

An ethnography of the everyday practices of people with dementia and their informal carers with assistive technologies and telecare in community-based care

A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy.

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October 2018

Word Count: 80,921

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## Abstract

Industry, government and care service providers claim that assistive technologies and telecare services will enable people with dementia to continue living independently and safely in their communities. Yet there is little research that examines how people with dementia actually use these technologies in their everyday life. This thesis presents an ethnographic study, A Collaborative COMMunity-based ethnography of people with Dementia using Assistive technology and Telecare at home in England (ACCOMMODATE). This ethnographic study examines everyday practices of people with dementia and their informal carers using assistive technologies and telecare.

The study design departs from conventional ethnographic approaches which rely on situated, immersive, and sustained fieldwork commitments. Instead, this study purposively sampled participants from a pragmatic, randomised controlled trial entitled Assistive Technology and Telecare to maintain Independent Living At home for people with dementia (ATTILA). ACCOMMODATE, therefore, draws on recent methodological insights to design an 'embedded ethnography' to address the research problem.

Embedding ethnographic activities within the ATTILA trial settings influenced how I initially conceptualised assistive technologies and telecare in dementia care in the community as part of technology-enabled dementia care services. Yet this 'imagined community care' de-contextualised the personal experiences of living with memory problems, care practices, and community-based relationships. Through partially disembedding my ethnographic activities from ATTILA, I re-framed these concepts to illustrate tensions about how different people understood care, inhabited spaces within their home, and enacted new technological practices. Such diverse practices and understandings from participants suggests 'assistiveness' and 'care at a distance' can be seen as actively co-constructed to fit within the complexities of everyday practices.

Future policies should more precisely distinguish 'imagined' goals, such as 'community care', from the reality which people with dementia experience with assistive technologies as 'home care'. Such a shift may better locate and articulate the current practices constituting technology-enabled dementia care.

# Table of Contents

Abstract .....	2
List of Tables .....	5
List of Figures.....	5
Acknowledgements .....	6
Chapter 1: Introduction.....	8
1.1 Background.....	8
1.2 Defining and justifying an examination of the everyday practices of community-dwelling people with dementia and their informal carers with assistive technologies and telecare .....	13
1.3 Genesis of the ACCOMMODATE study and its relations to ATTILA .....	15
1.4 Structure of the thesis .....	17
Chapter 2: Literature Review .....	20
2.1 Introduction.....	20
2.2 Search Strategy.....	20
2.3 Assistive technologies in community-based dementia care .....	22
2.4 Telecare in community-based dementia care.....	29
2.5 Introducing ‘imagined communities’ as a theory for exploring ‘care’ and ‘communities’ .....	34
2.6 Methodological and substantive limitations from the literature.....	36
2.7 Research questions for this study .....	37
2.8 Chapter Summary.....	37
Chapter 3: Methodological and Philosophical Approaches to Study.....	39
3.1 Introduction.....	39
3.2 Ontological and epistemological assumptions of this study .....	40
3.3 Using an ethnographic approach .....	43
3.4 Methodological challenges of carrying out ethnography with people with dementia living in the community .....	52
3.5 Adapting an ethnographic approach to address methodological challenges.....	56
3.6 Chapter Summary.....	63
Chapter 4: Data Collection and Analysis .....	64
4.1 Introduction.....	64
4.2 Negotiating access to the trial.....	64
4.3 Ethical commitments.....	66
4.4 Sampling strategy and recruitment.....	73
4.5 Monthly, multi-sited research visits as ethnographic fieldwork.....	82
4.6 Data management and analysis .....	84
4.7 Presenting findings as ethnographic cases .....	89
4.8 Allocating case pseudonyms and considering fieldwork relationships.....	91
4.9 Chapter summary.....	96

Chapter 5: Understanding 'memory problems' in everyday and technological practices .....	98
5.1 Introduction.....	98
5.2 Memory problems as 'forgetting' .....	99
5.3 Memory problems as 'misremembering'.....	111
5.4 Chapter summary.....	116
Chapter 6: Understanding 'care' through everyday and technological practices.....	118
6.1 Introduction.....	118
6.2 Care as concern: Caring for people's happiness and wellbeing.....	119
6.3 Care as surveillance: Contested interpretations of using CCTV and telecare .....	127
6.5 Chapter summary.....	142
Chapter 7: Understanding 'home' and 'community' through everyday and technological practices	144
7.1 Introduction.....	144
7.2 Reconfiguring rooms in the home.....	145
7.3 Abandoning rooms in the home.....	156
7.4 Accessing communities outside the home.....	170
7.5 Chapter Summary.....	177
Chapter 8: Discussion .....	178
8.1 Introduction.....	178
8.2 'Imagined communities' of dementia care and research .....	178
8.3 Appropriateness of the research design .....	185
8.4 Consequences of embedding and disembedding ethnographic work with ATTILA on data collection and analysis.....	192
8.5 Memory problems and co-producing 'assistiveness' .....	197
8.6 Transforming care with assistive technologies and telecare .....	200
8.7 Reconfiguring how people with dementia occupy the home and community through technologies .....	205
8.8 Value and limitations of the work of this thesis.....	209
Chapter 9: Conclusions.....	212
9.1 Introduction.....	212
9.2 Imagined and realised communities .....	212
9.3 People living with memory problems: attending to memory rather than dementia? .....	214
9.4 Care and technologies: care realised, reconsidered, and reconfigured .....	215
9.5 Community care and home care: the importance and implications of more precise concepts...	216
9.6 Futures and omissions of ethnography in realising technology-supported care.....	217
9.7 Directions for future research.....	218
References:.....	221
Appendices .....	235
Appendix I : Participant Information Sheet.....	236

Appendix II: Informed Consent and Consultee Declaration Forms.....	248
Appendix III: Indicative list of ethnographic interview principles and topics .....	255
Appendix IV: Opinion Letters from Research Ethics Committees .....	257
Appendix V: Consultation letter from Patient and Public Involvement Group.....	272
Appendix VI: Processes for ensuring trustworthiness.....	283
Appendix VII: Examples of coded fieldnotes .....	286
Appendix VIII: Presentation conventions for fieldnotes and conversations .....	295
Appendix IX: Pictures of indicative assistive technologies from ethnographic cases .....	298

## List of Tables

Table 1. Databases searched using the University of East Anglia’s Primo OneSearch .....	21
Table 2. Inclusion/Exclusion Criteria for Articles in Literature Review .....	21
Table 3. ICF Core Set of Body Function Codes for Dementia (Adapted from Scherer et al. 2012) .....	26
Table 4. Participants’ purposive sampling characteristics .....	81
Table 5. Domains and different instances.....	88

## List of Figures

Figure 1. Data Analysis Process. ....	85
Figure 2. Map of Violet Draper’s sitting room from September 2015 visit.....	148
Figure 3. Map of Violet Draper’s sitting room from January 2016 visit .....	152
Figure 4. Map of Violet Draper’s sitting room from April 2016 visit .....	155
Figure 5. Map of Mrs Archer’s flat from recruitment visit .....	158
Figure 6. Map of Mrs Archer’s flat from February 2016 visit.....	162
Figure 7. Map of Mrs Archer’s flat from May 2016 visit .....	169
Figure 8. Map of Mr Anansi’s flat from recruitment visit .....	174
Figure 9. Electronic calendar-clock, a similar model to the one located in the home of the Stewarts and Violet Draper. ....	299
Figure 10. Door alarm, a similar model as those located in the homes of the Campbells and Christopher Smith. ....	300
Figure 11. JustChecking, an activity monitoring system, the same model as located in Christopher Smith’s home.....	301
Figure 12. Bed occupancy sensor, a similar model as the on located in the Campbells' home.....	302
Figure 13. Automatic cooker shut-off device, a similar model as one located in Mrs Archer’s home. ....	303
Figure 14. Buddi, a GPS tracking system, the same model as the one William Anansi wore. ....	304

## Acknowledgements

First, I want to profoundly thank all of the participants in this study. Each participant not only invited me into their homes, but they also shared stories about their lives. This study would not have been possible without their willingness to take part in ACCOMMODATE. Spending time with both people with dementia and informal carers taking part in this study has forever changed how I 'imagine' care and ageing and their potential futures for us all to realise.

I am indebted to my academic supervisors, Fiona Poland and Chris Fox, for their considered and considerable support which greatly benefited not only ACCOMMODATE but also my sense of future directions for development as an independent scholar and ethnographer.

I owe much to the University of East Anglia and the Norfolk and Suffolk NHS Foundation Trust who funded my studentship and fieldwork costs, respectively. I could not have carried out this study without this support. I am also thankful to the University of York, the British Sociological Association, and the European Association for Social Anthropologists for additional financial support to present material from ACCOMMODATE at conferences in the UK and Europe.

I would also like to thank the ATTILA trial team. I learned a great deal about dementia and assistive technologies from the different investigators and research workers located around England. I would like to especially thank Rebecca Gathercole, Robert Howard, Barbara Dunk, John O'Brien, Andrew Bateman and John Woolham. I am also grateful to each of the local ATTILA research workers who helped with recruitment for this study. Thank you Emma Talbot, Rachel Winson, Samantha Nunn, and Beth Scutt.

This study also greatly benefitted from discussing my ideas with colleagues at the University of East Anglia and further afield. I very much appreciate all those members of staff in the School of Health Sciences, the wider Faculty of Medicine and Health Sciences, and the Qualitative Research Forum at the University of East Anglia who kindly shared their time. I would like to thank: Charlotte Salter, Andrea Stockl, Bridget Penhale, Linda Birt, Anne Killeth, and Jamie Murdoch. I truly valued our collective qualitative research enclave in the Faculty. I am also grateful to: Grant Gibson, Louise Nygård, Joe Wherton, Trisha Greenhalgh, and Louise Robinson for discussing current and future research related to older people using assistive technologies and telecare. I would also like to thank fellow early career medical anthropologists: Sally Atkinson, Rebecca Lynch, Erica Borgstrom, and

Joanna Reynolds. Our discussions helped me consider how this 'applied' study could also attend to anthropological concerns.

I am also grateful to members of the Postgraduate Research Room in the Queen's Building at the University of East Anglia, affectionately dubbed 'Team QB' who provided so much inspiration and friendship. I would like to thank: Katey Collins, Ciara Shiggins, Mohamed Elsheemy, Sarah Hanson, Beverly Garrigan, Monica Curran, Julie Pass, Tom Withers, Mark Ashwood, Caoimhe Bennett, Bryony Porter, Priti Biswas, Esra' Hamdan, Allie Welsh, Fiona Ellis, and Lindsey van Bokhorst. You all were a fantastic support and sounding board during my doctoral journey.

Finally, thank you to my mom and dad, Adrian and Val Lariviere. I cannot thank you enough for your love and for supporting me to pursue my dreams.

# Chapter 1: Introduction

## 1.1 Background

Health and social care services in Europe and North America have increasingly provided technologies to support people with disabilities and chronic illness since the 1950s. These technologies have often been called different yet interchangeable names: social alarms, telecare, telehealth, e-health, m-health, assisted living technologies, smart homes, and assistive technologies. Policy makers and formal care service providers identified people with dementia as a potential population for using these technologies to support their continued independent living in the community despite complex care challenges.

Governments across the world emphasised the increased costs that will arise from ageing populations. Predominately Western nations, in particular, described this expected increase in the percentage of the population of older people, aged 65 years and older, and the oldest old, people 80 years of age or older, as a 'silver tsunami' that will swamp health and social care systems (Fried and Hall 2008; Roehr 2012; Schwartz 2012; Bartels and Naslund 2013). One particular focal point for government policy was the anticipated increase in the prevalence of dementia such an ageing population would also entail.

The World Health Organisation defined dementia as a syndrome, a diagnostic category based on a person experiencing several distinct symptoms. According to the International Classification of Disease, the standard for the global reporting of diseases, these symptoms included 'disturbances' in a person's 'memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement' (World Health Organisation 2016). The two most commonly described causes of dementia were Alzheimer's disease and vascular dementia. Alzheimer's disease referred to a progressive and degenerative disease of the brain with two primary types: 'early onset Alzheimer's disease' for people before the age of 65 and 'late onset Alzheimer's disease' for people aged 65 or over with late onset usually starting in the late seventies (World Health Organisation 2016). Vascular dementia resulted from damage or changes to the shape and structure of blood vessels in the brain caused by events such as a stroke (Alzheimer's Society 2014; World Health Organisation 2016). A number of other diseases may also cause dementia, such as Pick's disease, Huntington's disease, and Parkinson's disease (World Health Organisation 2016). Dementias were usually progressive with different types affecting the severity and trajectory of the person's symptoms. Many people with

dementia received support and assistance from ‘informal carers’, family members or other people in the social network of a person with dementia.

This chapter introduces the policy, practice and research contexts attending to assistive technologies and telecare as part of community-based dementia. Each of these contexts helped to frame and justify the empirical study reported in this thesis that examined the practices of people with dementia and their informal carers with assistive technologies and telecare.

### 1.1.1 Policy for ‘living well with dementia’ and ‘dementia challenges’ in England

In 2009, the Department of Health produced the National Dementia Strategy for ‘improving health and social care services’ for people with dementia and their carers in England. The strategy entitled *Living Well with Dementia* provided 17 objectives for the Department of Health to meet this goal, including: educate the public about dementia to reduce stigma, provide earlier diagnoses for people with dementia, more accessible information and care services for people with dementia, improve support for carers, improve quality of care for people with dementia in hospital, provide better ‘intermediate care’ for supporting people with dementia to stay at home, consider the role of housing services and technology to support people with dementia and carers, improve care in care homes and at the end of life, and improve regulatory and evaluation systems for assessing quality of care and services (Department of Health 2009).

The objectives of the National Dementia Strategy were superseded when David Cameron announced his *Dementia Challenge* in 2012. The *Dementia Challenge* was a three-year initiative designed to focus on improvements in three areas: health and care, research, and ‘dementia friendly communities’ (Department of Health 2015a). The *Dementia Challenge* resulted in the development and support of one particular programme: Dementia Friendly Communities.

