioned devices necessitated additional unexpected labour from both the key participants and the (mostly informal) wider caring networks. Thus, empowerment can be a double-edged sword what is considered empowering for the resident can be considered disempowering for the wider caring network member, and vice versa, which may also change over time. Linking to Chapter 4 (and RQ3a), had my parents utilised more smart and assistive devices, a different and more positive future may have been possible.

Throughout section 8.4, I draw on futures studies and speculative fiction to argue that due to the multiple materialities/realities through which older residents and their networks experience HSH living, there will not be a singular utopic future for living with smart and assistive devices as is often promoted in popular culture. In section 8.4.2 I highlight how DIY HSH are enabling the imagining of a new potential vision for the future through a process of hope. I then draw on the temporal paradox and anticipatory action to highlight some discrepancies in expectations of smart and assistive devices, such as a loss of social interactions via in-person carers. In section 8.4.3 I build on this, drawing on ideas of the vertical noir and hierarchies to illustrate the range of types and levels of access that exist in creating or preventing the utopic future vision for smart and assistive devices and the impacts this may have on older residents and their networks. Finally, in section 8.4.4 I conclude with my contributions to RO3 and my conceptual framework.

8.4.2 Smart and assistive home devices and the temporal paradox

Smart and assistive devices are often presented as an anticipated solution and utopian vision to several perceived burdens (Amiribesheli et al. 2015). These are burdens that may worsen in the future including the informal care burden on family members, a financial burden of a move to a care home, or a physical burden on health and social care services (Wiles et al. 2012; Aceros et al. 2015), particularly within remote and rural communities (Currie and Philip 2019). This utopian vision is often out of sync with the realities and experiences of DIY HSH living. I argue that much of the vision, as well as being a means for cost savings, gains in efficiency, and decreases in state responsibility, has been framed around the idea of hope. For Bryant and Knight (2019), hope is defined as something that does not presently exist but potentially could; hope is based on more than a possibility and less than a probability. In this section (8.4.2), I

build on my findings for RQ3a and RQ3b, highlighting the positive impacts of DIY HSH in enabling the imagining of new potential futures and drawing on Anderson's (2010) anticipatory action to suggest that DIY HSH are creating a paradox in which the envisioned potential futures may not become a reality.

Envisaging a positive future is an important activity for maintaining and developing wellbeing (Ferreira et al. 2017; Ahmadpour et al. 2019). In imagining the future as being positive, we are offering ourselves hope, which in turn can motivate our actions in the present (Andrews 2018). However, for older people, envisaging any future requires them to believe they are going to live long enough to enjoy this future, i.e., something that George no longer believed, which again goes against many of the negative stereotypes of ageing. For Randall and Kim (2004: 242), the process of ageing 'works both retrospectively toward the past and prospectively toward the future.' As such, the process of ageing is a constant reworking of our anticipations and expectations for the future, in line with emerging changes in health (Liu et al. 2016), housing (Hooyman and Kiyak 2011) and socialising (Lee et al. 2017) capabilities and opportunities. Within my research this constant reworking is also demonstrated in the bricolaged approach to accumulating smart and assistive devices.

Relatedly, the notions of 'the future' that we anticipate and desire are inextricably linked to our identity, in how we view ourselves and are viewed by others (Andrews 2018). Thus, the vision that we have of ourselves in the future, and that others may have of us, can be powerful images to either strive for or to resist (Urry 2016; Bina et al. 2020). This also links to Sools' (2020) understanding that an individual's vision for the future highlights how they see their place in the world, for instance, in the type of future they anticipate (if any). This supports my findings for RQ3b, in which different futures where often anticipated by the key participants and their wider

networks. Also, Rogers and Mitzner (2017) highlight that envisioning the future can be difficult as we age, i.e., the dementia carers group identified with this, as their now expected futures were not what they had hoped for. This is also increasingly important in terms of involving older people themselves in processes which make their anticipated futures a reality. This raises the issue of who exactly owns the future (Lanier 2014) and who can change its path – the key participant, their wider caring networks or policy-makers. This research demonstrates that each of these actors have a role to play in owning the future of the older resident, however, given the negative stereotypes and stigma associated with ageing, the older residents had to work especially hard to hold the majority of this power over their future. This again was especially difficult when (supporting RQ3b) key participants and their wider networks often had conflicting motivations and experiences (of empowerment) of using publicly and privately commissioned devices.

Meanwhile, for policy-makers, the vision and expectations of smart and assistive device use in rural homes helps to bring existing rural areas, which have 'been left behind', back into relevance, much like the arguments for smart cities (Guelzim et al. 2016; Bina et al. 2020). I believe smart and assistive devices (particularly in rural areas) have the potential to create fairer and more just utopian futures, with smart healthcare in homes available as a sustainable option for anyone who wants it irrespective of financial position or geographical location. However, this future could become increasingly dystopian, concerning the associated high costs of some devices and the risks of dying alone at home, if we do not recognise the importance of the lived experiences of both current and potential residents and their wider caring networks. Such moves towards a more dystopian future with smart and assistive were expressed by my key participants. Drawing on Anderson's (2010) notion of anticipatory action (Chapter 2, section 2.2.4), I argue that my key participants were simulating living with HSH through their DIY

attempts. Furthermore, conceptualising the future expectations of smart and assistive devices is a form of imagined practice. The utopic vision for smart and assistive devices offer one imagined future. The imagined future vision, although something to hope for – a utopia – is unrealistic, as highlighted by some of my findings (i.e., for RQ3a and RQ3b). Building on Anderson's notion, when DIY HSH become more than simulations or imagined futures – they become reality. At this point, the potentials for what the older resident and their wider caring networks can anticipate and hope for begins to shrink (i.e., the best future they can then imagine is what is possible through their existing smart and assistive devices). Thus, I would argue that Anderson's theory needs to go further and consider what happens to simulations when they unintentionally become reality, as in the case of DIY/ bricolaged versions of HSH.

Feelings of (dis)empowerment can also be strengthened with smart and assistive device introduction. My RQ3a findings demonstrated that the lived experiences of DIY HSH are not always 'full of hope' (Bryant and Knight 2019). Although DIY HSH bring some additional opportunities for independence and control (Reeder et al. 2013), there are also some fears and worries emerging from the consideration of a future-proofed by smart healthcare (i.e., as expressed by Georgette) leading to the potential for more dystopian futures. As such, the potential for DIY HSH to offer better futures for my key participants was already in question. These fears also related to misuse because the devices were developed around non-disabled, or specifically-abled bodies (Lupton and Maslen 2018). Also, many smart and assistive devices are being used to replace activities that once were undertaken by physical people such as carers. Although the motivations may be positive given the lack of carers in Scotland (Scottish Government 2018e), smart healthcare technologies have been promoted by some policymakers and health and social care sectors as a suitable replacement for specific activities once undertaken by carers (French and Tulloch 2018). This has resulted in reduced in-person care work and the relationship between carer and resident has become more transactional, in which only the physical care act is replaced. The additional benefits of social interaction, routines and security risk being lost. This connects to research by Currie et al. (2015) who found that older adults with chronic pain were broadly accepting of eHealth within their future care but only if it was delivered alongside existing in-person visits from health and social care professionals. In other words, social interactions were of utmost importance and eHealth did not replace face to face interaction in this respect.

The numbers of people 'left behind' from this move to smart and assistive devices may increase as the general knowledge of the public of these devices continues to rise (Bina et al. 2020). Most of my key participants had some knowledge and motivation to use their smart healthcare devices. However, as society continues to expand its knowledge and the potentials of what technology can do (Urry 2016), those with limited knowledge, acquired through learning routines (e.g. of how to use their TV remote or smartphones) may be left behind as their devices become obsolete (Philip et al. 2017). Such routines are depicted in my film regarding Georgette learning how to converse with her Alexa, or Geoff memorising how and where to tap to use his tablet. With a move to new devices these routines may no longer be useful, thus creating potential disempowerment.