The Dementia Friendly Communities initiative started as a result of the Alzheimer’s Society pursuing its goal to improve the wellbeing of people with dementia and public awareness of the illness. Dementia Friendly Communities refer to local people, services, businesses, and government working together to include people with dementia more fully in ‘the community’. Although the Alzheimer’s Society did not define ‘community’ in their literature, they identified areas that may require development based on their importance to people with dementia: arts, culture, and leisure; businesses and shops; children and young people; community, voluntary and faith-based organisations; fire brigade and police; health and social care; housing; and transport (Alzheimer’s Society 2017).

David Cameron renewed his commitment to prioritise dementia as a national concern in the *Prime Minister's challenge on dementia 2020* (Department of Health 2015b). The statement reiterated the plan to continue the strength of dementia care and research in the United Kingdom. The challenge also issued new goals to meet for 2020: improved public awareness about dementia, equal access to diagnosis, coordination of continuity of care in primary care, improved post-diagnosis care, training about dementia for all NHS staff, all hospitals and care homes designated as dementia friendly, an additional three million Dementia Friends for the Alzheimer's Society, development of more dementia friendly communities, encouraging all businesses to be dementia friendly, developing dementia research as a career area, and doubling the investment into dementia research.

The development and expansion of 'dementia friendly communities' appeared to indicate the perceived importance for people with dementia to feel included and take part in local services. Recent research estimated between 670,000 (Mathews et al. 2013) to 685,000 people live with dementia in England (Alzheimer's Society 2014c) with two-thirds of people with dementia estimated to live in the community (Alzheimer's Society 2007; Alzheimer's Society 2014c). Most people developed dementia later in life with an estimated 42,000 people in the UK developing dementia before the age of 65.

Although the last decade provided policy for considering how the Department of Health and the government intend to improve dementia care services, there is very little policy that defines current social care services for people living with dementia. The next section attends to policy guiding care provided to older people living in the community.

### 1.1.2 Policy for 'community-based care' in England

In their review and plan to care for older people, The King's Fund (2006) described the historical policies that led to the development of social care based in the community. Initial policies started following the Second World War in the National Assistance Act 1948, the Act provided outlined the duty of local authorities to provide housing, care and attention for older people (King's Fund 2006). In the 1960s, Peter Townsend's (1962) *The Last Refuge*, described the poor conditions of for older adults living public assistance institutions, the precursor to modern social housing and care homes. The King's Fund (2006) suggested that Townsend's work helped influence the change in public attitudes about housing arrangements for older people that eventually led to the Hospital Act 1962 and further deinstitutionalisation for older people and psychiatric patients.

Following the deinstitutionalisation of care and the closure of asylums, 'care in the community' became the *de facto* form of care for people older and people with mental health problems. During the latter period of Thatcher's Prime Ministership, she contracted Sir Roy Griffith to evaluate current 'care in the community' (King's Fund 2006). Griffith's report (1988) concluded that poor leadership led to ineffective 'care in the community'. He suggested: local authorities hold budgets and determine appropriate care packages for recipients living in the community and residential care, and social care should have the responsibility for providing long-term care (Griffiths 1988). In 1989 the government responded to the Griffith's report with the government white paper, *Caring for People*, that suggested needs-based approaches for providing care to 'promote independence' for people who wish to live in their own home instead of residential care (Renwick 1996). Therefore, the aim of community care was to help older people live in their own homes for as long as they wish. Although the assessment of needs for older people has changed and people are now allocated personal budgets with the implementation of the Care Act 2014, social policy still focuses on older people living in the community for as long as they wish. Policy makers and service providers increasingly see technological interventions as a means to meet this goal.

### 1.1.3 NHS England's *Five Year Forward View* and the provision of 'technology-enabled care services'

Technologies have continuously been a part of care service provision since at least the 1980s with the introduction of social alarms (Fisk 2003). Prior to social alarms, people still used relatively simple objects such as crutches and wheelchairs. However, the miniaturisation of computers, the introduction of the internet and mobile telephone technologies have provided new forms and relations through technologies.

The current strategy for NHS England, the *Five Year Forward View*, suggested areas where health services in England can innovate to cut costs whilst increasing the quality of care provided (NHS England 2014). The strategy particularly emphasised the need to harness new technologies, especially in combination with other elements in care packages, to achieve these goals. More recently, 'Test beds' represented a new approach to develop and evaluate technologies designed to improve health and social care through digitising care with new innovations such as Big Data and the Internet of Things (Galea, Hough and Khan 2017). Yet the current evidence for technological interventions did not suggest that technologies were always appropriate or effective care interventions.

The Department of Health-funded Whole System Demonstrator trial was the largest trial of telehealth and telecare products. The research programme examined the effectiveness of these technologies for people with chronic obstructive pulmonary disease, diabetes and social care needs. The overall results were mixed: Telecare was more expensive than normal care (Henderson et al. 2013), nominally reduced hospital admissions (Steventon et al. 2012), did not reduce people's use of formal care services (Bardsley, Steventon and Doll 2013), and only slightly reduced the number of people who moved into residential care after twelve months (Steventon et al 2013). Despite these results, policy makers and service providers continued to promote telecare and telehealth as potential solutions to address health and social care needs.

In 2015, the NHS Commissioning Assembly published the *Technology Enabled Care Service Resource for Commissioners* that promoted 'technology-enabled care service' as the use of 'telecare, telehealth, telemedicine/teleconsultation and self-care apps that help people manage chronic illness and sustain independence (NHS Commissioning Assembly 2015). NHS England appeared to expect these technologies to make primary care more efficient, help provide care seven days a week, improve access to services for people living in rural areas, and personalise care (NHS Commissioning Assembly 2015). They emphasised self-care and active monitoring of one's own health and wellbeing. For older people, they suggested telehealth will help support management of long-term conditions, telecare will be used to support independence, and teleconsultation will help an older person stay in contact with friends and family.

The provision of these technologies continues now despite research evidence which appeared to counter the specific needs of care recipients. Policy and practice guidance also cannot attend to how a potentially diverse range of people use these technologies and why. The guidance also seemed to suggest that the needs for older people are defined by their age rather than the diverse set of experiences and illnesses they may live with in later life.

#### 1.1.4 Telecare and assistive technologies in community-based dementia care in England

Dementia was one particular illness where policy makers especially considered technologies as a solution to support people with dementia and their informal carers. As previously described in the *National Dementia Strategy*, a key objective was to consider the potential role of technologies for reducing the reliance of people with dementia on more 'intensive services' and support independent living (Department of Health 2009: 55). One result of the consideration was the Alzheimer's Society's *Friendly Technology Charter* (Alzheimer's Society 2014d). The charter identified three areas that

technologies may address for a person with dementia or their carer: technology aimed at improving safety for a person with dementia, technology aimed at managing the physical health of a person with dementia, and technology intended to improve the quality of life for a person with dementia. The charter suggested that any technology provided should ‘fit’ into the routine of a person with dementia. Technologies should also not replace human contact for the person with dementia.

Despite the uptake of assistive technologies, like medications dispensers and memory aids, and telecare systems that monitor the movement or location of a person with dementia, there is currently little evidence to suggest that these technologies help support a person with dementia to continue living in the community. A randomised controlled trial in England called Assistive Technology and Telecare to maintain Independent Living At home for people with dementia (ATTILA), currently investigates the effectiveness of these technologies for delaying a person with dementia permanently moving into residential care (Leroi et al. 2013).

The guidance provided by policy, NHS commissioners, and voluntary organisations suggested a disconnect between the priorities of how best to support older people with dementia and their informal carers through technologies. Policy also cannot provide understandings of how and why people with dementia and informal carers use these technologies. I decided to examine these everyday practices of ‘technology-enabled care services’ to inform better care.

## 1.2 Defining and justifying an examination of the everyday practices of community-dwelling people with dementia and their informal carers with assistive technologies and telecare

Policy makers considered community-based dementia care and the provision of technology-enabled care in a relatively abstracted way from the everyday experience of living with dementia. They appeared to apply this language to provide generalizable and practicable guidance to a range of different commissioning organisations, managers and front line staff in both health and social care services. However, relatively imprecise language such as those articulated in policy, could not attend to the range of ways in which people with dementia and their informal carers living in the community potentially use assistive technologies and telecare. Therefore, the study described here took an approach that examined the situated *practices* of people with dementia and their informal carers using assistive technologies and telecare.

### 1.2.1 Defining 'practices' in the context of community-based dementia care

The Oxford Dictionary (2017) defined 'practice' as the 'actual application or use of an idea, belief, or method, as opposed to theories relating to it'. 'Practice' has been a central concept in the social sciences. The concept was often linked with Pierre Bourdieu as described in his *Outline of a Theory of Practice* and *The Logic of Practice*. In these texts, Bourdieu described his own theory to explain the interactions between social structures and human action. Bourdieu differed from earlier scholars in sociology and anthropology who adopted a structuralist approach where socio-cultural structures of each group shaped human action and thought. In contrast, Bourdieu suggested that humans could also act contrary to the systems and structures in which they lived. In other words, Bourdieu accounted for human agency. Bourdieu suggested that agency and structures interplayed into what he called 'habitus' (Bourdieu 1977). Bourdieu's habitus identified that society provided humans with certain 'dispositions'. Dispositions provided structure for how humans should act in specific locations, points of time, and with specific individuals. However, dispositions were not inert or static, human action could change these dispositions (Bourdieu 1990). Therefore, if I examined the 'everyday life' or 'practices' of a specific group of people, then I might learn about the patterns of their culture or social systems and processes of human action working to change them.

Other scholars such as the anthropologist Sherry Ortner defined 'practices' as 'anything people do' with 'unintentional or intentional political implications' which she noted as including all human activities (Ortner 1984). Ortner (1984: 158) suggested that 'theories of practice' attended to all three aspects of Berger and Luckmann's 'essential characterisation of the social world': 'Society is a human product. Society is an objective reality. Man is a social product.' (Berger and Luckmann 1971: 79). Here I once again noticed the relationship between human action and society. Society, culture or social structures existed as an objective reality, i.e., a phenomenon that social researchers could investigate. Yet social structures were not fixed. Human action could shape them just as they confined and shaped human action. Neither human agency nor social structure were wholly independent from each other. Instead, they co-produced each other. More recent work from social theorists identified the 'core' of practice theory as 'embodied, materially mediated arrays of human activity centrally organised around shared practical understanding' (Schatzki 2001: 11). Although theorists differed in how they conceptualised 'practice' in their different theories of practice, human activity remained a central feature, especially social activities such as interactions.

The study described in this thesis, therefore, applied the broad concept of ‘practices as human activity’ to community-based, technology-enabled dementia care. In this thesis, I limited the ‘humans’ who took part in these ‘arrays of activities’ to people with dementia and informal carers living in the community. I chose these participants because they represented the people who would actually use either the assistive technology or telecare after it was installed.

### 1.2.2 Justifying empirical research of the practices of community-based people with dementia and their informal carers using assistive technology and telecare

Policy appeared to occupy a unique position to my own sensibilities. It not only set new goals for specific groups, organisations, or society more widely to achieve, but it also attempted to describe present practices. Here I noticed a potential dilemma to understand how technology-enabled dementia care was realised. Policy could not attend to current situated practices whilst it described its vision for the future of dementia care. Policy could not also attend to the variety of ways in which people may experience progressive symptoms of their dementia. The Alzheimer’s Society explained in their ‘Dementia Friends’ awareness campaign that ‘Once you know one person with dementia, you know one person with dementia’ to highlight how dementia affects each person in uniquely specific ways (Alzheimer’s Society 2014). Therefore, empirical research could identify potentially divergent types of assistive technologies and associated practices with each device to address different care needs for a particular person with dementia. Conversely, empirical research could also demonstrate how and why people with dementia and informal carers decide to abandon or never take up using assistive technologies or telecare if they did not perceive potential practices with these devices. This could also illustrate how understandings of concepts such as ‘care’ and ‘community’ shift or continue as a result of, or despite, new technological practices by undertaking empirical research to examine the practices of people with dementia and their informal carers living in the community using assistive technologies and telecare.

## 1.3 Genesis of the ACCOMMODATE study and its relations to ATTILA

The study described in this thesis began as a planned supplementary qualitative study linked to the ATTILA Trial. The ATTILA Trial was a successor study from the Whole System Demonstrator (WSD) programme (Steventon *et al.* 2012) designed to investigate the efficacy of telehealth products and systems supplied to people with diabetes, heart failure and chronic obstructive pulmonary disease (COPD), and telecare for people with unmet social care needs. Participants in WSD had to meet the Fair Access to Care Services criteria determining individuals’ financial responsibility to pay for their care services. The National Institute of Health Research-funded ATTILA, by contrast, seeks to

investigate the efficacy and cost-effectiveness of assistive technologies and telecare to support people with dementia to remain independent in the community. All of the outcome measures for ATTILA involved quantitative data collected from validated questionnaires, such as the Bristol Activities of Daily Living Scale [BADLS] for people living with dementia (Bucks and Haworth 2002), Service User Technology Acceptability Questionnaire [SUTAQ] (Hirani et al. 2017), and a proxy version of the EuroQoL [EQ]-5D to assess quality of life across five domains (Tamim, McKusker and Dendukuri 2002). Its primary outcome measures included the time from randomisation to when the person with dementia moves permanently into residential care and the cost-effectiveness of assistive technology and telecare. Secondary outcomes included caregiver burden, health-related quality of life for carers, and the number and severity of serious adverse events (Leroi *et al.* 2013).

As a condition of funding the ATTILA trial team needed to include a qualitative component that examined acceptability, reliability and applicability for people with dementia and informal carers using assistive technologies and telecare in the trial. Professor Fiona Poland and Professor Chris Fox, my primary and secondary supervisors respectively, were ATTILA co-applicants. Poland led the qualitative component of ATTILA and Fox held responsibility for East Anglia site as its Primary Investigator. They secured a University of East Anglia studentship to support these research areas as a distinct but related qualitative study. The supervisory team planned an ethnographic approach to examine participants' use of assistive technologies and telecare products. The approach would involve observations in the homes of people with dementia and ethnographic interviews with informal carers and people with dementia participating in ATTILA,

I started my MPhil/PhD programme in October 2013, immediately working with Professors Poland and Fox to integrate within the ATTILA team. They introduced me to the trial manager and management team. I attended meetings at the Institute of Psychiatry to learn about the everyday processes of the trial from the trial manager and local ATTILA 'research workers', the researchers who recruited and collected data from the principal sites located in nine NHS Trusts across England. This active work to integrate, or 'embed', my ethnography secured my access to the battery of validated questionnaires the team used for data collection. However, in my interactions with the trial team and review of the literature, I was struck by the relative lack of shared, specific and current knowledge of how and why people with dementia and informal carers used assistive technologies and telecare. The trial instruments could measure carer burden, quality of life and the frequency of adverse events more generally. Yet there was no way to account for how, or whether, people with dementia *actually* used these technologies as part of their everyday routines.

I refined the study brief described in the studentship application to focus more closely on ATTILA participants with a dementia or their informal carer in their homes to examine in-depth how people with dementia used (or chose not to use) these technologies in their homes and in the context of their everyday life. I argued that this work could also provide insights about how people with dementia and informal carers may conceive the applicability, reliability, and acceptability. I continued to embed myself and my study in the activities of the ATTILA trial team, especially with the local research workers with whom I intended to collaborate for recruiting participants from ATTILA. These activities helped to define materials as relevant for this study as **A Collaborative COMMunity-based ethnography Of people with Dementia using Assistive technology and Telecare at home in England (ACCOMMODATE)**. This study differed from the wider set of research questions and outcomes which constituted the ATTILA team focus. I continuously developed relationships with members of the ATTILA team to ensure the design and research questions from ACCOMMODATE would complement the primary outcomes of ATTILA, a key aim of this study's design. These activities would help to ensure findings generated from ACCOMMODATE could help contextualise interpretation of outcomes from ATTILA. My supervisory team and I hope that the in-depth, ethnographic cases, presented here, will help illuminate and situate statistical analyses from the trial to frame more comprehensive answers about the efficacy of the technologies investigated.

## 1.4 Structure of the thesis

This thesis describes an ethnographic study that examined how and why people with dementia and their informal carers living in the community used assistive technologies and telecare. The purpose of the study was to examine the practices of people with dementia and their informal carers with assistive technologies and telecare to consider how practices with these technologies may affect their experiences of living with dementia, their meanings and practices of care, and their relations with their own homes and communities.

**Chapter 1** provides the policy context and definitions for dementia, community care, and technology-enabled care services.

**Chapter 2** reviews previous empirical and theoretical research related to people with dementia and older people, more generally, using assistive technologies and telecare.

**Chapter 3** describes my philosophical assumptions and methodological choice to pursue an adapted ethnographic approach to examine the practices of people with dementia and their informal carers living in the community using assistive technologies and telecare.

**Chapter 4** outlines the methods of recruitment, data collection and analysis used to carry out the ethnographic study. The chapter describes the iterative analytical process which led to the development of ethnographic case studies for this thesis where participants enacted 'memory problems', 'care' and 'relations with home and the community'.

**Chapter 5** presents findings about 'memory problems' as everyday practices of people with dementia. Here I examine memory problems as an everyday practice of people with dementia as either 'forgetting' or 'misremembering'. I use these two ethnographic cases to explore potential limitations of assistive technologies to address forgotten and misremembered information for people with dementia.

**Chapter 6** builds off the apparent centrality informal carers had for maintaining assistive technologies and helping people with dementia to recall appropriate information in Chapter 5. Here I examine the practices of informal carers as two distinct types of 'care' after the introduction of telecare: 'concern' and 'surveillance'.

**Chapter 7** draws on the central theme of 'community' as both a location for 'living in' and a network of people and services which people with dementia may occupy. Here I examine the apparent effect of progressive symptoms of dementia and practices with assistive technologies and telecare affect relations with different spaces.

**Chapter 8** discusses and evaluates the suitability of the research design, effects from embedded activities, and the findings from this study.

**Chapter 9** closes the thesis with reflections on the key methodological and conceptual contributions of this study.

The thesis, therefore, aims to contribute a possible new approach for ethnographers to work within applied health contexts incorporating technological innovations and interventions whilst still attending

to conceptual and empirical disciplinary interests alongside addressing wider social and health problems people with dementia and their informal carers encounter in their everyday lives.

# Chapter 2: Literature Review

## 2.1 Introduction

The previous chapter introduced key concepts and relevant policy this study's research problem: understanding the everyday practices of community-dwelling people with dementia and their informal carers with assistive technologies and telecare. It described current British policy for caring for people with dementia in the community with technology-enabled care services. However, these policies do not attend to how and why people with dementia actually use assistive technologies and telecare including the roles that these technologies will play in promoting 'living well' with dementia and 'ageing in place'. In this chapter, I evaluate previous empirical and theoretical research literature that examined telecare and assistive technology in community-based dementia care to consider

## 2.2 Search Strategy

I carried out a search of recent research studies to answer the question, 'How and why do people with dementia use telecare and assistive technology in the community?' I searched fifteen databases to represent the diverse range of disciplines where researchers examine the experiences of people living with or caring for a person with mental illness (Table 1). I chose medicine, psychology and applied health research databases as the corresponding professions treated or supported people with dementia in clinical and community settings. I also searched social science databases to identify empirical research that investigated the everyday practices of people with dementia using assistive technologies or telecare. To ensure I did not miss other relevant articles or literature, I searched non-discipline specific databases, like Web of Science, discipline specific databases may have excluded (e.g. computer science research). I used the search terms 'dementia', 'at home', 'Alzheimer's disease', 'community', 'assistive technology' and 'telecare' to locate literature capable of answering the review question in these databases. I selected these terms to produce the broadest set of research literature possible that may answer the research question. To structure my review, I divided the articles into those that examined 'assistive technologies' in dementia care or 'telecare' in dementia care then used these two categories to organise this chapter. However, the review showed that different organisations and research groups defined 'assistive technology' and 'telecare' in different ways or, occasionally, not at all. These definitions provided a framework to organise and interpret the primary role or goal of the technology when people with dementia and informal carers used them.

Table 1. Databases searched using the University of East Anglia's Primo OneSearch

Database	Discipline
AMED (Ovid)	Medicine
ASSIA (CSA)	Social Sciences
BioMed Central	Medicine
Cochrane Library	Medicine
Embase (Ovid)	Medicine
Google Scholar	All
International Bibliography of the Social Sciences	Social Sciences
JSTOR Arts & Sciences Collection I-IV	Social Sciences
Medline (PubMed)	Medicine
PsychARTICLES (EBSCO)	Psychology
PsychINFO	Psychology
Science Direct (Elsevier)	All
SCOPUS	All
Social Care Online	Allied Health Professions/Nursing
Social Sciences Citation Index	Social Sciences
Web of Science/Knowledge	All

Table 2. Inclusion/Exclusion Criteria for Articles in Literature Review

Inclusion	Exclusion
Published in English	Published in language other than English
Mention of assistive technologies, telecare, or specific types of these devices (e.g. GPS trackers)	No mention of assistive technologies or telecare
Article considered provision or use of technologies in care for people with dementia and/or older adults living in the community	No mention of people with dementia or older adults OR they did not live in a community setting (e.g. care or nursing home)
Article reports a review or empirical study	Article is not a review or empirical

To ensure the returned literature's relevance to ACCOMMODATE, I evaluated it based on inclusion and exclusion criteria to identify its substantive focus on assistive technologies or telecare for people with dementia (Table 2). I also reviewed each article's references for additional literature which met the inclusion criteria. These methods represented some elements of a systematic review, such as

'snowballing' additional references from relevant literature (Booth, Papaioannou and Sutton 2012). However, this literature review was not a systematic review. The purpose of this literature review was to investigate the breadth of the contexts and practices of community-dwelling people with dementia and their informal carers using assistive technology and telecare. In order to do so, I included additional literature that examined older people as 'users' of assistive technology or telecare. I decided to include these additional studies based on the relatively limited return of relevant literature explicitly linked to people with dementia from most databases.

## 2.3 Assistive technologies in community-based dementia care

I identified three widely used definitions to describe assistive technologies. The first definition came from ASTRID, an evaluation funded by the European Medicines Agency's Telematics Programme to assess social and technological responses to meeting the needs of people with dementia and their carers (Marshall 2000). They described assistive technology as 'any item, piece of equipment, product or system, whether acquired commercially, off the shelf, modified or customised that is used to increase, maintain or improve the functional capabilities of individuals with cognitive, physical or communication disabilities'. A year later the King's Fund, an independent English think tank, co-led a consultation with the now-defunct Foundation for Assistive Technology which defined assistive technologies as 'any product or service designed to enable independence for disabled and older people' (King's Fund 2001). Finally, the World Health Organisation, the international public health agency of the United Nations, described assistive technologies as 'an umbrella term for any device or system that allows individuals to perform tasks they would otherwise be unable to do or increase the ease and safety with which tasks can be performed' (World Health Organization 2004).

Although all definitions were published in respective reports within the span of only four years, I noticed a problem for evaluating research on assistive technology in any context. All definitions of assistive technology focused on their capacity to provide support to the person using this device. Yet each definition identified this person in different ways. ASTRID identified the user of the technology as a person with 'cognitive, physical or communication disabilities'. The King's Fund included 'disabled people' without the level of nuance that the ASTRID team provided yet also identified 'older people' as a distinct group of assistive technology users. Whereas the World Health Organisation only identified users of assistive technology as 'individuals [...] who would otherwise be unable to [or safely] do' particular 'tasks'. However, although the definitions differed in how they described the user – older person or a person with disabilities or difficulties completing tasks, they clearly identified the 'user' as only the person who received benefits from of the technology. In other words, the person

with dementia *must* benefit from using assistive technology, not a family member or other informal carer.

Each report also identified the benefit the user received from the assistive technology in different ways. ASTRID defined the aim of assistive technology as ‘increasing, maintaining or improving the functional capabilities’ of the user. On the other hand, the King’s Fund described the aim as ‘enabling independence’. Whereas the World Health Organisation considered the aim of assistive technology to allow people ‘to perform tasks they would otherwise be unable to do or increase the ease or safety’ with which they do them. Although these aims could overlap in some ways, for example, helping a person to increase the ease of completing tasks may enable independence, they appeared to me as distinct from one another without additional interpretive assumptions from the reader.

I also noticed that each article varied in how they defined assistive technology to inform the design or conduct of their study. Most studies identified with one of the previous definitions or did not define the technology they investigated at all. I also noticed new terms in the literature used to describe emerging types of technologies - telemedicine, telecare, assisted living technologies, smart homes, telehealth – which also at time blended with previous definitions into an amalgamation without clear distinctions between older types of assistive technologies and newer digital alternatives (Barlow and Knapp 2014; Knapp et al. 2016). The next three subsection attend to literature through how the researchers or reviewers conceptualised the role of assistive technology for people with dementia: to improve the functional capacity, to enable independence, or help the person with dementia performs tasks more easily or safely.

### 2.3.1 Assistive technologies 'improve functional capabilities'

Some studies focused on the potential of assistive technologies to ‘improve functional capacity’ for people with dementia aligned with the ASTRID team’s definition for assistive technologies. ‘Functional capability’ refers to the capacity for a person to complete ‘work movements’ and ‘tasks’ (Isernhagen 1992; Soer et al. 2008). Reviewed studies drew on the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation 2001) to identify impaired functions related to a person’s dementia an assistive technology may address. Scherer and colleagues created a framework that combines ICF functions with the ‘Matching Person with Technology’ model (Scherer and Craddock 2002) to create the ‘Matching Older Adult with Dementia and Technology’ (MOADT) model for providing a ‘science based’ approach for how formal care providers ought to provide assistive technology assessments (Scherer et al. 2012). The Matching Person with Technology model identified

43 body functions for the ICF core set of dementia (Table 3). Although Scherer and colleagues provide a framework for matching assistive technologies to address the impaired functions of people with dementia, there is no assessment of suitable technologies which meet these needs. Yet the MOADT model was not designed to provide an overall assessment of technologies. Instead, it was meant to help people carrying out 'assistive technology assessments' to match appropriate technologies to address the functional needs of people with dementia. This suggests that Scherer's approach emphasises how technologies address the individual needs of a specific person rather than relying on abstracted and de-contextualised understandings of whether each assistive technology was suitable or efficacious. Instead, people with dementia create suitability and efficacy when they use appropriately matched technologies which fit within their individual lives.

Despite the emphasis on functional capabilities as described in the ASTRID definition of assistive technologies, there were relatively few empirical or review research articles who also adapted this language. Some researchers emphasised 'cognitive functions' yet the research did not focus specifically on people with dementia as it included people with other progressive, developmental or acquired conditions which caused cognitive impairment (Hammel, Lai and Heller 2002; Bharucha et al 2009). Indeed, technologies listed in such studies included memory aids which sensed the environment and provided prompts to complete contextually relevant activities of daily living (ADL). Yet we must consider whether such devices actually 'aid' memory.

### 2.3.2 Assistive technologies 'enable independence'

Other studies identified the role of assistive technology to help a person with dementia remain or maintain their 'independence' or 'independent living' as described by the King's Fund. 'Independence' was not imposed as a definition through the particular interests of this study. Rather the reviewed articles, defined 'independence' in their own way, which was usually only a vague reference to 'independence' or 'independent living'. Although some of the reviewed literature described 'completing tasks' as a sign of 'independence', for example, through prompting people with dementia (Bewernitz et al. 2009).