These potential discrepancies between the imagined and actual future living with DIY HSHs, I argue, is a temporal paradox. This notion is taken from similar discussions around a temporal or time travel paradox in which there is a contradiction between the ideas of time and time travel (Miller 2008). This temporal paradox represents a causal loop in which a future event is caused by a past event, which then, in turn, causes the future event (Lobo and Crawford 2002). In the case of this research, this can be understood as the dominant and utopian future visions of smart

and assistive devices as one-size fits all solutions, which are causing older people to have simultaneously unrealistic and unachieved visions for their futures. This paradoxical notion builds on the work of Anderson's (2010) idea of anticipatory actions, whereby a simulated action (performance) can become a reality, which can then create a new potential future. The range of DIY HSH being created are attempts to create more positive futures for older people, however, the range of DIY HSH solutions could lead to misappropriation or reappropriation of devices, and thus a paradoxical future in which no imagined futures are obtained.

Through section 8.4.2 I have highlighted that multiple futures, rather than a single utopian future, are likely to be created through DIY HSH. Rather than attempting to create innovative, but ultimately unachievable visions for ageing, it may be useful and more productive to anticipate that many aspects of ageing are negative and accept the process as something natural. Rather than being the fault of older people or as something to be poorly solved through technology. Although a utopian future is likely impossible, so too is a dystopian future, whereby in-person care is partially or fully replaced by machines. Several issues are emerging from the current performances and simulations of DIY HSH utopian living concerning differing and potentially competing levels of access to smart and assistive devices (e.g., along financial, health and geographical lines). These access levels are now discussed.

8.4.3 Future (vertical noir) hierarchies of access

Throughout this thesis, I have highlighted how different levels and types of access to smart and assistive devices have led to differing experiences. This builds on the digital divide concept, but also what Graham (2016: 28) has referred to as vertical noir, 'where profound social inequalities are underpinned by ubiquitous and unequal access to technology'. Furthermore this unequal

and ambiguous access to technology devices will not impact all people equally, leading to further inequalities. In this section (8.4.3) I build on my findings for RQ3a and RQ3b, highlighting that the paradoxical futures created through DIY HSH may be further strengthened through vertical noir (hierarchies). As such, I take the concept of vertical noirs (taken from smart city imaginaries) and apply it more broadly to discussions on differing levels of access to smart and assistive devices. Firstly, I discuss the relevant vertical noirs (i.e., financial, spatial, health, career, knowledge), and then how these vertical noirs are not simply have- or have-nots, but varying hierarchies of access.

Regarding financial inequalities, Philip et al. (2017) argued that there is a financial aspect to the digital divide. For RQ3a, I found that financial background, in connection with other characteristics, had an important role to play in the specific type or quality of DIY HSH that was possible. Connected to this were spatial inequalities, specifically housing tenure. The housing tenure type means that different changes and adaptations are possible (i.e., owner-occupied, private rented, housing association/ council rented). DIY HSH represent both those residents who cannot legally (due to their rental agreement), or financially, afford to significantly adapt their homes, or those few who can only afford to financially create a DIY HSH. These DIY homes can result in less overarching official support, and thus more unintended labour lands on the wider caring networks.

Vertical noir should not simply be understood as having or not having devices (Graham 2016). Instead, it should be concerned with the ability to access informal support for physical and technological-based care, of which technology devices are only one form. The knowledge level of both the older resident and their wider caring network can be key. This knowledge concerns the existence of devices, how they work and how they work in connection with other existing

smart and assistive devices. Many smart and assistive devices gather data that can create new knowledge and new forms of digital accountability to create ontological insecurity and anxiety (Beer and Owens 2018; Bergroth 2019). Moreover, digital accountability can differ between and across residents and their wider caring networks, creating differing intersectionalities (D'Ignazio and Klein 2020), materialities (Pink et al. 2018) and experiences of ontological insecurity (Colic-Peisker et al. 2015; Bergroth 2019).

All of this could further debates on the hierarchies of use (Selwyn 2006; Thielke et al. 2012; Nimrod 2016), whereby it is not simply a divide between who has and does not have the skills, knowledge and funds to use technology, but also different hierarchies of this. Thus, there is a future concern of what I term 'vertical noir hierarchies' where experiences of DIY HSH will differ depending on an older users' access and knowledge to various smart and assistive devices. These smart and assistive devices may be publicly- or privately- commissioned, or a mix of both. Authors such as Wilton and Hall (2012) and Power and Hall (2018), identified that spaces can make the impacts of people's disabilities more profound. Similarly, there are risks that 'vertical noir hierarchies' can mean that individual residents experience their health concerns in more or less extreme ways depending on their future access and ability to use certain smart and assistive devices and variations in expectations and likely experiences of smart and assistive devices at home dependent on knowledge of, and ability to access, technological and physical support manifest through multiple hierarchies.

8.4.4 Summary: Connections to RO3 and conceptual framework

RO3 aimed to explore the extent to which DIY HSH enabled older people and their wider caring networks to plan for the future. In response, in section 8.4 I drew on speculative fiction (via the original vertical noir concept), temporal paradox and anticipatory action (Anderson 2010) to argue that, especially with the prevalence of DIY HSH, there are likely to be a range of potentially disempowering experiences of future DIY HSH, rather than a utopic imagined future as envisioned by many (i.e. policymakers and DIY HSH marketing companies). These imagined futures are nevertheless powerful and offer hope to older DIY HSH residents. Furthermore, simulations (based on anticipation and hope) of HSH are created through DIY HSH, and subsequently relate to the potential futures that can then be anticipated and hoped for. The degree to which this anticipation and hope may be met is linked to the mix of vertical noir hierarchies experienced by the older DIY HSH resident and their wider caring networks. In other words, the types of devices older DIY HSH residents and their wider caring networks can access (and degrees of this access) can directly impact their sense of home and identity. Experiences can also differ according to the commissioning source.

My finding for RO3 emphasises the importance of my film as this footage can offer a more realistic narrative to DIY HSH living for other older people and their networks. It also highlights the potential for varying experiences, further rejecting a single utopian future for living at home with smart and assistive devices. Returning to my conceptual framework, my key findings for RO3 and its RQs highlight that spatial inequalities are one of several inequalities that may impact on the experiences of DIY HSH living for older people. They each need consideration within my revised framework, as now discussed.

8.5 Updated conceptual framework

My conceptual framework (Figure 31) was originally developed through my literature review. It highlighted the importance of promotion of relational living, consideration of spatial inequalities and maintaining a sense of home (Creaney et al. 2021).



Figure 31: Original conceptual framework: For encouraging optimal experiences (of home and place) for older residents through smart and assistive devices

Throughout my results and discussion chapters, I have returned to this framework to discuss its relevance to my findings. I now present an updated framework (Figure 32) based on these evolving findings. The unchanged elements remain in grey, new elements are in green, and adapted elements are in blue.



Figure 32: Updated conceptual framework: For encouraging optimal experiences (of home and place) for older residents through smart and assistive devices

Given this framework is now based on my literature review and empirical findings, it is well placed to act as both a means for developing more optimal experiences of home and place for older residents and their networks over a range of settings (i.e., the vertical noir hierarchies), and as a heuristic and theoretical device to help explain the intricacies of both place, and of living with smart and assistive devices for older residents and their networks. I explore each of these updated criteria in turn. The order of discussion has no bearing on their importance, they are of equal weighting in this regard, hence the circles in the framework remain the same size.