One form of independence could be considered people with dementia reducing how often they used formal care services. Early evaluations such as Safe at Home suggested that current assistive technologies could reduce the frequency of people with dementia using formal care services (Woolham 2005). However, people with dementia appeared to benefit most from relatively simple

devices such as calendar-clocks which they found easier to use than more sophisticated technologies such as telecare.

The Keeping In Touch Everyday (KITE) project used a participatory study design which consulted people with dementia throughout the design process of two new assistive technologies to help them maintain their independence (Robinson et al. 2009). Participants in this study suggested that future technological designs should be less visible able to disguise or integrate into everyday clothing or other objects yet sophisticated enough to allow for the technology to help them find their way home or communicate with a family member. Whilst this in-depth research and design process may benefit people with dementia, the costs associated with scaling this process and intervention were prohibitive. Further research in England identified the potential for assistive technology to 'prompt' people with dementia to initiate or continue in sequential order with carrying out activities of daily living as an approach for improving independence (Wherton and Monk 2008). However, the design of current assistive technologies limited how people with dementia and family carers perceived the technologies as supporting them dress, take medication and prepare meals.

Table 3. ICF Core Set of Body Function Codes for Dementia (Adapted from Scherer et al. 2012)

Body Functions	List of Associated Categories
<b>Mental Functions</b>	Consciousness Functions, Orientation Functions, Intellectual Functions, Energy and Drive Functions, Attention Functions, Memory Functions, Psychometer Functions, Emotional Functions, Perceptual Functions, Thought Functions, Higher-level cognitive Functions, Mental Functions of Language, Calculation Functions, Mental Functions of Sequencing Complex Movements, Experience of Self and Time Functions
<b>Sensory Function and Pain</b>	Seeing Functions, Functions of Structures of Adjoining the Eye, Hearing Functions, Vestibular Functions, Sensations Associated with Hearing and Vestibular Functions, Proprioceptive Functions, Touch Function
<b>Voice and Speech Function</b>	Articulation Functions, Fluency and Rhythm of Speech Functions
<b>Functions of Cardiovascular, Haematological, Immunological and Respiratory Systems</b>	Heart Functions, Blood Vessel Functions, Blood Pressure Functions, Haematological System Functions, Immunological System Functions, Respiration Functions
<b>Functions of Digestive, Metabolic and Endocrine Systems</b>	Defecation Functions, General Metabolic Functions, Water and Mineral Balance Functions, Endocrine Gland Functions
<b>Genitourinary and Reproductive Functions</b>	Urination Functions
<b>Neuromusculoskeletal and Movement-related Functions</b>	Muscle Tone Functions, Muscle Endurance Functions, Motor Reflex Functions, Involuntary Movement Reaction Functions, Control of Voluntary Movement Functions, Involuntary Movement Functions, Gait Pattern Functions, Sensations Related to Muscles and Movement Functions

Findings from the ENABLE study in Ireland suggested that people with dementia found assistive technologies 'useful' yet informal carers often needed to prompt people with dementia to use the technologies (Cahill et al. 2007). This suggests a potential disconnect between how people with dementia and informal carers identified different forms of dependence and independence. People with dementia found a 'sense of independence' despite informal carers actively managing how they used the technologies.

Therefore, although 'independence' was described as the perceived role for assistive technology in dementia care, the articles rarely identified what or from whom the assistive technology was meant to provide independence for the person with dementia. Furthermore, research that focused on 'independent living' suggested that people with dementia may reduce their use of formal care services especially GP surgeries and emergency departments with the aid of assistive technology. However, the research did not consider whether assistive technology may diminish the frequency of people with dementia using these services in situations where they may represent the most appropriate resource. In other words, they may help people with dementia 'live independently' but at the cost of reducing their use of formal care services that they may require. It is worth considering who benefits from a person with dementia accessing services less frequently.

### 2.3.3 Assistive technologies 'increase ease and safety for performing tasks'

Some previous research seemed to draw on the World Health Organization's definition for assistive technologies where these technologies helped people with dementia perform 'tasks', including 'activities of daily living'. Activities of daily living describes the everyday practices of grooming, hygiene, dressing, toileting, moving around, and eating (Katz 1983; Mlinac and Feng 2016).

One study examined the potential of assistive technologies to help people with dementia complete 'meaningful daily activities'. Researchers conducted semi-structured interviews with occupational therapists (n=10) and family carers (n=3) to identify types of assistive technologies people with dementia used and barriers and enablers to their use (Boger et al 2014). Respondents commonly identified medication reminders and signs as the most common types of assistive technology. The study identified perceived effectiveness, low cost and familiarity with the assistive technology as key enablers with caregiver burden, 'poor fit' for the home environment, and perceived unsafety when using the technologies as barriers. However, the researcher's exclusion of people with dementia from the study raises questions about how the 'meaningfulness' of daily activities were defined and by whom. Informal and formal care providers may have some insight into what people with dementia

want and why they use assistive technologies. However, directly involving people with dementia in research would provide better insights into their own choices and processes of sense-making related to using assistive technologies.

Nygård and colleagues found timing devices for stoves (i.e. cookers) provided to older people living in Sweden were predominately used as a 'safety precaution' rather than supporting independence when they audited 945 files from the Agency for Home Modifications (Nygård, Starkhammar and Lilja 2008). This study highlights the distinction between people with dementia using assistive technologies to support their independence, as defined by the World Health Organisation, whilst actual provision from local authorities may focus on preventing what they perceive as risks in the home of a person with dementia. These themes were further explored in subsequent ethnographic research which examined the how people with dementia or other memory problems actually used stove timers. The findings from the study noted that people with dementia were rarely involved in decisions to choose or install the timers yet actively tried to use the technologies (Starkhammar and Nygård 2008). People with dementia often had unforeseen difficulties understanding the different alarms and lights and how to use the 'magnetic key' to reset the stove after it was shut off. However, people with dementia did not believe that the stove timers changed their habits.

#### 2.3.4 Challenges with assistive technology

Other research attended more specifically to the ethical and practical challenges assistive technologies may introduce to community-based dementia care as people with dementia often had difficulties 'fitting' assistive technologies into their everyday lives.

One interview study conducted with GPs, people with dementia and informal carers identified how difficult participants found acquiring information about available assistive technologies and processes for procuring technologies in current care system (Newton et al. 2016) This study was based in the Northeast of England, however, other research suggested that individual providers in England possess different assistive technology products at different price points with health services, social care providers or both acting as variable providers of assistive technologies in formal care services (Gibson et al. 2016). The lack of familiarity with how to attain assistive technology may not only prevent some people with dementia from acquiring the technologies all together but also how to use the technologies after they are installed.

The issues encountered in Starkhammar and Nygård's study with stove timers also illustrated how using these technologies to support independence, functional capabilities or safely performing tasks can also create unforeseen problems that arise when technologies are added into everyday practices such as activities of daily living (Starkhammar and Nygård 2008).

On the other hand, a participatory, qualitative interview study examined what people with dementia, care professionals and carers identified as the ethical challenges arising from using assistive technologies. People with dementia disliked what they perceived as remote monitoring and surveillance perpetuated through using assistive technologies, contrasted with carers' views that using such technologies to mitigate risks was reasonable (Godwin 2012). Here we see a difference between how people with dementia and informal carers view assistive technologies. People with dementia raised concerns about monitoring whilst the carers viewed the need to ensure safety a more important consideration.

## 2.4 Telecare in community-based dementia care

'Telecare' refers to information and communication technologies enabling electronic sensors and aids vulnerable people may use to make their home safer so they can live there longer (Department of Health 2009). Telecare helps people manage potential risks through 'continuous, automatic and remote monitoring of real-time behaviours' (Siotia and Simpson 2008) so as to enhance patients' independence and self-management (Schermer 2009). Technologies identified as telecare include sensors detecting whether beds are occupied, environmental sensors for detecting carbon monoxide levels, 'home hub units' with pendant alarms used for requesting help via a call centre (Department of Health 2001; Siotia and Simpson 2008; Department of Health 2009). This definition suggests there is a relative consensus for what constitutes telecare compared to assistive technologies.

### 2.4.1 Telecare as a 'remote monitoring' system

Previous research focused particularly on the potential benefits for personal safety through the application of such technologies. One survey that took place before the wide provision of telecare suggested that 20% of people with dementia risked a traffic accident whilst 45% of people with dementia risked getting lost, however, a tracking device that monitored activities of a person with dementia was only viewed as appropriate for 7% of the participants (McShane et al. 1998). Yet it is unclear why the surveyed health professionals viewed the tracking device as inappropriate for most people with dementia. However, the feasibility study of people with dementia using the GPS device resulted in two cases where a person with dementia was located through using the device. A more

recent literature review on 'safer walking technologies' including tagging devices for GPS systems noted that current research continues to address the acceptability of the technologies yet there is little research that attends to the use and views of stakeholders (Wood, Ward and Woolham 2015). Therefore, if GPS devices were provided there is currently little evidence to suggest whether people with dementia would actually use it.

Yet Hughes and Louw (2002) argued that tagging and tracking devices are necessary, 'good clinical practice' due to the limited alternative options of care providers or family: institutionalise or restrain a person with dementia. However, this suggests that care providers and family members may operationalise their choices to restrain or move a person with dementia into residential care based on its perceived clinical appropriateness. A clinical judgement may inappropriately decontextualize the social relations and emotional connections between carers and people with dementia. Informal carers are not necessarily clinicians and may, therefore, consider other factors which contribute to whether and when informal carers and people with dementia (if they are included) decide to move into permanent residential care.

#### 2.4.2 Challenges with telecare

Research on telecare as a component of technology-enabled dementia care is a relatively new focus for empirical research. Four themes were identified from the reviewed empirical and theoretical work focused on challenges associated with older adults, including people with dementia, using telecare: autonomy, surveillance, changes in care provision, and new forms of dependency.

##### 2.4.4.1 Autonomy

Autonomy considers a person's ability to make their own choices about how they wish to live, i.e. their independence. Autonomy is a key ethical concern for people with dementia whose cognitive abilities deteriorate as their illness progresses. Informal carers, family members and health professionals, and government organisations may undermine the independence of a person with dementia to mitigate potential risks. A critical consideration given risk management is the primary function for telecare in dementia care. Managing risk with technology may exacerbate issues already encountered in dementia care: ignoring the person's other needs, denial of a person's right to choice and self-determination, loss of a person's sense of self-esteem and respect, a form of institutionalisation with loss of individuality and volition, an increase in dependence, and abuse of vulnerable people (Clarke and Mantle 2016). However, this does not mean that there are not different perspectives about telecare's use. People with dementia fear loss of 'control' (Fisk 1997) through telecare where their

authority to make their own decisions – even decisions interpreted by other as risky – is constrained through technological care practices. Loss of autonomy and feeling controlled are the antithesis of telecare’s therapeutic promise. People with dementia expressed feeling a ‘need for independence’ (Robinson et al. 2007) through these systems rather than the loss or reduction they felt. Risk management through telecare therefore maybe at odds with how people with dementia want to live their lives.

#### 2.4.4.2 Surveillance

Another key ethical consideration for using telecare in dementia care is ubiquitous ‘surveillance’ (Greenhalgh et al. 2013; Rauhala and Topo 2003). Telecare systems are designed to manage risks through monitoring behaviours and domestic environments. Motion sensors indicate whether a person with dementia rose from bed today or if the door was left open perhaps indicating whether a person with dementia is unwell or left their house. However, people with dementia may find this constant monitoring of their home and personal activities ‘intrusive’ (Fisk 1997). Telecare is framed as mitigating risks through monitoring ‘compliance’ with prescribed care and normative routines rather than developing agreed approaches to its use (Schermer 2009). Ethicists also note that people with dementia at risk of ‘wandering’ are outfitted with ‘electronic tags like terrorists’ (Sorell and Draper 2012). Further critical essays demonstrated a connection between remote monitoring of people with dementia as equating them with ‘babies, convicted criminals, and animals’ illustrating processes of infantilising, criminalising, or dehumanising people with dementia (O’Neill 2003). Hughes (2008) concluded in her essay that surveillance for people with dementia walking must balance the right for a person to take risks with the perceived concerns about personal safety.

Whilst surveillance was identified as an ethical challenge based on informal carers and care professionals monitoring a person with dementia, no studies attended to actual practices of monitoring. One (Greenhalgh et al. 2013) reported findings where surveillance was identified as a concern. Other articles included in the review (Fisk 1997; Hughes 2008; Rauhala and Topo 2003; Schermer 2009; Sorell and Draper 2012) were essays or thought pieces that identified the potential use of telecare as form of surveillance. This suggested to me a distinction between how critical scholars imagine the role of telecare in dementia care from policy and applied research. Attending to the realised, actual practices of people with dementia and informal carers may help clarify or address these apparent discrepancies.

#### 2.4.4.3 Changes in care provision

Another challenge identified in the reviewed literature was a change to the current care they received if they used telecare. One interview study in the UK focused on the experiences of older people using telecare highlighted their concern with losing access to current face-to-face care if they used telecare (Mort et al. 2015).

#### 2.4.4.4 New forms of dependency

Another challenge that the reviewed literature identified was whether telecare may construct 'new forms of dependency' (Milligan, Roberts and Mort 2011). In this case, the older person or family member becomes dependent on telecare for helping them complete everyday activities or providing care, respectively. This challenge indicates a potential dissonance from how researchers identify telecare as providing care at a distance to help people with dementia live independently in the community for longer compared with the concerns of older people who do not want their independence diminished through a reliance on a technology.

These challenges highlight distinct ways that older people and people with dementia may express using telecare as part of their care provision. It also suggests their use of telecare may not fully align the ways in which they want to live their lives. Few studies attended to how and why people with dementia and informal carers use telecare as part of their everyday practices. Yet the research literature also suggests that using telecare may reduce and help address other challenges that people with dementia encounter in their everyday lives such as getting lost.

Revealing such diversity in discourses about assistive technologies and telecare highlights that while policymakers and manufacturers may promote telecare as designed to enable older people, including people with dementia, to live independently in their own home, the diversity of discourses adopted by a wide range of other stakeholders identified challenges with adopting telecare in their own practices. Peoples' uses of telecare may shift still further as older people experience fluctuating care needs and priorities from developing multiple illnesses in later life, especially if their condition threatens their ability to make decisions about their care and to take part in everyday activities.

Reviewing this literature confirmed how academics, clinicians and policy makers differently framed and articulated the potential and reality of assistive technologies and telecare. Policy makers and practitioners more often focused on the assumed transformative potential of these technologies to support a person living with a disability or in later life to manage their independence or participate in

diverse occupations and everyday activities. Conversely, social researchers more often problematised the role of technologies as they examined how introducing technologies within a wider set of practices often created ethical dilemmas and unintended consequences when set within everyday life routines. For me this insistently points up the disparity between any intended potential for technology-enabled care to transform people's lives with the unintended consequences of their implementation in everyday routines and patterns of life. Despite these conflicting approaches to framing assistive technologies and telecare, I noted some common themes in the literature that initially sensitised my ethnographic interests.

I noticed distinctions between how different organisations defined user groups in the reviewed literature. I already drew attention to how the ASTRID team, King's Fund, and the World Health Organisation differently identified users of assistive technology based as people with a disability or older person. These distinctions alone justify a reason to understand how people with dementia may use these technologies in ways potentially distinct from older people. However, I also noticed that health researchers often focused on the benefits to family and service providers for telecare provision. For telecare family, other informal carers and service providers – including call centres - often actively monitored people with dementia whilst they may passively activate sensors in their home without their knowledge. This insight led me to examine how *both* people with dementia and informal carers use assistive technology and telecare. Such attention could draw attention to how we define and create boundaries between groups defined as 'technology user' and 'service user'. This focus on how participants used technologies later led me to reconsider how 'use' represented forms of 'care' in terms of conceptual relevance in social science and, perhaps more importantly, to how participants made-sense of their own relationships and care arrangements.

I also observed the apparent lack of research about people living with dementia more advanced or later stages of the illness. Most research studies about technology-enabled dementia care appeared to include only people with mild or moderate dementia. However, people living with dementia may experience and apply qualitatively different practices for changing care needs as their symptoms became more severe or difficult to manage. This insight led me to examine severity as a purposive sampling criterion for this study and also later informed my interest in how people experienced their memory problems.

Although the reviewed literature broadly categorised technologies into 'assistive technologies' and 'telecare' – two concepts which I used consistently throughout this thesis – they did not specifically

consider the wide array of technologies covered by each of these broad concepts. They, therefore, could not attend to how different technologies mediate care practices and living with dementia in qualitatively different ways. The literature revealed this diversity and alerted me to the likely implications for practices I would observe, which is why I selected the 'type of technology' as another criterion for my purposive sampling.

These initial themes helped to establish my purposive sampling strategy, however, they remained flexible throughout the life of ACCOMMODATE. I used them as starting points to reflect on my understanding of technologies in community-based dementia care. Through my links with ATILA and my own individual research activities, I later problematised these initial concepts to illustrate how different groups 'imagined' technology-enabled dementia care.

## 2.5 Introducing 'imagined communities' as a theory for exploring 'care' and 'communities'

The literature already reviewed in this chapter highlighted that assistive technologies and telecare are commonly seen in terms of their capacity to enable or support people with dementia. Such roles included assistive technologies enabling the independence of the person with dementia or helping them perform tasks more safely. Telecare could be seen as reassuring informal carers about the safety of the person with dementia under their care through monitoring their activities. However, the research literature also highlighted how people with dementia, or older people more generally, and informal carers using assistive technologies and telecare may experience reduced autonomy and creating new forms of dependencies with these technologies. How could these technologies be seen as both reducing autonomy and forming new dependencies yet also enabling independence? These discourses appear to contest each other. Yet policy makers and industry promote assistive technologies and telecare as a potential cost-saving solution to providing care whilst its suitability for helping older adults live in the community is still debated.

Differences in the perspectives of diverse groups involved in care were highlighted in a recent discourse analysis study of 'organising visions' for telecare and telehealth in the United Kingdom which identified four competing discourses from observations and reviewed literature (Greenhalgh et al. 2012). This study contrasted some peoples' use of a 'modernist' discourse to promote telecare development and use as progressing safer care, with others expressing 'humanist' issues raised by telecare potentially replacing more personally-responsive care services; some groups drew on a

'political economy' discourse to highlight the effects of industry shifting funding from public services to private companies while commissioners and care managers more often used a 'change management' discourse to represent organisational changes in implementing telecare at scale. These varied discourses suggest different beliefs and values which underpin why certain groups prefer technology-enabled care service whilst others prefer care provided directly through human contact. Different stakeholders frame the roles, opportunities and challenges of technological care interventions in ways that are commensurate with these values.

The previous chapter identified the research problem for this study as examining the practices of people with dementia and their informal carers *living in the community* using assistive technologies and telecare. 'Living in the community' remains a relatively recent way for policy makers, service providers, and researchers to describe people located outside of institutional settings. In the context of this study, 'living in the community' referred to people with dementia who are not in long-term residential or hospital care. Yet people may understand 'community' in different ways. Therefore, they may also impart diverse meanings to 'community care' and its future incarnation as technology-enabled dementia care. As the study progressed, I observed that these different discourses represented different ways that people *imagined* communities. To help consider the context and findings of this research, I draw on Benedict Anderson's theory of 'imagined communities'.

Anderson developed the concept of 'imagined communities' to explain how people formed nations based on identifying 'imagined' commonalities between them and strangers. In *Imagined Communities: Reflections on the Origin and Spread of Nationalism*, Anderson (1983) argued that nations were a social construct – 'an imagined political community' – used to differentiate a shared 'commune' of individuals from other groups. He argued that nations were socially constructed because individuals will never meet every person that identifies with a particular nationality. Instead, people drew on and shared images, iconography, and texts that marked their identity as distinct from how the imagined others (Anderson 1983). Therefore, nations were also limited; insiders demarcated who did and did not belong to a particular nation through their shared imaginings. Anderson (1983) suggested that language, maps, and cultural artefacts allowed capitalists, dynastic empires, and the modern secular state to construct these imagined communities.

This study did not address nationality, nationhood, or nations as its substantive focus. However, imagined communities was a theoretical concept that seemed especially appropriate to make sense of the way different people's practices and language led to distinct ways for imagining technology-

enabled dementia care whether directly informed by experiences of such care or not. In particular, 'imagined communities' were used here to distinguish between how policy makers, researchers, and people with dementia differently envisioned and enacted their own imagined communities of technology-enabled dementia care. It allows for accounting for the multiplicity of everyday life as people with dementia experience it compared to how policy makers and researchers discuss their own imagined ideas of practices.

## 2.6 Methodological and substantive limitations from the literature

The reviewed literature in this chapter suggested methodological and substantive limitations for further examining the practices of people with dementia and their informal carers living in the community using assistive technologies and telecare.

The first limitation was routinely excluding people with dementia from participating in research about their experiences of care. If researchers wish to identify whether and why people with dementia use particular technological innovations, then people with dementia should be approached as participants in the study. Many research relied on informal or family carers as participants to provide proxy data about how they viewed the acceptability of assistive technologies or telecare. However, informal carers may not always live with the person with dementia. Furthermore, informal carers may not always know why a person with dementia under their care acted in a specific way. They refer to their own interpretation and judgement to inform these decisions yet people with dementia may contest these interpretations if they were approached.

The next limitation was using interviews or focus groups as methods for data collection when people with dementia were participants in a study. The accounts produced through these methods may not necessarily reflect the lived experiences or practices of people with dementia as people with dementia may have forgotten the events which appropriately answer the researcher's questions if the researcher relies on retrospective questioning. Additionally, people with dementia may experience communication difficulties that make taking part in these studies difficult.

Another limitation was the relatively finite amount of empirical work examining how people with dementia and their informal carers living in the community actually use assistive technologies and/or telecare. Previous studies which relied on interviews with people with dementia and informal carers suggested that people with dementia or informal carers adapted technologies to fit into their lives

(Gibson et al 2016) yet there was limited data about how they adapted it. Additionally, they did not consider how the progressive symptoms of a person's dementia may require informal carers to further adapt these technologies to meet new or additional care needs.

Finally, there was limited empirical work which situated people with dementia and their informal carers using assistive technologies and telecare in the wider context of living with dementia in the community. Theoretical work reviewed in this literature suggested that assistive technology and telecare may reduce autonomy and create new dependencies yet no empirical research found in this review considered the implications of these ethical issues within the context of everyday life. How do we understand care and living in the community if practices with these technologies monitor and constrain rather than support independence? What does 'living in the community' mean in such circumstances?

## 2.7 Research questions for this study

To address the methodological and substantive limitations identified from this literature review, four research questions will address the 'intellectual puzzle', examining the practices with assistive technologies and telecare of people with dementia and their informal carers living in the community. Each of the four research questions attend to one particular facet of the research puzzle.

1. How do people with dementia experience everyday life in the community?
2. How do carers provide community-based care and through what activities?
3. How and why do people with dementia and their informal carers use, or choose not to use, assistive technologies and/or telecare in the community?
4. How do assistive technologies and telecare fit into the communities of people with dementia?

The next chapter considers an appropriate methodology for answering these questions.

## 2.8 Chapter Summary

This chapter reported a review of relevant research literature to examine recent studies of community-dwelling people with dementia and their informal carers using assistive technology and telecare.

Many of the articles in this chapter focused on the development of new evaluation tools or considered the perceived role of assistive technology for helping people with dementia improve their functional capacity, enable their independence, or increase their ability to complete tasks safely and with greater ease. Assistive technologies provided unintended challenges based on issues 'fitting' them into how

people with dementia live their lives. There were also very few articles that attended to how and why people with dementia and their informal carers used telecare. Many of the reviewed articles focused on the challenges that older people and people with dementia using telecare may face including reduced autonomy, concerns about constant surveillance, concerns about potential reductions in face-to-face care, and a new dependency or reliance on technologies. Although the reviewed literature managed to cover some ground related to how and why people with dementia use assistive technology and telecare, there were a few gaps in the literature.

These assertions based on relatively limited empirical work led me to consider how current research interests appear to be based on how different stakeholders linked their own 'organising vision' (Greenhalgh et al. 2012) to how they 'imagined' people with dementia will or should use technologies. This identification with people's 'imagined' uses of assistive technology and telecare led to drawing on Benedict Anderson's (1983) 'imagined communities'. Imagined communities can allow us to consider what other facets of dementia care are also multiply imagined and how they contrast to the actual practices of people with dementia and their informal carers using assistive technologies and telecare in their everyday lives in the community.

The next chapter explains the rationale for selecting ethnography as the methodology for examining practices with assistive technology and telecare of people with dementia and their informal carers living in the community.

# Chapter 3: Methodological and Philosophical Approaches to Study

## 3.1 Introduction

The previous chapter identified a lack of consensus between researchers, policy makers, and practitioners about what care or support needs assistive technology and telecare may be designed to meet. Despite the absence of a unifying definition for either assistive technology or telecare, British policy makers still champion the potential for these technologies to innovate how health and social services provide more patient-centred care through ‘technology-enabled care services’. I suggested earlier that the lack of consensus about the role of ‘technology-enabled care services’ may represent different ‘imagined communities of care’ rather than the practice of ‘care in the community’. These ‘imagined communities of care’, however, do not necessarily reflect how people with dementia or their informal carers in the community use assistive technologies or telecare in practice. To consider these assumptions about technology-enabled care and community living for people with dementia, this study examined how these technologies fit into the everyday and care practices of people with dementia and of informal carers living in the community. Four research questions framed the focus of the study:

1. How do people with dementia experience ‘everyday life’ in the ‘community’?
2. How do carers provide ‘community-based care’ and through what activities?
3. How and why do people with dementia and their informal carers ‘use’, or choose not to use, assistive technologies and/or telecare in the community?
4. How do assistive technologies and telecare ‘fit’ into the ‘communities’ of people with dementia?

To answer these questions, the study needs a methodology and methods which may be appropriate to collect data about the practices of people with dementia and their informal carers in the community using assistive technology and telecare.

This chapter aims to justify ethnography as a relevant methodology for examining how people with dementia and their informal carers living in the community use assistive technology and telecare. The first section examines the ontological and epistemological assumptions framing how I examined people with dementia and their informal carers based on their practices of using assistive technology

and telecare. The second section explores how ethnography is a suitable methodology for answering these research questions. The third section considers the methodological challenges for using ethnography for studying people with dementia and their informal carers' practices in community-based settings. The fourth section draws on adaptations from contemporary ethnographic research in education, sociology, communication studies, and anthropology to address these challenges.

### 3.2 Ontological and epistemological assumptions of this study

This section outlines the ontological and epistemological assumptions guiding how this study examined the practices of people with dementia and their informal carers living in the community using assistive technologies and telecare.

Ontology is the study of what exists or can be. How the present study sets out the research problem as examining the practices of people with dementia and their informal carers living in the community using assistive technologies and telecare assumes that 'practices' exist externally to individual capacity to hold ideas. Here practices are presented as enacted by people rather than merely as ideas that people think about. If people enact practices, then this suggests practices will be observable phenomena. In the specific context of this study, this means it will be possible to observe the practices of a person with dementia as they use an assistive technology. If these practices are observable, then this will also tell us something about what else will exist that the design and processes of carrying out this study entails, so that reality exists as external to human thought and action. Therefore, this study prescribes to a realist ontology.