8.5.1 Sense of home

Sense of home remains key. As I highlighted in Chapter 5 and section 8.2 of this chapter, maintaining feelings and meanings of home are of utmost importance within both considerations of ageing in the right place and in living with smart and assistive devices. This is

particularly true within DIY HSH in which multiple experiences of sense of home are possible – both for the resident and their wider caring networks. Without maintaining a sense of home (and therefore independence through continued ageing-in-place), there is little motivation to pursue DIY HSH living. This sense of home, much like the DIY HSH, could be attempted through bricolage in which residents and their wider caring networks use whatever devices they have available to make a home to the best of their ability. These devices and abilities also connect to the vertical noir hierarchies. Finally, sense of home is especially important within DIY HSH given the potential for multiple realities where the resident risks being undermined (through surveillance) in their own home. Sense of home is also implicit within the other criteria.

8.5.2 Relational living and consideration of wider caring network experiences

Strong connections with wider caring networks by way of relational living remains important regarding the relationship between the older resident and their network; however, the consideration of wider caring networks' experiences is an important addition. My findings highlighted the importance of this relationship for multiple reasons: (1) with the reduction or absence of the backstage, wider caring networks are more involved and aware of the DIY HSH resident's activities in their home; (2) the wider caring networks are often responsible for introducing and maintaining smart and assistive devices through their technical guru role to achieve peace of mind; and, (3) both the wider networks and the older residents can feel pressure to perform and maintain their 'empowering roles' through smart and assistive devices, meaning that understanding this relationship is increasingly important. Drawing on ideas of hope (Bryant and Knight 2019) and anticipatory action (Anderson 2010), experiences of DIY HSH living and expectations for the future, can vary between older residents and their networks.

Therefore, exploring the experiences of the wider caring networks is valuable to understand the fuller picture of DIY HSH living.

8.5.3 Recognition of specific characteristics

Although spatial inequalities were recognised in my original framework, throughout this research, additional types and levels of access to device introduction, use and upkeep, have become apparent. These vertical noir hierarchies (section 8.4.3) are a key contribution of my thesis and thus each (i.e., spatial, financial, health, career and knowledge characteristics) needs specific attention in my revised framework. The hierarchies identified in my research have been discussed in section 8.4.3, thus here I discuss the aspects that I expected to have a greater impact in my research, given their prominence in the existing literature around DIY HSH living and ageing (i.e., rural specific aspects).

As I highlighted in Chapter 2, there are some specific rural issues concerning ageing in place, healthcare provision and the use of technology by older people. There was also a literature gap regarding rural specific experiences of DIY HSH. Hence I devised my methodology and RQs to explore these experiences and included 'spatial inequalities' as a key criterion of my conceptual framework. Most of my key participants lived in accessible or remote rural areas (see Chapter 3, Table 8), however, specific rural issues did not emerge as I expected, for instance, difficulties accessing or using devices (Dowds et al. 2018) or idyllic notions of rural areas (Shucksmith 2018). Instead, other aspects (i.e., home, identity and futures) emerged more strongly as the key findings from this research. My findings also emphasised the importance of wider caring networks. Smart and assistive devices made physical distances between key and network participants seem smaller as they could stay in contact more easily. As Degnen (2016) and Cloke

(2006) have argued, rural is an embodied experience in which our experiences shape the degree to which we consider somewhere as rural. This supports existing calls for an individual and placebased approach to ageing (Currie and Philip 2019) and housing (McCall et al. 2020). Nevertheless, existing literature has highlighted specific rural issues relating to healthcare (Henning-Smith et al. 2019) and the digital divide (Philip et al. 2017), so it should remain as part of the framework.

In this section (8.5.3) I have illustrated there are a range of vertical noir hierarchies that have become apparent through this research. My research was conducted with a small but dedicated sample, and so further hierarchies may emerge through additional research.

8.5.4 Productive language

Although highlighted as an initial consideration, greater attention needs to be paid to the role of language, as a key criterion for consideration in its own right. As I highlighted throughout this thesis, language and stereotypes can have a profound effect on how older people are discussed and considered in society, as well as how their desires for their current and future living is considered regarding more or less acceptable identities. The use of language and stereotypical considerations of older people (Fealy et al. 2012; Neven 2015) impacts on the various devices available to older people and their wider caring networks. Greater initial focus on this criterion would likely have a positive impact on the level of interest in DIY HSH that older people are allowed and allow for themselves.

8.5.5 The importance of 'the right' place

Finally, throughout all of these discussions, the importance of a consideration of 'the right place' is key (Sixsmith et al. 2017). As such, 'the right place' deserves a central role in my updated framework. The right place links to the importance of (sense of) home and community, relational living and a range of inequalities perpetuated through varying access to smart and assistive devices. Ageing in the right place (Golant 2017a) recognises that a diversity of experiences of ageing is possible, across a wider range of settings or places. It also recognises that these experiences can differ depending on the level of support from wider caring networks, and the emotional connections to, and feelings of (dis)empowerment in, various spaces and places (Cristoforetti et al. 2011). Thus, older people (and their wider caring networks) need to be consulted regarding the suitability of their homes, caring networks and communities to create the right conditions for ageing in the right places, which may or may not be aided by smart and assistive devices.

8.5.6 Next steps for the framework

In contrast to the conceptual framings that I discussed in Chapter 2 (section 2.1.1), this framework is not based around a dichotomy and recognises the range of potential individual ageing experiences (within DIY HSH). Given the current reliance on DIY HSH, the addition of specific vertical noir hierarchies could be beneficial in helping policymakers, developers and residents to create DIY HSH that offer more optimal experiences for older residents, if these hierarchies can be recognised or even removed. Awarding more consideration to the role and motivations of the wider caring networks will also be helpful. My thesis has highlighted the importance of these networks in promoting and assisting older residents with DIY HSH living. The enhanced focus on productive language also recognises the role of stereotypical versions of older people (perpetuated through the media) play in older people's abilities and likelihoods to
accept and utilise certain smart and assistive devices, which ties in with discussions on the motivations for use.

My conceptual framework could be further refined within focus groups with policymakers, smart and assistive device designers and potential older residents and their networks for creating viable future opportunities for living well with smart and assistive devices. Through such an approach, prospective residents could gain a better sense of what living with smart and assistive devices at home might entail in terms of both potentially empowering and disempowering experiences. It could also serve as a new theoretical framework to promote and test the experiences of living at home with smart and assistive devices for older people, building on other frameworks exploring housing and ageing (Wiles and Jayasinha 2013; McCall et al. 2020) or (smart home) technology adoption (Rogers 1995; Carnemolla 2018).

8.6 Conclusions: Connecting back to my research aim

My discussion chapter has highlighted the multiple ways in which DIY HSH are experienced by older residents and their wider caring networks. Specifically, these relate to a sense of home (RO1), identity (RO2) and planning for the future (RO3).

RO1 aimed to explore the experiences of older people living with DIY HSH concerning meanings of home. I found that DIY versions of HSH have been created to regain a sense of home through a process of bricolage in which a mixture of smart and assistive devices have been used for unintended purposes to improve ontological security. However, feelings of ontological insecurity can also be perpetuated through DIY HSH living, as older residents feel further disempowered by intrusive smart and assistive devices. Given the supposed objectivity of reality created through smart and assistive devices, the older resident may feel the need to monitor their behaviours to appease their wider caring networks. Such behaviour modification may simultaneously improve the resident's safety and diminish their ontological security and sense of home.

RO2 aimed to explore the extent to which living with DIY HSH impacted the identities of, and relationships between, the older residents and their wider caring networks. I utilised Goffman's dramaturgy approach to explain how and why older DIY HSH residents utilise multiple roles (performances) within DIY HSH living. These performances simultaneously award DIY HSH residents more independence to age-in-place but also necessitate greater dependence on smart and assistive devices. Exploring the experiences of the wider caring networks highlighted that they too have to perform certain roles as well as acting as (one of several) audience(s) for their older DIY HSH residents. The performances of my key participants and their networks are a careful balancing act which may be especially difficult given older residents often already have a diminished level of power in decisions about their futures, coupled with a reduced backstage or offline space. By simultaneously exploring the experiences of the older DIY HSH residents and their wider caring networks I found that the dramaturgy and panopticon concepts lacked consideration of the impacts on the audiences or those conducting the monitoring. In the case of these privately commissioned devices, constant monitoring is still required by the wider networks to create a sense of ontological security, as with or without this monitoring the health emergency may still occur.