Epistemology is the study of how knowledge is produced, i.e. how we learn about reality. In order to explore how people with dementia and their informal carers use assistive technology and telecare, which we have now defined in terms of observable practices, then we must first account for the ways in which these people habitually interact with these technologies. As discussed in the first chapter, dementia is still a poorly understood syndrome caused by a multitude of different diseases. Clinical practitioners diagnose dementia based on a loss or impairment of 'memory, thinking, orientation, comprehension calculation, learning capacity, language, and judgement' and 'deterioration in emotional control, social behaviour, or motivation' (World Health Organisation 2017). Every person may experience dementia in slightly different ways due to how different types of dementia result in different levels, rates and affected symptoms of deterioration. The progressive and diverse expressions of the symptoms of dementia means that each person with dementia may not only use assistive technology and telecare in ways which are unique for reasons specific to how they imagined

the devices role in their lives, but we need to take into account that how they use assistive technologies and telecare may continually change over time as they experience further impairment. Informal carers may enact practices for using assistive technology and telecare which differ from the practices of the people with dementia for whom they provide care. Being identified as a 'carer' already implies a way of locating themselves in the world based on their own distinctive practices which cannot be the same as those of the person who is living with dementia. Their social role as carer in this relationship is about 'providing care' rather than 'receiving care'. Therefore, how people with dementia and their informal carers perceived and included assistive technology and telecare in their care practices may vary widely. Previous research illustrated how older people using assistive technology and telecare interpreted the role of such technology as undermining their own privacy and autonomy whilst also providing peace of mind for family members (Topo 2009; Mort *et al.* 2015). People's practices will reflect and reproduce their understanding of social reality through their interactions with other people and objects with the world around them, constituting their practices. People with dementia and their informal carers may both appear to enact similar practices yet how they understand these practices may delineate different ways of understanding or interpreting these interactions within the context of their lives. To appreciate such subjective as well as objective constituents of practice, and the multiple constructions of practice these may give rise to, this study adopted a constructivist epistemological stance based on people interpreting their perspective of reality.

This stance enabled the research to engage with and understand these multiple constructions of how individuals understand their own reality. In this case, as a naïve observer to how dementia care was provided in the community or at home when this study started, this position offered an opportunity to explore this research context remaining open to noticing variation in the range of types of practices of people with dementia and of ways people might articulate their perceptions of reality. In other words, I would not turn a 'medical gaze' (Foucault 1989) to or 'medicalise' (Conrad 2007; Bond 1992) the practices of people with dementia as a symptom of their illness. In fact, my training in sociology of health and medical anthropology sensitised me as to how we unconsciously ascribe certain actions or 'behaviours' as problematic social problems or symptoms of illness. To different from this approach, I focused on how people with dementia and informal carers' performed their routine everyday practices in the home, to note how assistive technologies and telecare may or may not fit with (and become embedded with) these practices alongside how people with dementia and their informal carers made sense of their own practices with these technologies. The epistemological approach was to seek to understand people with dementia and their informal carers' everyday

practices and practices with and through assistive technologies and telecare how they themselves explain how they understand and orientate themselves.

Ontological and epistemological tensions are therefore posed if and when people with dementia and their informal carers contradict each other's understanding of social reality through their multiple interpretations of reality. These multiple interpretations need to be accommodated in a single 'comprehensive' research account of these understandings alongside what is observed. This study therefore adopts its ontological stance of 'subtle realism' so as not to be limited only to subjective understandings or to more objective observations. . To more fully understand how and why (both in terms of reasoning and in action contexts) people with dementia and their informal carers used assistive technology and telecare, this study also, therefore examines these contradictions and tensions with how they interpret and made sense of their own social reality through shared and personal interactions with each other and the world around them.

Attending to how people with dementia performed everyday practices, perhaps with and through assistive technology and telecare, and how they make sense of these practices requires a research methodology that can attend to the mundane and tacit importance of everyday living. Everyday life is composed of social relationships, and social and material interactions which help define our habits. These components of everyday life are grounded in how people perceive the world around them and interact through social practices. Examining the multiple practices and interpretations of them by people with dementia and their informal carers is the crux for examining how they use assistive technologies and telecare and how they 'fit' into their everyday lives. I need to be able to describe both the mundane and the extraordinary events and the material and social relations of people with dementia and their informal carers to understand how and why people with dementia and their informal carers living in the community use assistive technologies and telecare.

Qualitative methods are designed to describe and analyse complex phenomena including their multiple interpretations as situated within local contexts and circulated between them. Qualitative methodologies provide means to answer 'intellectual puzzles' which examine mechanistic and processual phenomena. Everyday practices may be seen as typified by 'how and 'why' questions about social reality (Mason 2002). Several qualitative methodologies rely on interpretivist approaches to illustrate that quantitative approaches which reduce the granularity and specificity of the phenomena examined outside of the local contexts cannot explore complex, multiple and contested understandings about particular phenomena in relation to their situation. These are therefore

particularly pertinent to exploring the complexities entailed in the diversity of how people with dementia and their informal carer may interpret their everyday practices and perceptions of a locally situated phenomena, such as practices with assistive technology and telecare provided as part of formal community care services. Particular complexity is introduced by the ongoing communicative and cognitive challenges the person with dementia may experience, to their own expression in organising their lives and relationships, including any relationship with the researcher. This called for a qualitative methodology that can handle the generation and interpretive analysis of descriptions of the practices of people with dementia and their informal carers using assistive technologies and telecare within their everyday lives. An ethnographic approach therefore seemed likely to provide this, this is argued in the next section.

### 3.3 Using an ethnographic approach

This section considers the core methodological requirements of this study to address the research questions and the appropriateness of an ethnographic approach.

#### 3.3.1 Considering the methodological requirements of this study

People with dementia and their informal carers will reflect and articulate their experiences of community care through their enacted practices and language, which will provide a range of different insight into how and why they may have used assistive technology and telecare. Observational methods which focus on anything that can be observed therefore seemed especially likely to enable me to examine the practices for how people with dementia and their informal carers use assistive technology and telecare. Conversations and interviews conducted with people with dementia and their informal carers about their everyday life and use of assistive technology and telecare may generate data *about* practices related to assistive technology but may also abstract details from where the activity takes place and may correspond to differing representational priorities. For example, many telecare devices can be installed in peoples' homes. Conducting a study with people with dementia based on discussion or observed practice outside of their home will decontextualize how people reflect on their practices with assistive technologies and telecare. On the other hand, a series of observations a situated, local context would help build processual records of the practices of people with dementia and their carer with assistive technologies and telecare by observing how they perform these practices over time in a situated, local context (Lüders 2004).

As an observer, I need therefore also to account for the enactment and affordances of my role in what I observe and my presence and interactions with people with dementia and their informal carers as

they continue with their everyday activities. Earlier work in sociology (Gold 1958) suggests that there are four strategic roles that an observer adopts: complete participant, complete observer, participant-as-observer, and observer-as-participant. Observational researchers may fluctuate between such roles which are evaluated here in terms of their likely appropriateness in this case and how these judgements shaped my orientating myself and my attention whilst spending time with people with dementia and their informal carers.

‘Complete participant’ is a role that focuses on fully taking part in the daily activities of the observed people in order to understand how and specific actions are performed. As a researcher who is attempting to engage with and understand the everyday lives and practices of informal carers and people with dementia using assistive technology and telecare within their own home, I argue that it is inappropriate for me to act as a complete participant due to no professional clinical or care-providing training. Additionally, complete participation may cause distress to the person with dementia who is accustomed to a specific routine with a known carer. It would also be difficult to immerse fully in the everyday practices of people with dementia and their informal carers whilst also being able to record what I witness if I completely participated in such practices with people with dementia and their informal carers.

The second role, ‘complete observer’, is a role that focuses on only observing participants in a study rather than taking part in their practices. Complete observer is a more appropriate role for me to adopt for this study since I can attend to the particular practices of people with dementia and their informal carers whilst limiting my direct interference with how they enact their practices with assistive technologies and telecare. However, I argue that it would be inappropriate not to interact when directly addressed by either participant. Since both the person with dementia and his or her informal carer will be aware of my overt research role observing their everyday activities, they may ask questions which I would feel obligated to respond to. I also argue that by completing overt observational research, then my presence entails a certain form of participation in the everyday lives. I am not an invisible presence to people with dementia or their informal carer; they will see me when I observe them. I am a human whose own perceptions, feelings, and actions are grounded in the manner in which I try to ‘fit in’ with people with dementia and their informal carers where I encounter them in a community-based setting. Therefore, observation is inseparable from participation. Yet how and to what degree I am able to participate is worth considering.

The final two of the four roles, 'participant-as-observer' and 'observer-as-participant', differ from emphasising either participating in, i.e. taking part in the practices of people with dementia and their informal carers, or observing these activities as the primary method for understanding how and why people with dementia and their informal carers use assistive technology and telecare. The hybrid roles of participant-as-observer and observer-as-participant are relevant means for interacting with people with dementia and their informal carers more directly. Talking with them about their experiences may provide more detail about the practices that I observe. Therefore, informal conversations need to play a role here as a means for eliciting more information about how people with dementia and their informal carers perceive the world around them, their place in the world, and how and what they do in it. Such conversations differ from semi-structured and structured interviews as they are used to probe for more information about their practices and how they make sense of them as they occur in the moment. In other words, they are an approach which allows both people with dementia, their informal carers and me to construct and articulate how we understand our experiences as they occur.

A single observation with people with dementia and their informal carers would only reveal a little about their routine practices with and through assistive technologies and telecare no matter how much participation is involved in making that observation. Subsequent observations would clarify further detail about the practices of people with dementia and their informal carers. It would help contextualise which of their practices are mundane from which ones are extraordinary. Both mundane and extraordinary events suggest something to the observer. When people with dementia and their informal carers, themselves frame events as 'routine' or 'odd' may highlight how they may understand event frequency and perhaps their perceived importance to participants depending on their sense of and explanations for how and why the event takes place. Multiple observations over time would help to illustrate what people with dementia and their informal carers feel as commonly experienced by them and also suggests how their activities and behaviours change over time. This longitudinal approach would illustrate what people with dementia and their informal carers experience as everyday practices *at any given moment* whilst being sensitive to *changes over time*. Observations and any notes from conversations with people with dementia and their informal carers would need to be recorded within a field journal (Emerson, Fretz and Shaw 2011). These notes, or 'jottings', serve as an *aide-memoire* which with supported by reflective reviewing practices, could also construct 'thick descriptions' (Geertz 1973) of fieldnotes which detail and contextualise what I observed and did during the time I spent with the person with dementia and his or her informal carer. 'Thickness' arises from the depth and attention to context. Therefore, thickly descriptive fieldnotes

allows readers to feel as though they are 'being there' (Geertz 1988). In this study this would mean being with the person with dementia and his or her informal carer as they perform practices that constitute their everyday lives in the community. Description is a means for delineating the processes and practices that may be hidden, backgrounded or tacit, in how people with dementia and their informal carers understand their own lives, but a trained or naïve observer may come to notice differently. Description of these observed activities may contradict what people with dementia and their informal carers explicitly discussed with me. Observation, therefore, is a helpful method for attending to what may be unsaid because people with dementia and their informal carers feel they cannot or choose not to say them. This allows the observer to lead the reader toward alternative interpretations or to invite the reader to make their own interpretations about what is happening and why based on their own reading of the researcher's composite account. Researcher-constructed accounts may not necessarily follow a chronological order, but may pursue another logical order such as by themes or concepts consisting of phrases people with dementia and/or their informal carers used during observations.

Therefore, an appropriate methodology for examining how and why people with dementia and their informal carers use assistive technology and telecare must be able to satisfactorily address four criteria:

- i. Offers a longitudinal approach
- ii. Places primacy on participating and observing people with dementia and their carers' experiences and performances of everyday activities
- iii. Where an overt (not covert) researcher immerses themselves in the socially- and physically-bounded research field of the local community of each study participant with dementia
- iv. To reflect and to interpret participants' social realities represented through 'thick descriptive' accounts.

### 3.3.2 What is ethnography?

Ethnography is variously defined as a method, methodology or the written product of these approaches where the researcher, i.e. the ethnographer, examines the 'culture' of a specific group through their values, social systems, rituals, and practices, based on first-hand immersion with members of the group, usually for a prolonged period of time (Hammersley and Atkinson 2007; Bryman 2008). Ethnographers have taken different approaches to describing local communities, in their various research enterprises, over the last 130 years. A brief history of ethnography and its multiple 'turns' where these may be relevant to the present study is presented illustrate how the

central features of ethnography and the commitments an ethnographer makes about his or her philosophical assumptions (ontology and epistemology), methods, analytical predispositions, and perhaps most importantly, relationships with people being described are ever-shifting. This subsection provides a brief history of potentially-relevant different ethnographic approaches from its earliest development in Western anthropological traditions, a tradition where I locate myself based on training in cultural anthropology in the United States and social and medical anthropology in the United Kingdom, as a means to describe cultures, to subsequent critiques which resulted in 'interpretive' and 'reflexive' turns in how ethnographers frame their enquiries. This history shows how ethnography may be multiply understood and continually negotiated and refined in social and cultural anthropology, sociology, and other cognate disciplines. The term 'history' here delineates the core features of an ethnographic approach before turning to how their specific relevance and feature for examining here how people with dementia and their informal carers use assistive technology and telecare as part of their community care with an ethnographic approach.

Ethnography emerged as a methodological tradition in social and cultural anthropology in the late nineteenth and early twentieth centuries. It's scholar-practitioners envisioned anthropology as a 'science of humanity' founded on the same premises as the natural sciences, in that 'cultures' were 'out there' to be discovered, recorded, and described in similar ways to like gravity, thermodynamics, and chemical reactions. The aim of this early form of ethnography was to 'collect everything' (Bastian 1881; cited in Bernard 2011). 'Ethnography', literally, writing about people, was a means for anthropologists to codify cultures from around the world, into specific 'domains' classifying their practices, belief systems, subsistence strategies amongst others (*cf.* Murdock 1971) for ethnological studies which compared cultures (Radin 1966; Bernard 2011).