RO3 aimed to explore the extent to which DIY HSH enabled older people and their wider caring networks to plan for the future. I argued that, especially with the prevalence of DIY HSH, there are likely to be a range of potentially disempowering experiences of future DIY HSH, rather than

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a utopic imagined future as envisioned by many policymakers and marketing companies. These imagined futures are nevertheless powerful and offer hope to older DIY HSH residents. Simulations of HSH are created through DIY HSH and subsequently relate to the potential futures that can then be anticipated and hoped for. The degree to which this anticipation and hope may be met is linked to the mix of vertical noir hierarchies experienced by the older DIY HSH resident and their wider caring networks. Such experiences can also differ according to the commissioning source of the smart and assistive devices, and the novel use of vertical noir hierarchies helps to highlight this.

My multimodal ethnographic methodological approach allowed me to identify these vertical noir hierarchies and different experiences of older people and DIY HSH living. Figure 33 highlights how the different methods worked together to help identify my key findings and theories.



Method: Traditional ethnography with key participants and dementia group Perspective: Their experiences of their devices and homes and desires for the future

Method: Informal and formal interviews with wider caring networks

Perspective: Their competing experiences for the future and emphasised the dramturgy approach/ impacts on identity

Method: Visual ethnography including HSH device tours

Perspective: The more than spoken interactions with HSH devices of my key participants

Method: Autoethnography and field diary Perspective: This strengthened my

reflexivity and fieldnotes. Enabled me similar first hand experience to my participants



This range of methods also enabled the utilisation of multiple concepts and theories. Many of the concepts and theories utilised within this research are useful beyond their specific results chapter, discussions section or RO. I argue that the notions of bricolage (Lévi-Strauss 1962; Greenhalgh et al. 2013a), dramaturgy (Goffman 1971), and simulations (Anderson 2010) are useful for understanding the wider experiences of DIY HSH living, and not simply in how they specifically relate to home, identity or future. Bricolage, as a means to use whichever tools one has at their disposal in a way that helps better their experience, can help to explain how and why older residents and their wider caring networks not only make a home in a DIY HSH but also form their identity and plan for their future. Such bricolage is not simply through adopting various smart and assistive devices, but also in moderating their behaviours to create simulations of the roles and therefore identities that best fit within that specific situation.

In utilising their devices and identities within their simulations (i.e., DIY HSH), these simulations become a reality which consecutively creates a new boundary of what future is possible for the older resident and their wider caring networks. When smart and assistive devices are adopted by older residents, this can signal to wider caring networks that these residents are in need of constant monitoring. Complexity is added when smart and assistive devices are utilised for unintended purposes, or in other words, when devices are used to simulate other smart and assistive devices or care practices. For example, CCTV cameras are not designed to alert viewers to when an unexpected event occurs (i.e., a health emergency) and rather are used as both a means of surveillance (Foucault 1995) (i.e., behaving well because they do not know when they are under surveillance) and as evidence after an event has occurred (i.e., to see how a health emergency occurred). Thus, these simulations are not fully fit for purpose and require both older residents and their wider caring networks to perform their frontstage roles more often to ensure

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that any health emergency is both (1) unlikely to occur, and (2) noticed by the wider caring networks straight away if they do occur. Such activities undermine the notion of utopian expectations for smart and assistive devices which often implies that ubiquitous background monitoring does not require active use/ wider network involvement.

Many smart and assistive devices fails to recognise the existing power imbalances between older residents and their devices and their wider caring networks and instead promote the potential for objective reality. These realities are often situated within exiting power imbalances, leading to moderating of behaviours which impact on the sense of home, identity, empowerment and ultimate quality of the relationship between older DIY HSH residents and their wider caring network. I argue that Goffman's concept fails to recognise these imbalances of power and the impacts on the audiences or those conducting the monitoring (i.e., the wider caring networks). My thesis offers a potential means to extend Goffman's approach. As in the case of these more DIY and privately commissioned devices, constant monitoring is still required by the wider networks to create a sense of ontological security, as without this monitoring the health emergency may still occur.

Finally, the focus on a bricolage approach to DIY HSH living would not have been identifiable without my multi-modal ethnographic methodological approach. It was only by working with both my key participants and their wider caring networks, over time and across networks, that I could gain insights into how and from where decisions over specific smart and assistive devices were made. Through such an approach I could identify the vertical noir hierarchies, which are another novel contribution of this research, in addition to my conceptual and theoretical framework. This approach enabled the collection of visual and autoethnographic data, which offered an additional angle on my positionality within an evolving wider caring network and an

identification of the frontstage and backstage roles that both my participants and my mum performed throughout this research. My discussions throughout this chapter, including the cumulative discussion in this section, along with my conceptual framework, represent the key contributions of this thesis.

9 Conclusion: Implications for the future of ageing within healthcare smart homes

9.1 Introduction

Through this thesis I aimed to create and utilise a multi-modal ethnographic approach to understand the experiences of older people (and their wider caring networks) living with DIY HSH. My review of the literature revealed that the lived experience of DIY HSH is not well captured, particularly in terms of the relations with other people (sharing or caring in the home) or how these lived experiences are differentiated by device. Furthermore, existing literature fails to adequately acknowledge the diversity of desire and experiences, and how these may change over time. I undertook multiple forms of ethnographic research (e.g., interviews, observations, auto and visual ethnography) with older residents and multiple members of their wider caring networks to understand the potentially multi-faceted experiences of home, identity and futures within DIY HSH. I drew on and weaved together multiple theoretical approaches and concepts to address my research objectives and questions. I also offered several suggestions as to how these theories could be extended. Within this concluding chapter, I highlight the key contributions, specifically my empirical contributions (9.2.1), broader methodological (9.2.2) and theoretical contributions of this thesis (9.2.3), as well as a discussion of how well this thesis has addressed the overall research aim (9.2.4). I then offer some recommendations for policy and practice (9.3), some reflections on the research (9.4), indicate potential future avenues for research (9.5) and offer some final thoughts (9.6).

9.2 Key contributions

9.2.1 Empirical contributions

My novel empirical contributions of this thesis are as follows. For RO1, concerning meanings of home, I found that DIY versions of HSH have been created in an attempt to regain a sense of home and ontological security. This occurs through a process of bricolage in which a mixture of smart and assistive devices have been used for unintended purposes. Feelings of ontological insecurity can also be perpetuated through DIY HSH living. I also found that my key participants could moderate their behaviours to appease their wider caring networks, which may simultaneously improve safety and diminish ontological security and sense of home.

For RO2, concerning the impacts on the identities of, and relationships between, my key participants and their wider caring networks, I utilised Goffman's dramaturgy approach to explain how and why older residents utilise multiple roles (performances) within DIY HSH living. These performances award the resident more independence through extended ageing-in-place, but this ageing-in-place also increases the resident's dependence on smart and assistive devices. Exploring the simultaneous experiences of the wider caring networks of older DIY HSH residents has highlighted that they too must perform certain roles as well as acting as (one of several) audience(s) for their older DIY HSH residents. The performances of older resident and their networks are a careful balancing act which may be especially difficult given older residents often already have a diminished level of power in decisions about their futures, coupled with a reduced backstage or offline space.

Finally, regarding how DIY HSH residents and their wider caring networks plan for the future (RO3), I argued that, especially with the prevalence of DIY HSH, there are likely to be a range of

potentially disempowering experiences of future DIY HSH, rather than a utopic imagined future as envisioned by many (i.e., policymakers and DIY HSH marketing companies). These imagined futures are nevertheless powerful and offer hope to older residents. Simulations (based on anticipation and hope) of HSH are created through DIY HSH, and subsequently relate the potential futures that can then be anticipated and hoped for. The degree to which this anticipation and hope may be met is linked to the mix of vertical noir hierarchies experienced by the older residents and their wider caring networks. Such experiences can also differ according to the commissioning source of the smart and assistive devices.

9.2.2 Methodological contributions

This thesis contributes to the growing body of literature exploring lived experiences of ageing, in this instance at home with the aid of smart and assistive devices through ethnographic approaches. By drawing on visual and auto-ethnography, as well as traditional observations and ethnographic interviews, I was able to gather robust data and ensure my analysis was as rigorous as possible, leading to novel empirical and theoretical findings. The inclusion of a networked approach enabled a more well-rounded approach to understanding the experiences of people living with DIY HSH and their wider networks. I learnt that experiences of HSH living are not always as clear cut as would have been highlighted through a sole consideration of DIY HSH residents. The inclusion of interviews and observations with the wider caring networks enabled me to see the multiple perspectives and experiences of DIY HSH living, as well as some negatives which were experienced by the wider caring networks. On occasions, risks and feelings of disempowerment were simply displaced to wider caring networks rather than removed altogether. Added insecurity was also felt by wider caring networks who were now responsible for caring for their older DIY HSH residents from afar via privately commissioned devices.

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Additionally, this approach enabled me to identify the consideration of whose experience is believed, the DIY HSH resident's lived experience or the experience which the smart and assistive device produced via movement sensors or cameras. This is also known as 'situated objectivity' (Pantzar and Ruckenstein 2017). Without these additional interviews and layers of interaction I would not have uncovered such findings. Overall, this multi-modal and networked ethnographic approach enabled the collection of more robust and multi-faceted data to better understand the complex and competing experiences of ageing within DIY HSH.

9.2.3 Theoretical contributions

I created my conceptual framework as a heuristic device to help me to best approach my research, however, through the inclusion of empirical data and application and extensions of various theories and concepts, it has emerged as a new theory for understanding DIY HSH experiences. My initial conceptual framework (Chapter 2, section 2.4) highlighted the importance of sense of home, relational living and spatial considerations for exploring experiences of DIY HSH living for older people. From my empirical data and my utilisation of several theories/concepts, I added the importance of vertical noir hierarchies, wider caring network experiences and productive language. I highlight these below as well as some other theoretical contributions of this thesis.

Given the increasing desires, or perhaps need, for ageing-in-place (Carnemolla 2018), HSH have become a powerful innovation to achieve such needs and desires. However, older people, their wider caring networks, and technology companies have increasingly turned to privately commissioned devices to simulate DIY versions of HSH. I argue that this has led to a process of bricolage (Lévi-Strauss 1962) to DIY HSH development in which residents and their networks have drawn on whatever devices and commissioning sources they can avail themselves of to fulfil several needs and desires of ageing-in-place such as independence, peace of mind, reduced risks in the home. There are other ways in which bricolage is useful. It has been used not only to make a home in a DIY HSH but also to form identities and plan for their future. Moreover, bricolage is not simply achieved through adopting various smart and assistive devices, but also in the moderation of behaviour to create simulations of roles and identities that best fit within that specific situation. However, these DIY homes are still offering reactive rather than proactive care and support as they do not prevent risks (i.e., falls) from occurring and may increase feelings of ontological insecurity (Colic-Peisker et al. 2015) for both the residents and wider caring networks.

In utilising their devices and identities through simulations (Anderson 2010), these simulations (i.e. DIY HSH) become a reality which consecutively creates a new boundary of what future is possible for the older resident and their wider caring networks. Adopting specific smart and assistive devices signals to wider caring networks and society that the older resident needs small amounts of monitoring. Consequently, they may be stereotyped as frail older people who require constant monitoring, creating a future vision in which constant monitoring is required. Complexity is added when smart and assistive devices are utilised for unintended purposes, or in other words when devices are used to simulate other devices or care practices.

Many smart and assistive devices fail to recognise the existing power imbalances between older residents and their devices and their wider caring networks and instead promote the potential for objective reality. These realities are often situated within exiting power imbalances and can lead to the moderating of behaviours that connect to experiences of sense of home, identity and empowerment of both the older DIY HSH residents and the wider caring network. I argue that Goffman's concept fails to recognise the power and the impacts on the audiences or those conducting the monitoring (i.e., the wider caring networks within this research). Through this suggestion, I offer a potential means to extend Goffman's approach. As in the case of these more DIY and privately commissioned devices, constant monitoring is still required by the wider networks to create a sense of ontological security, as without this monitoring the health emergency may still occur.

The experiences and simulations that are possible for older residents and their wider caring networks from DIY HSH very much depend on their access to a range of vertical noir hierarchies (building on the work of Graham (2016)), which can dictate the level of empowerment and sense of home that residents and their wider caring networks can achieve from DIY HSH living. Moreover, these DIY HSH experiences can change as their vertical noir hierarchies may change, and so they should be considered as constantly evolving, rather than static.

Thus, along with these extensions of bricolage, dramaturgy, simulations and the creation of vertical noir hierarchies, all of which are considered within my updated conceptual framework, this framework is an additional theoretical contribution of this theory, as it can serve as a means through which to create optimal DIY HSH experiences, taking account of the range of vertical noir hierarchies of access as well as a sense of home, productive language and the role of the wider caring networks.

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9.2.4 Addressing the research aim

My overall thesis aim was to create and utilise a multi-modal ethnographic approach to understand the experiences of older people (and their wider caring networks) living with DIY HSH. I believe this research has met my aim well due to the range of empirical, methodological and theoretical contributions that my research can make to better understanding the experiences of DIY HSH living. Specifically, the decision to undertake multiple forms of ethnography and to explore the experiences of both older DIY HSH residents and their wider caring networks has enabled particularly rich data around the multiple realities of DIY HSH living, and the role of pre-existing power relations. The inclusion and interrogation of a range of theoretical vantage points, resulting in the creation of extensions of existing concepts and the creation of a new conceptual framework to explore what it means to age within a DIY HSH, as well as what it means to support an older resident to do so. The inclusion of a visual ethnographic element offered an additional way through which to explore (and present) my data and findings. I hope that this film will act as a good introduction (and standalone piece) to the multiple experiences of ageing with DIY HSH.

Finally, this thesis also sought to contribute to the fields of geography and sustainable development by offering an in-depth study into the importance of place for ageing. I found that place (i.e., the home and also the wider associated community and networks) was of utmost importance to both my key and wider participants as they continued to age. Place was more than simply the location in which ageing occurred. It also impacted on the quality of life and sense of home experienced by my participants. Good connections to place, by which I mean both the home and the wider community, could be considered as key aspects of the social

sustainability of ageing-in-the-right-place through smart and assistive devices. These connections can also help to address SDG11 in terms of creating more sustainable communities, but only if social inequalities perpetuated through varying levels of access to smart and assistive home devices can be reduced.

9.3 Recommendations for policy and practice

For both policy and practice, I have created a new conceptual framework for developing and reviewing DIY HSH and smart and assistive devices that could encourage optimal experiences for older DIY HSH residents. Given Scotland's focus on digitalisation within healthcare (Scottish Government 2018a), this framework could act as a useful guide for developing these homes. Thus, this framework could act as a blueprint for developing DIY HSH which offer optimal experiences for older residents. Throughout this thesis, I have also highlighted the power of language and stereotypes of older people which can play a part in the roles and identities of older people.