Sociology also developed its own tradition of ethnography in the early decades of the 20<sup>th</sup> century. Ethnography influenced the development of sociology as a discipline away from the 'grand theory' of Émile Durkheim, Karl Marx and Max Weber to examine the everyday lives of people in Western societies as opposed to non-Western, 'primitive' societies in early anthropological scholarship. Sociologists and social anthropologists continue to research society and cultural systems, but there is more attention paid to how and who is collecting the data and how it is represented. Critiques from within anthropology and sociology about how researchers represented culture problematised the disembodied lens that mystified fieldwork and how ethnographers learnt about a cultural or social group (Wolcott 2008). This led to the first dramatic change in how anthropologists approached

ethnography: the so-called 'interpretive turn' in anthropology and other social sciences (Rabinow and Sullivan 1979).

Interpretivism is an approach which originated from hermeneutics, the textual analysis of the Bible, where stories are not read for the literal representations they offer to readers, but rather how the reader can interpret implicit meaning of the text to apply in their own life (Bernard 2011). In other words, knowledge is situated. Interpretivist ethnography no longer postulates that 'culture' is reducible to a series of structures and functions. Interpretivists believe that 'practical understanding' is learnt through the ethnographer 'reflecting upon his [sic] own actions in the world as a subject not only of experience but intentional action' (Rabinow and Sullivan 1979: 3). In other words, culture cannot be reduced to a series of interrelated systems based on an objectivist science approach, all enquiries are shaped by how the ethnographer intentionally attends to, takes part in, and builds relationships with particular people doing and saying particular things. Although many pioneering anthropologists and sociologists of the classical ethnographic traditions (i.e. structuralism, functionalism) learnt by spending time with a particular group, they were challenged by a new paradigm that espoused describing the culture through one's own first-person vantage point rather than a third-person omniscient narrator in order to demonstrate their authorial authority. This principle is defined in interpretivist ethnography as 'being there' (Geertz 1988), the ethnographer articulates their immersion in the event taking place. However, representing an event through writing requires 'translation' or 'textualisation' (Ricoeur 1971) where social phenomena are rendered as 'fixated, autonomised and classified' text (Van Maanen 2001: 91). Clifford and Marcus's (2010) edited collection, *Writing Culture*, challenged ethnographers to consider the politics, epistemology and practice of writing about people. They suggest that culture is *not* out there to be collected; it is inscribed through an active and intentional writer based on how they interpret their experience in the culture. Writing description based on prolonged and immersive contact with a group of people, therefore, remains central to ethnography, but how ethnographers articulated these encounters through their text changed.

Principles commonly shared across most and even experimental forms of ethnography in assessing ethnography as methodologically appropriate for studies are:

1. Immersion in the field to understand people's everyday practices and the contexts in which they are situated
2. Data generated primarily through participant-observation and conversations
3. Focus on a few individual cases or a small-scale community

4. Unstructured approach where concepts emerge through analysis (Hammersley and Atkinson 2007)

### 3.3.3 Justification for an interpretivist ethnographic methodology

This subsection considers how an interpretivist ethnographic approach aligns with the four qualitative methodological requirements for this study:

- i. A longitudinal approach
- ii. Based on the primacy of participating and observing the practices of people with dementia and their informal carers with assistive technologies and telecare
- iii. Where an overt researcher immerses himself in the socially and physically bounded research field of the local community of each person with dementia
- iv. To reflect and to interpret these practices represented through 'thick descriptive' accounts.

These will be considered in relation to methodological literature in the context of examining the practices of people with dementia and their informal carers in the community using assistive technology and telecare.

#### 3.3.3.1 Longitudinal design

This study's focus examines how people with dementia and their informal carers use assistive technology and telecare in their everyday lives. Here 'use' means the practices of people with dementia and their informal carers take part in with and through assistive technologies. 'Use' is often reduced into a single broad statement about how people interact with particular *things* (i.e. material objects) and *people*. However, 'use' cannot be a static description of a form. Use, or more appropriately, 'using' is a process. Processes will be enacted over a period of time and are susceptible to change. How people with dementia and their informal carers use assistive technologies will vary for at least two reasons: i) the process of familiarising oneself with a new piece of technology and ii) how the changing care needs of people with dementia may affect the ways they use the technology. In other words, a longitudinal design is required for examining how people with dementia and their informal carers multiply experience and enact use of assistive technology and telecare.

Ethnographic design is most commonly longitudinal and qualitative. One of the central tenets of ethnography, especially in anthropology, is to spend extended time with a group of people (Ingold 2014). This is to learn as much as possible with members of the different communities they visited; often living with them. Such sustained and extensive contact was argued to build rapport and negotiate access (Hammersley and Atkinson 2007; Bryman 2008; Bernard 2011) to different groups of

people or practices in the community, including rituals, ceremonies and other exclusive practices that unlikely to be encountered during a single visit typified in a cross-sectional design. Longer time helped to build relationships, ethnographer-participant trust, building more authoritative presentation of findings.

### 3.3.3.2 Observation and participation

As described in the previous subsection, ethnographers spent time *with people* who enacted a practice of particular interest to their inquiry or exhibited a form of the domain they studied. For many ethnographers, this required observing and participating in the mundane and everyday practices of people carrying out their everyday routine. This participant-observation was a principled means to learn about the local culture through taking part and observing it as it occurred. The means of observing and participating is especially pertinent when working with people with dementia.

Emphasising doing and watching events as they happen removes part of the need to rely on the participant's ability to recall and draw on memories to share understanding. Many people with dementia experience acute and sustained loss of short term memory and altered perception (World Health Organisation 2017) that may affect their ability to recall information about their everyday life and practices. They may not even be aware that assistive technology or telecare was installed in their home and if they are aware, then they may not recall it during a later conversation. If they can recall the information, then they may still have trouble finding words to articulate their memory due to having aphasia (World Health Organisation 2017). This does not mean that interviews with people with dementia are impossible but need to be organised and perceived in specific ways and alongside sufficient contextual data.

The clinical psychologist Sabat's (2001) *The Experiences of Living with Dementia* illustrated that people living with dementia were still capable of articulating their experiences although the symptoms of dementia may slow down the creation and alter the structure of how they respond. As the symptoms of people with dementia progressed, their ability to reflect and articulate their thoughts may diminish. Yet practices and talk of people with dementia, even if limited or seemingly unintelligible, still possesses social meaning to people who know them, such as their informal carers. Therefore, observing and participating in the practices of people with dementia and their informal carer is a method for understanding how they use assistive technologies especially if examined through immersive and sustained contact situated in a specific location relevant to people with dementia, what ethnographers often refer to as 'the field' (Hammersley and Atkinson 2007; Bryman 2008).

### 3.3.3.3 Field and fieldwork

The methodological approach to this study needed examine how people with dementia and their informal carers use assistive technologies and telecare as part of their everyday lives through their practices with these technologies. Participant-observation has been proposed here as a relevant method for generating data about people with dementia and their informal carers using assistive technology and telecare. Assistive technology and telecare are technological interventions designed to promote independence and risk management *in the community* (Hanson *et al.* 2007; Robinson *et al.* 2007). Examining everyday life, or the 'culture', of communities is a central interest of ethnographic research. The precise ways in which the ethnographer conceptualised and bounded their community is called 'the field'. 'The field' is an area – both socially and materially constituted – where the ethnographer spends their time with a group of people. Ethnography historically approached understanding indigenous knowledge and ways of life through accessing and participating in the field conceptualised as locales determined by a specific community's presence. Ethnicity or affiliation with a particular group of people situated in a specific geographic area linked the work of several classic anthropological ethnographies from Malinowski's (1922) ethnography of the Trobrianders of New Guinea and Evans-Pritchard's ethnographies of the Nuer (1951) and Azande (1937) people from the Nile basin. This conceptual design continues in the work of contemporary ethnographies such as Goffman's (2014) research on the institutional racism and criminalisation black Americans face living in Philadelphia's most deprived neighbourhoods and Montoya's (2011) study about how racial politics on the Mexican-American Border become tied up in genomic research on type 2 diabetes. Although a century separates the earliest work from the most recent, location still remains a prominent way of defining participants in ethnographies and where data collection, i.e. fieldwork, will take place.

### 3.3.3.4 Interpretive analysis of descriptive accounts

The final criteria for the methodology of this study was to allow. Interpretation of how people with dementia and their informal carers use assistive technology and telecare. Interpretivism has characterised most ethnographies by the 1970s (Bernard 2011) as studies found their work was challenged to accommodate plural understandings. Here we were likely to encounter multiple views of people with dementia and their informal carers on how and why they use assistive technology and how individually they make sense of its use. Writing is the central feature of interpretive analysis, both in recording fieldnotes on all phenomena examined during fieldwork to be inscribed for analysis. Ethnographers generate data by directing 'meaningful action' to particular events or practices. However, there is still tension between the distinction and conclusions about how situated, local knowledge can help define universal human patterns in anthropology (Ingold 2014).

*We imagine culture. We create culture.* Indeed, this highlights the distinction I made in the previous chapter about how policy makers and practitioners *imagined* communities of care from the potential reality of how people with dementia and their informal carers use assistive technologies and telecare.

This section presented the methodological considerations required to undertake this study to examine the practices of people with dementia and their informal carers living in the community using assistive technologies and telecare. Ethnography was presented as a suitable methodological approach for examining this research problem. Yet the conventions of ethnographic inquiry provided methodological challenges for realising this study. The next section pre-empts a discussion of these challenges.

### 3.4 Methodological challenges of carrying out ethnography with people with dementia living in the community

This section examines the methodological challenges, I initially encountered when planning ethnographic work with people with dementia and their informal carers.

#### 3.4.1 Geographically-dispersed population

Ethnographers in social anthropology, sociology and other cognate disciplines continue to design their ethnographic work based on an understanding how a specific group of people live in a specific place at a specific time (Ingold 2014), often within a specific community and participating in localised traditions and practices. Therefore, place was important to problematise whether and to what extent this 'dispersed' study could be defined as ethnographic. When people with dementia live in the community, they do not often co-habit with another person with dementia nor do people with dementia live in geographically-bounded enclaves. When policy describes 'care in the community' or 'community-based patients' they are referring to people with dementia who still live in their own home. By extension people with dementia who have not moved into residential care or nursing homes live in the same neighbourhoods as people without dementia. Whilst this is a key policy area linked to assumptions that people should be encouraged to 'live well with dementia' and 'age in place' in their own homes, this also means that an ethnographer cannot live and participate in a village or community of people with dementia in order to understand how they live every day, what activities they complete, how care is understood and provided, nor how assistive and technologies infuse these practices and their perceptions about them. People with dementia will almost always live separately from other people with dementia when they live in 'the community'. However, they may still cohabit

with other people, such as adult or young children, spouses, other relatives, or friends. Many may also live alone. People with dementia live, therefore, in different cities, towns, villages or smaller localities where they may have a strong or weak affinity with the local community members and traditions. This poses a methodological challenge to the ethnographer. If people with dementia do not occupy the same space, then traditional concepts of the field as a territorialised (Marcus 1995) and bounded location are no longer feasible for this study. This raised several important questions when I began to consider this study as ethnographic. For example,

- How can I immerse myself in my participant's lives and practices if they are geographically dispersed around England?
- How do I represent 'thick descriptions' about 'care in the community' provided to people with dementia through assistive technologies and telecare when people with dementia occupy and take part in different communities?
- How can I explore the experiences of people with dementia in the community when they occupy multiple different spaces?

All of these features were further amplified in this study where I had contacted participants who were living in even more-dispersed neighbourhoods than with a local community population, because they had been initially recruited to a multi-site randomised controlled study (ATTILA) across N sites, This meant I had to answer the question of, 'how can I 'be there', borrowing Geertz's (1988) parlance, when I also must be *there* and *there* and *here*?' These questions challenged conventional approaches to carrying out ethnographic work in terms of its central concepts of 'community' and 'field' with further effects for considering how people with dementia could participate in this study, how data could be generated about participants' lives and practices, the claims I make about their lives through analysis, and how these findings could be represented. As well as conceptualising and operationalising field and space in this study, time was found to pose a further methodological challenges.

### 3.4.2 Other obligations for participants' time

The previous subsection identified the geographically-dispersed nature of people with dementia in England created a methodological challenge for concepts such as immersion in field for an ethnographic approach designed to examine the practices of people with dementia in the community using assistive technologies and telecare. Ethnography was also often predicated on spending extensive lengths of time co-located with participants in a particular location for several months or years (Bernard 2011). This time was often spent getting settled into the field where ethnographers

may face relatively unfamiliar languages, rituals, and everyday practices. Ethnographers also required this time for gaining proper entry permissions to different countries, locating 'key participants' and developing a rapport with them in order to access other participants or get nearer to examining the specific phenomena of their study. Classic ethnographies represented this initial *mise-en-scène* through an arrival or 'confessional tale' (Van Maanen 2001) often used as the first chapter. However, these classical texts often mystified the day to day research practices of the ethnographer. Whilst ethnographers may have spent many months or even years in the field, we can question the extent to which this time was spent observing and participating in answering their research questions. The requirement of such critical preparatory work for accessing particular locations or events and developing rapport with key participants is an intensive and extensive time commitment. Yet time spent in the field is often used as a measure of the quality and depth of ethnographies. The singular focus about what ethnographers can reveal about a particular cultural domain or other social phenomena obfuscates how participants manage their own social commitments, responsibilities and other constraints that may also shape our ethnographic work. These time commitments present a particular challenge for how I can complete ethnographic fieldwork and the quality of observations and interpretations based on encounters with people with dementia and their informal carers.

As I previously discussed, people with dementia are geographically dispersed around Britain and may not live with their informal carer. To observe their experiences and everyday practices around using assistive technologies and telecare, then both the informal carer and I may need to travel to and from the local community of the person with dementia. Although the difference in placement between two locations is often measured by distance, it is also often measured in time, e.g. it takes twenty minutes to get to the shop. The geographically dispersed locations of people with dementia and their informal carers also highlights the nature of care commitments, other forms of work and the amount and types of travel involved to collocate people with dementia and their informal carers. The multitude of these different activities and their location limits the amount of time that informal carers may want to spend with me. People with dementia may also not have the energy for long research visits. If they are having a 'bad day' where they have limited clarity or awareness or are especially tired, then they may not want me to visit at all.