Overall, I recommend that policymakers:

- Ensure that health, social care and housing support services are appropriately funded so that smart and assistive technologies can be utilised to create more proactive and tailor-made support rather than technological support which is reactive and based on stereotypes.
- Recognise, in line with Scottish Government's Housing to 2040 strategy, that the use of DIY HSH and technology enabled care at home for older people should take a placebased approach recognising that appropriate homes and places are directly connected to the health and wellbeing of their older residents, to enable ageing in the right place.

- Again, linking to the Housing to 2040 strategy make digital connectivity, smart and assistive devices available to all irrespective of age, housing tenure, location or affordability, so that everyone can have a right to an adequate home (which may include the use of smart and assistive devices).
- Ensure that both older people and their wider caring networks, are closely involved in decisions around future care, housing and technology-use to ensure that their needs may evolve and will continue to be met in the future.
- Appoint an Older People's Commissioner in their countries to help to protect and promote the rights of older people and to recognise their wider needs and desires over and above ageing-in-place.

Such considerations will enable older people more choice over their future decisions around ageing, housing and healthcare, which may, or may not be, ageing-in-place through DIY HSH.

9.4 Reflections

I have already discussed my specific methodological limitations in Chapter 3 (section 3.6). Here I offer some reflections from undertaking this research. Firstly, due to developments in ageing and care practices, smart technology developments, and the lived experiences and desires of older people, the experiences of older people living with DIY HSH are diverse. Given that fullyfledged HSH are not yet in abundance, attempts to create these homes have been more DIY. Different devices are available, and used by, different older people, dependent on age, capabilities, geographic location, financial standing and career history. The experiences of ageing in DIY HSH are particularly diverse and my research findings highlight this diversity rather than give a concrete prediction of the lived experiences of these homes. Thus, my research offers a snapshot of the experiences of living in these homes at this particular time in their lives and with their specific levels and types of access (vertical noir hierarchies).

During recruitment, I was often faced with expressions of fear by some potential key participants around using technology (Aceros et al. 2015; Knowles and Hanson 2018), and what they thought my research would require of them, for instance, during one lunch club recruitment visit many members expressed their participation fears. This was not fear over what the devices (i.e., Alexas, smartphones) would do, or not knowing how to use them. Instead, it was a fear of thinking my project would mean they would not have the time to do their existing hobbies such as baking and gardening. Many here, as at other recruitment events, remarked that they had fall alarm bracelets but that they were 'at home on the dresser', or 'out of battery'. Many potential key participants seemed to view these pieces of technology as an inconvenience of one form or another (Golant 2017b; Knowles and Hanson 2018). Most potential key participants were happy to use basic (non-smart) mobile phones because they were familiar with those and had built their own routines for using them. Similar findings were identified by Dowds et al. (2018) in which older people were happier to use devices and applications (i.e. Facebook) that they were familiar with and had used before.

My sample-size limitation highlights both the difficulties of carrying out research of this methodological and topical nature, and the necessity for such research given the rate at which these devices, homes, and the desires of older people, are changing. This research was undertaken at a very early stage of HSH development. If for instance I was starting this research now, there would have been a greater number and range of potential key participants, especially given the uptake in smart and assistive devices during COVID-19. This too highlights the

importance of my findings at such an early and mouldable stage of HSH development, especially for a post-COVID society.

9.5 Future research

For future research, I offer three suggestions. Firstly, it would be interesting to further explore the 'vertical noir hierarchies' concept (i.e., more remote Scotland and beyond) to determine the extent to which these hierarchies are accurate and robust. Using it to undertake research between rural and urban areas, between countries or age groups could identify further hierarchies. Such hierarchies may also expand as older people and their wider caring networks identify new smart and assistive devices. Interesting too, would be the use of the networked approach within this thesis with a larger number (and range) of participants to further illustrate its potential importance as a novel methodological approach.

Secondly, greater interrogation of the language and discourse used within HSH developments, and the conceptualisation of home would be an interesting supplementary area of research. Discourse analysis could be conducted on the language used within the promotion of these homes and devices. Such research would further support (and test) the usefulness of my conceptual framework.

Given the Scottish policy focus on the green recovery (Scottish Government 2020a) and digitalisation of rural areas after COVID-19 (Scottish Government 2020b), and digital connectivity across all homes (Scottish Government, 2021), there is potential for a follow-up or adjoined research project related to COVID-19 experiences. The research could explore the experiences of living in DIY HSH during COVID-19 or the motivations for adoption and utilisation

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of these homes in the face of increased digitalisation and isolation through the lockdown. Finally, exploring the adoption of devices according to commissioning type (and moves towards more DIY HSH) resulting from COVID-19 could offer interesting reflections.

9.6 Final thoughts

My research sought to gain insights into the lived experiences of older people within DIY HSH. In that vein, I will bring this thesis to a close with a poem from George.

<u>All Hail</u>

All hail the wrinklies ... the irritating ones who block the check-out queue and can never find the correct change ... dropping coins all over the place making customers wait ... the very same that hesitate at Zebra crossings making others push impatiently by to get to where they are going in time All hail to them ... as now I have reached the age where "two for one deals" have no appeal and I have time to talk to old wifies who now I find are interesting, and reply to saucy suggestions with belly laughs and speak of interesting pasts not always totally respectable but interesting nevertheless... what tales they tell of husbands going for a little walk and never heard of again

of past loves now famous and known by all... all at once I feel at home in their company heaven knows why.

Poem by George White (written May 2019)

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Appendix one: Future(s) of technology-enabled care: A short story

The year was 2017

Rose sighed and sat back in her chair, taking a break from her baking for the local coffee morning. Rose was 65 years old and had lived in the same rural village nestled in the mountains for most of her life. She looked across at the dozens of photos that she and her husband Phil had carefully hung on their living room wall. There was a recent aerial print of their village that their good friend and neighbour, Paula, had given to her on her 60th birthday, interspersed by some older faded photos of her and Phil in their hospital uniforms. The newest additions to their collection were some photos of their young grandchildren and from their joint-retirement party. Rose was excited about their future; in terms of where they would travel and the extra time they could spend with their family and community.

Meanwhile, Phil was spending his afternoon fishing. Phil, 67, had led a very active life. When he wasn't working, he would spend much of his free time out cycling, hillwalking, or fishing much like this afternoon. He had met Rose when they had both been working in the hospital and they had moved back to the village she had grown up in to raise their family. Rose had always spoken so fondly of her childhood that this was something Phil desired for his own daughter. Phil had excitedly looked forward to his retirement. There were many things in their house that they had put off fixing until their retirement, so these DIY jobs, along with a well-deserved holiday, were top on his list, well Rose's list, of jobs for him, now they had retired. Out of nowhere, there was a tug on his fishing line, and Phil sprung to action to try to win his catch.

Rose rested her eyes on one particular photograph, of their daughter Jane. Jane was 35 and lived nearby with her young family. She had recently moved back from the city, keen to raise her family where she was brought up. She tried to help her parents when she could with odd jobs and what her parents deemed 'problems for their tech-guru', such as retuning the TV and the intricacies of their smartphones. However, Jane still worked full-time in the city so she didn't get to see her family as much as she would have liked.

The year 2019

Satnav: You have reached your destination.

Andrea, 23, reached across her pile of Scottish Law books on the passenger seat and turned off her satnav. She sighed and leaned back in her car, exhausted as this was her fourth temporary job in as many months since arriving in the UK. Her Scottish law books scattered across the passenger seat. She had graduated in law from a university in her hometown but couldn't find a full-time job afterwards. She looked admiringly at the view; of this pretty village nestled in the mountains.

At the same time, and just around the corner, Rose and Phil were getting alerts on their Fitbits to increase their steps for the day. They were starting to use more technology devices at home. Jane had been trying to convince them for a while to 'keep up with the times' and make better use of their smartphones. The Fitbits had been last year's Christmas presents from her and the kids. Phil, having worked in healthcare administration, was more comfortable with technology and took these new opportunities in his stride. However, the devices frankly made Rose more anxious. The Fitbit alert always made Rose jump. She ran into the study to check with Phil that she hadn't damaged it. For other more complicated concerns, she would check with her technical guru (Jane).

The year 2022

Rose was sitting in her living room watching a documentary about COVID-19. She sobbed as she watched it, the hundreds of thousands of unnecessary deaths -including Phil and many friends. Rose and Phil had been very careful, shielding as much as they could. However, Phil still caught the virus and soon developed increasingly severe symptoms and was admitted to intensive care. She thought back to the three weeks spent in ICU, in a hospital they were both all too familiar with. As he was admitted at the height of the pandemic there were simply not enough staff and resources to save him. It was still devastating, and Rose found it all hard to think about, he was just 70, only five years into his long-awaited retirement. There was then a knock at the door. Rose composed herself and got up to let Jane in. She had come with another 'gadget'.

Jane: Hi Mum, what's wrong?

Jane could see her mum had been upset. She had found all of this particularly hard, having to watch her mum come to terms with her new life without her dad. Jane had also lost her job during the pandemic and was forced to move back to the city for new employment. She felt isolated from her mum and guilty at having to replace her physical support with Alexas and Skype calls. She also watched her mum get increasingly frail. She found everyday tasks such as cooking and cleaning increasingly difficult. Jane would have loved to be in a position to help her mum with these tasks herself, but she now lived too far away. She began to look for some home care support, but after Brexit and the health risks that home care staff faced through COVID, home care was harder and harder to come by.

Meanwhile, Andrea passed Jane on the way to visiting Rose. Andrea smiled at Jane, she recognised her as she and her family had recently moved onto her street. She too had lost her casual work for a law firm and so began to consider other options for employment, realising that the job situation would be no better back home.

The year 2027

Rose was sitting at her kitchen table doublechecking the settings on her new smart heating system. She was determined to sort this without asking Jane for help. Andrea was busy cleaning the dishes. In the last few years, Rose had become much more comfortable with her devices. This increased technological comfort was lucky though, given the digital-by-default nature of many services after the COVID-19 pandemic, and the degree to which devices such as voice assistants, ambient motion sensors and smart heating systems were now commonplace. She still relied on Jane for help sometimes but was keen to avoid this where possible. Jane, however, liked being able to help her mum as it made her feel less guilty at living far away. Luckily, Jane had been able to employ her neighbour Andrea who had started working as a carer, to help her mum at home, which offered her peace of mind. Rose had quickly become very fond of Andrea.

The year 2040: utopian version

Rose: Alexa, what time is it?

Alexa: It is 09:05 on the 21^{st} of February 2040.

Rose: Thank you. What is in my diary for today?

Alexa: Today you have your weekly GP home visit at 10:00, then you have your lunch club from 12:00 to 14:00 and a visit from Andrea at 17:00. I will let you know when both Dr Harris and Andrea are on their way.

Rose: Thank you, Alexa.

Rose sat back in her chair and thought about just how far she had come with Alexa. By 2040 Rose and her family were able to have full control of her health and social care with the aid of smart health devices. She had her Alexa to help her with her diary and sensors to predict and intervene before a potential fall. Over the years Rose had obtained more and more smart devices to help her at home. Now her whole house was kitted out with ambient technologies - motion sensors in the floor and walls and voice activation throughout her house. Jane had been fearful to move her to a care home after all confidence was lost in care homes being the final place for people to live after the COVID-19 scandal of the 2020s. Furthermore, it was what Rose had wanted, she loved living in her rural community and wished nothing more than being able to do this for as long as she could.

What was more, since the advances in free-to-use smart technology and better internet connectivity and speeds across all areas of Scotland (a.k.a. Smart Care) her daughter Jane was able to return home and now worked (from home) and lived around the corner from Rose. Also, each week, her GP visited her just to check in with her. The additions of smart health devices in the homes and better funding and conditions for health and social care staff made this GP service possible. Due to advances in health and medical technology, any health concerns were dealt with proactively rather than reactively. In other words, people were becoming healthier. Rose was highly appreciative of the assistance and enablement that her smart house offered, and what's more, looked forward to seeing her lovely carer Andrea each day. This, along with daily visits from her daughter were the highlights of her day. Rose was also able to get out and into her

community, and out of her house more because of the improvements in her healthcare and her assistive devices.

It was a lovely day, so Andrea had decided to walk to Rose's house that day. She was happy as she always enjoyed her daily visits to Rose. In fact, with the gradual introduction of Smart Care, Andrea had more quality time to spend with Rose. She enjoyed the stories Rose would regale - of her childhood and of the friends she had made at her lunch club. Meanwhile, Andrea would update her with stories of her children, much like she would her own mum.

Dr Harris was sitting in the sunshine enjoying his lunch. He loved his job now he could spend more time visiting his patients. With the introduction of smart care within his surgery and the sector he spent much less time making his way through endless paperwork, and he now had the time to get to know his patients better and offer more personal and proactive healthcare options. This was of course his main motivation for training to become a GP in the first place. Furthermore, with the free nationwide ultra-broadband, he could get updates and readings on his patients even in their homes. What is more, the advances in anticipatory healthcare meant that certain conditions, such as diabetes, had been all but eradicated. Although he wasn't meant to have favourites, he was very fond of Rose. They had lived in the same village for as long as he could remember, and he was even friendly with her daughter Jane. He often thought looking back he doesn't know how he coped without Smart Care.

The year 2040: dystopian version

Rose [in her thick Scottish Accent]: Alexa, fit's the time?

Alexa: Sorry, I didn't catch that?

Rose [trying to subdue her accent]: Alexa, what time is it?

Alexa: It is 09:05 on the 21st of February 2040.

Rose: Thank you. What is in my diary for today?

Alexa: Today you have your virtual lunch club from 12:00 to 14:00.

Over the years Rose had gotten more and more smart health devices to help her at home. First, it was a Hive heating system and then an Alexa. Now her whole house was kitted out with motion sensors in the floor and walls and voice activation throughout her house. Her children were fearful to move her to a care home given the devastating impacts from COVID and increasingly higher costs of care home residence over own-home residence. She had carers occasionally but since her care provider was bought by Uber, she rarely had the same carer more than once. Instead, the carer who was closest when Alexa or her family put a request in on the app was sent.

Alexa: There is a package for you at the door. I have signed for it. It is this month's smart technology delivery from Jane.

Rose: Thank you, Alexa. Please can you open the door?

Alexa: Opening the door, Rose.

Rose slowly got out of her chair and made her way across her living room, to the front door where this month's parcel lay in a neatly packaged box. Jane, Rose's daughter, would send her mum a package with a new piece of Smart Technology almost every month. This time it was a virtual reality headset connected to a drone to allow her to 'go outside' and interact with friends and neighbours along the way.

Alexa: Jane asked me to pre-load this headset with a virtual walk around your village.

Rose thought to herself, it would be great to go outside and see these views for herself. Rose had not been out of her house in several years, partly because of the set-up of her technology (devices that were more portable were unaffordable to Rose) and because of the dangers that still remained from COVID-38. She had a permanent tag on her wrist, much like a convict on early release might have, which prevented her from leaving the house. Her family had set this up as a means for her to continue living at home for longer, however even they had not realised the negative impacts which it has had on Rose.

Furthermore, she had not even spoken virtually with her doctor in months. Her heart rate and blood pressure were monitored, and readings sent to her GP every hour and her medication and activity levels were automatically adjusted to fit her current health condition. As such she could only visit a GP if Alexa sent worrisome readings. However, this didn't stop Rose feeling so lonely. She longed to speak to her GP about this or to even just have the trip out to the doctors – just something different – a reconnection with her old routines. She also longed to have a visit from a carer, but these were kept for extreme cases ever since the Brexit 'care drain' in the 2020s. She daren't tell her children about the feelings of isolation and disempowerment she was feeling, and she knew how hard they had to work to provide this 'smart care'. What's more, this was what she wanted in the beginning – living in her home and community for as long as possible. She just hadn't imagined this was how it would be.

Rose: Alexa, please call Jane for me.

Alexa: Calling Jane. I will record the call too.

Jane: Hi mum. How are you today?

Rose: Oh fine. I'm just calling to see how you are.

Jane: Yeah, all good here. I'm just at work. Is it okay to call you later, I've got to go back to work, my break has just ended.

Rose: Talk to you later.

Jane put down the phone. She always felt bad that she couldn't be there more to support her mum in person, but her job was very demanding. Since the new protocols on 'smart working' came in, she couldn't afford to be late. She and her brother had ploughed all their savings and a substantial amount each month to pay for her mum's smart care. But her mum seemed to like it, at least that's what she told her. She was always busy with some VR journey or virtual lunch club- her mum's social life was better than her own had ever been. She quickly checked on her mum's health levels and movements. Jane could view her mum, and her vitals, through her mum's television screen. She could see everything seemed normal and refocussed on her work.

Work Alexa: Your productivity just slipped below 90%, please quicken up.

Meanwhile, Rose tried to busy herself until her lunch club with her new VR toy. She took it out of the box but found it to be broken into pieces.

Rose: Alexa, please call the VR helpline?

Alexa: You will have to stay on the line with me, there is a 60-minute wait for assistance.

Rose got infuriated by this, there was always such a wait for tech support, especially when it was merely showing her what was outside of her front door anyway.

Alexa: Please calm down Rose, your blood pressure is rising. You need it to lower before you can attend the lunch club. If you cannot calm down, I will schedule an emergency visit with carer 71.

Rose racked her brain, carer 71, the number seemed familiar, but it was hard to remember all the different carer numbers in this new system.

Andrea looked down at her 'name badge' which read carer 71. She was sat at the bus-stop waiting to take the bus to her next client, Rose. She thought fondly of Rose, having cared for her regularly until the Uber takeover. She wished she could still care for her more regularly, but her family could not afford a dedicated carer package, and Andrea did not have the time, or more truthfully could not afford, to visit her more regularly than she was required.

Since the care drain in the early 2020s, she had to take on more and more 'unskilled' care work to make ends up and pay her annual resident fee to allow her to remain and work in the country. All of her family were 'back home', so she had begun to see her clients as her family, which made her too to feel isolated when her clients could no longer afford a dedicated carer package or would sadly pass away. She looked up; the bus was running 15 minutes late. She was going to be late for her appointment with Rose. She often totted up the costs of buying a car but always landed on it being simply impossible. She reluctantly made the sadly more and more frequent call to her boss to inform him that she was going to be late to see her client.

David (Uber Care Manager): Hello?

Carer 71: Hello this is carer 71. I'm just calling to let you know that my bus is running late so I'm going to be late to my appointment with Rose....eh sorry...I mean resident 10.

David: This is the third time this week carer 71. We will have to dock your wages and put you on a formal warning.

David sighed. He took this job to improve the experiences and conditions for carers and residents, however, since the takeover of Uber the top-down focus on experiences had been replaced by a systemic focus on efficiencies and targets. Carers and residents had lost their names and were simply referred to by a product number. But David felt helpless, he needed a job to pay for his parents' care, and jobs were becoming scarcer and scarcer unless your skills lay in smart technology development. It was a catch-22 situation. Nevertheless, he got back to requesting a new carer for client 10.

Rose: I feel calmer now Alexa.

Alexa: Your levels are still very high Rose. Carer 71 has now been replaced by carer 103. We can expect her in 20 minutes.

Rose despaired; this was not the future she had anticipated.

END

Appendix two: Pull out of research aim, objectives and questions



Appendix three: Activity and interview topic guides

Activities and topics explored with key participants

Topic guide for visits with key participants:

- Motivations for living in their home, length of time, importance of community.
- What doe independence means to the key participants?
- Motivations for using technology, ageing at home.
- The technology the key participants have and use at home.
- The role of (dis)empowerment.
- Their sense of home.
- Who are the members of your wider caring network?
- What support do they provide, how, why, where, when?
- What role does smart technology play within this network?
- How do these networks support your sense of independent living/ independence?
- Role of dis/empowerment within this network.

Observations:

- Role of (dis)empowerment.
- How the key participants use the space of their home.
- Key participants' interactions with technology.
- Sensory aspects of their homes such as temperature, sounds, smells.
- My own reflections for reflexive diary.

Walkabout home/ technology tours:

- Film key participants giving tours of their home highlighting sensory ways of knowing e.g., encourage resident to share how they made their home 'feel right' and their feelings of textures, air flows, temperatures, sounds, smells.
- I will aim to get key participants to highlight their experiences of living in their homes.
- Encourage key participants to show me how they use their technology, are there bits they do not use and why not/ re- enactment of experiences of using the technology.

Digital storytelling:

- Explain what digital storytelling is, why it is used.
- Show some examples.
- Discussion with key participants around what they want their story to look like.
- Structured around the key participant's story of empowerment/disempowerment of living in these homes.
- Gather interview data or whatever specific data the key participants would like to be in the stories e.g., input from wider networks.
- Verify final film with key participants.

Topic guide for wider caring network members (some questions specific to formal organisations)

- Can you tell me a bit about your background, how you came to work here in this role?
- Can you tell me a bit about your organisation and your role OR your relationship with XXX?
- What support do to you provide to XXX how, why, where, when?
- Does your organisation (or Do you) provide/ offer any support above and beyond helping with technology?
- Do you interact much with other people in XXX's networks e.g., family/ other orgs?
- How does the introduction of technology happen? e.g., where/ who do the ideas come from?
- If there is a problem with the technology, would XXX contact you?
- Does, and if so, how does power and empowerment play a role in the provision and use of the technology you provide? Has it changed with the introduction of the technology?
- Does, and if so how does, the provision of technology connect to independence and 'sense of home'? Has it changed with the introduction of the technology?
- Do you use much smart or health technology yourself? Examples

Appendix four: Ethical approval letter

Ethics Reference No: Please quote this ref on all	GG14259
Project Title:	Critically assessing health smart homes for older people in rural areas
Researchers Name(s):	Rachel Creaney
Supervisor(s):	Dr Louise Reid

Thank you for submitting your application which was considered by the Geography and Geosciences School Ethics Committee on the date specified below. The following documents were reviewed:

1	Ethical Application Form	1 st April 2019
2	Participant Information Form	1 st April 2019
3	Participant Consent Form	1 st April 2019
4	Advertisements	1 st April 2019
5	Semi/Structured interview questions/Focus Group Guide	1 st April 2019
6	DBS/PVG Documents	1 st April 2019

The University Teaching and Research Ethics Committee (UTREC) approves this study from an ethical point of view. Please note that where approval is given by a School Ethics Committee that committee is part of UTREC and is delegated to act for UTREC.

Approval is given for three years. Projects, which have not commenced within two years of original approval, must be re-submitted to your School Ethics Committee.

You must inform your School Ethics Committee when the research has been completed. If you are unable to complete your research within the three year validation period, you will be required to write to your School Ethics Committee and to UTREC (where approval was given by UTREC) to request an extension or you will need to re-apply.

Any serious adverse events or significant change which occurs in connection with this study and/or which may alter its ethical consideration, must be reported immediately to the School Ethics Committee, and an Ethical Amendment Form submitted where appropriate.

Approval is given on the understanding that the 'Guidelines for Ethical Research Practice' (<u>http://www.st-andrews.ac.uk/media/UTRECguidelines%20Feb%2008.pdf</u>) are adhered to.

Yours sincerely, Dr Louise Reid

Convenor of the School Ethics Committee

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