### 3.4.3 Relationship management

Another role that shifts is how the ethnographer's journey from first meeting participants until he or she leaves the field affects his or her understanding of a particular groups' way of life. From his or her starting point as a relatively naïve 'cultural outsider' until leaving the field as relative 'cultural insider' who writes a descriptive and analytical account of his or her experiences with the participants of the

study. These roles are usually considered as the *emic*, i.e. the cultural insider and the *etic*, cultural outsider (Headland, Pike and Harris 1990). The ethnographer would usually begin research as a complete observer who has limited knowledge about the culture and gradually establishes rapport with members of the community who instruct the ethnographer in the group's customs and allow for him or her to participate in specific cultural practices until they were able to completely participate. The ethnographer's prolonged period spent with members of another culture enable him or her to accomplish this transition. However, this understanding of cultures is contested here. The simple oppositional categorical reduction of cultural outsider and cultural insider presents cultures as objectified things that can be collected rather than something involving the ethnographer in engaging in processes of observing, writing and interpreting. Strathern (2004) noted that how people constructed their identity in relation to the group being examined was based on partial and contingent connections rather than static characteristics. To adopt these more recent constructions of the ethnographer role, rather than rigidly focusing on my insider/outsider status based on how the participants of this study and I as researcher, may affiliate with any particular group in the local research setting, I will consider and identify my status in relation to how and to what extent I take part in the practices of people with dementia and their informal carers.

As stated earlier in this chapter, ethnographers may occupy and continuously shift between the roles of complete observer, observer-as-participant, participant-as-observer, and complete participant as the situation demands and based on their intent. When and how these shifts occur may tell the ethnographer analytically relevant information about their status and relationship with participants in the study. For example, being invited into the kitchen to help make lunch where I may previously have stayed in the dining room as a house visitor. These changes in how activities are performed and by whom may indicate change in how participants and I view and relate to each other. It may mean, as other fieldworkers suggest, that I could now be contingently considered 'part of the family' or a 'friend'. From a more practical stance, it may just mean that I am another available pair of able hands who can be instructed to complete simple household tasks. Talk and sustained participation suggests a more situated understanding of how I might intentionally and/or serendipitously co-construct my position with participants during and after fieldwork. The ways in which I view my relations with participants or participants view me will therefore reflect and inform my relationship with participants in the study.

## 3.5 Adapting an ethnographic approach to address methodological challenges

This section draws on contemporary broad social scientific ethnographer scholarship to help address the previously described methodological challenges.

### 3.5.1 Multi-siting

People with dementia 'living in the community' are located across the nation; dispersed between several different localities that are conceptualised at a variety of different scales, e.g. neighbourhood, town, county, or region. In order to attend to the practices of people with dementia and their informal carers with assistive technologies and telecare, then I need to locate and move around and potentially occupy multiple localities in order to understand how practices are performed in each participant's particular local context. However, this de-territorialised conceptualisation of the field complicates how I, as the ethnographer, can immerse myself in the everyday lives and practices of people with dementia and their informal carers with assistive technologies and telecare. I draw on Marcus' (1995) concept of 'multi-sited ethnography' to address this methodological challenge and articulate the necessarily mobile approach to fieldwork.

Marcus (1995) described 'multi-sited ethnography' to describe new processes that enabled transnationalist research to describe diasporic migration by observing and speaking with people living in their nation of origin and following them as they moved to a new nation. He argues that researching phenomena or groups which were located across spatial boundaries requires ethnographers to 'follow' the focus of their specific research interests. He suggests several types of phenomena and actors that multi-sited ethnography may follow: people, material objects, associations, narratives and conflicts. Each approach was justified by the epistemological and ontological cases for what the ethnographic enquiry examined, for example, specific groups of transitory people or global events. Although these groups may disperse across great geospatial areas, they remained substantively linked to the ethnographer's enquiry. Multi-sited ethnography has received widespread use in subsequent research especially within the areas of culture studies, migration research and globalisation. Other ethnographers have adopted a multi-sited ethnographic approach to explore, for example, decision making related to economic immigration (Hage 2005) and travelling around different nations and conflicts as a foreign correspondent (Hannerz 2003). When the ethnographer uses multiple sites to construct the ethnographic field, then he can examine the phenomena or group of interest from different perspectives or locations. The ethnographer is not only 'being there' to return to Geertz, but

he or she is also being in other 'theres'. The resulting ethnography is not necessarily empirically or conceptually anaemic due to the ethnographer's limited time spent in each site. Instead, the transience of the ethnographer should be understood as how research contexts refract how ethnographies must be 'done' through fieldwork and writing.

The goal of ethnographic enquiry is to produce analytical accounts of everyday life (indigenous to a community) to include their activities, beliefs and the meanings ascribed to these categories. Van Maanan (1988) has described this process as 'the peculiar practice of representing the social reality of others through the analysis of one's own experience in the world of these others'. Geertz (1983) described the process of achieving these types of knowledge as predicated on 'experience-near' based on living with and becoming part of the indigenous community through participating within the practices of a community to whatever extent possible. Multi-sited ethnography was therefore criticised by other social scientists. Hage (2005) suggested that multi-sited ethnography is often applied 'mechanistically' without critically discussing how the research is multi-sited especially given the methodological dominance of 'the field' being traditionally defined as a geographically fixed location by anthropologists and other ethnographers. Whilst the field concept has evolved more recently to include non-traditional sites such as the internet, most ethnographies still have this geographic boundary to inform and reinforce the research scope. Since the multi-sited ethnographer may be seen as 'de-territorialising' their field, this may limit the claims such ethnographic research may make about specific groups. Here we need to address how the multi-sited ethnographer is seen as capable of being located with these groups so as to undertake participant-observation. This will entail establishing what Geertz (1988) described as 'being there' in this case. Multi-sited ethnography complicates this process as the ethnographer must move between its sites and must limit the length of time spent in each one. However, there is no guarantee that longer time spent in the field will necessarily create better knowledge about the local contexts studied nor does a shorter length of time necessarily mean inadequate 'nearness' of ethnographers to participants of understanding their ways of living. Instead, it is possible to articulate and justify the extent to which multi-site ethnography in this case could still enable close observations, and some participation, in the practices of people with dementia and their informal carers. 'Nearness', is established through carefully describing how and why I selected specific sites as ethnographic cases and how the accounts I produce in these settings reflect a shared way of living. The multi-sited ethnographer must therefore describe how the process of selecting sites can constitute a comparably complete ethnography by describing and evaluating analytical connections between the practices of different people with dementia and their informal carers living in the community using assistive technologies and telecare.

### 3.5.2 Focusing short-term visits across local sites

Multiple sites, did obligate me to divide and limit the time I spend with each participant. People with dementia and their informal carers may also have limited availability or find extended periods of observation intrusive and demanding to fit in with their lives. As seen in the previous section, I also need to grapple with how time constraints affects how and what claims could be made when the principle of extensive fieldwork is altered. To address this methodological challenge, I critically draw on Knoblauch's concept of a 'focused ethnography' (Knoblauch 2005) and Pink and Morgan's (2013) concept of short-term ethnography. Focused or short-term ethnographies are concepts used to describe an ethnographic methodology based on limited fieldwork predicated on 'data intensity' and 'time intensity' rather than 'experiential intensity' (generated by extensive time in the field) (Knoblauch 2005; Pink and Morgan 2013). Knoblauch acknowledges his debt to the early ethnographies in sociology (*cf.* Goffman 1952; Glaser and Strauss 1967) that aimed to focus on particular aspects of one's own society rather than a holistic account about an Other's way of life. Focused and short-term ethnographies may be informed by the ethnographer's previous knowledge about the setting that aids the ethnographer's method for attending to a particular phenomenon. However, drawing on theory and other accounts to inform such focused fieldwork, does not necessarily afford the ethnographer opportunities for reflecting on this accumulated knowledge and questioning its legitimacy or relevance for examining the practices of people with dementia and their informal carers using assistive technologies and telecare. Knoblauch's reliance on positivist stances about collecting data about a particular group, suggests he may have more in common with the epistemological concerns of conventional early and mid-twentieth century ethnographers that local knowledge is 'out there' to be collected. However, his premise about 'data intensity' does hold water. While conventional ethnographers may take months to develop a sense of a location, many contemporary settings such as here, community-based technology-enabled dementia care will impose limits to the amount of feasible time for carrying out fieldwork. Conventional ethnographers who spend months co-located in a single-site with participants may be enabled to develop general field notes about the day or week. The multiple sites of this study obliged me to spend extensive time away, between, and sometimes co-located with one person with dementia or another. The narrow research interest in technological interventions in dementia care for this study seem better-suited to suits a focused ethnographic approach. However, this focus must be broadened by examining how assistive technologies and telecare 'fit' into the lives of people with dementia living in the community. The tension for a focused ethnography predicated on short-term fieldwork, therefore, is balancing

attention to participants' everyday lives with the more focused concern attending to their practices with assistive technologies and telecare.

### 3.5.3 Collaborating

The final challenge considered was managing research relationships with people with dementia and their informal carers. As described earlier in this chapter, the potentially limited time spent sharing spaces with participants may have affected how far I could create and maintain meaningful relationships with them. Limited or socially strained relationships may affect the quality of data and what I can access during fieldwork. The gap in relationship between researcher and researched is reinforced when opportunities to generate rapport are diminished. In this case taking a 'collaborative' ethnographic approach may help address the limited opportunities to establish trust and build rapport with people with dementia and their informal carers taking part in this study. Lassiter's conceptualisation of 'collaboration' in ethnography is based on sharing authorship with participants (Lassiter 2005). Whilst authorship is not appropriate for this study due to including multiple sites and people with dementia and their informal carers, ethnographic collaborations can still be explored in diverse ways through attending to both people with dementia and their informal carers' perspectives. Dementia research continues to commonly exclude people with dementia as participants even when the phenomena of interest is directly related to choices that affect them (Gibson *et al.* 2004). Research that does include them may limit their ability to take part based on using retrospective interviews as method for eliciting their experiences despite people with dementia frequently having trouble recalling information and ordering the information into a narrative. People with dementia may also have aphasia which further limits their ability to vocalise their experiences. Ethnography that includes people with dementia as participants is therefore *already* collaborative compared to alternative methodologies and practices exercised by other health and social researchers. However, collaboration is a contestable term in practice if not in principle. How I articulate and demonstrate collaboration or why collaboration is difficult may also help me better understand the practices of people with dementia and their informal carers with assistive technologies and telecare. The test for collaboration comes through how I account for what collaboration meant within fieldwork and analytical practices more than methodological conjecture. I came to test collaboration as a concept and set of practices as I worked to engage with the lives of participants for ACCOMMODATE. Yet this would come later in the study. Collaboration for ACCOMMODATE began when I embedded my ethnographic activities and interests within the ATTILA trial networks, design, settings and participant pool. My embedding my ethnographic work with ATTILA helped shape not only my relationship

building with ACCOMMODATE participants but to refine my ethnographic approach as I developed my understanding of the field and its boundaries.

#### 3.5.4 Embedding this study in ATTILA: Setting the boundaries of the field

A crucial element for any study, but perhaps especially an ethnography, is how to determine the limits of what to examine, to set boundaries, for their field and how they interacted with the people, spaces and objects in it. Ethnographers traditionally set boundaries around the places they inhabited to co-locate themselves with the people they studied. Contemporary ethnographers often rely less on a geographic boundary than one constructed through a particular substantive interest or analytical framework. Multi-sited ethnographies often result from such work where boundaries may involve following mobile objects through a globalised market or people as they migrate. Working, or embedding the ethnographic work, with and within ATTILA helped to set the boundaries of the field in a similar way to this study. However, I came to realise that having to embed and also to dis-embed at different points in my fieldwork meant that the boundaries of my study did not remain fixed or impervious and I had to actively, review and reset them.

The particular term I use here, 'embedded', draws on previous work from Poland (e.g. Horton, et al 2010; Murdoch et al. 2010) and which framed the terms of my studentship and formally linked to ethnographic contributions to studies in public health research, e.g. Lewis and Russell (2011), medical anthropologists, who referred to 'embedded ethnography' to describe an approach where ethnographers 'embed' themselves into the systems, processes and networks of an organisation or project including a research project, so as to provide ethnographically-informed insights into the collaborative work entailed in such studies. The Lewis and Russell study involved the ethnographers working alongside a public health authority in the Northeast of England to evaluate a smoking cessation programme. 'Embedded', therefore, refers to practical and analytical processes that shaped how the ethnographer does or does not take part, in their collaborating partner's organisational processes whilst also maintaining some sense of independence to critique these processes or offer alternative interpretations of evaluations. However, Lewis and Russell's approach did not detail or analyse the nuanced context-influenced reasoning for varying in how and why ethnographers might embed or distance themselves from their collaborator or organisational context over the course of a project. Making explicit the relationship between ethnography/ethnographer and a trial was to be explored in this context and my ethnographic work provided a basis for contextualising and applying these principles in an ethnography embedded within a clinical trial.

ACCOMMODATE activities could be seen as initially being embedded within ATTILA so that I could learn about assistive technologies, telecare and dementia by drawing on ATTILA team colleagues' diverse disciplinary and professional backgrounds. Researchers and clinicians involved in the management and day-to-day work of ATTILA talked with me about each of these subjects as I took part in teleconferences and occasional face-to-face meetings. This also enabled me to recruit relevant and interested people to ACCOMMODATE by inviting people with dementia and their informal carers who were taking part in ATTILA to also take part in.

At this point, recreating these potential relationships as opportunities to realise ACCOMMODATE required me to work to build and sustain my own working relationships with members of the ATTILA trial research team. I could not just join teleconferences or meetings with members of the research team and then sit passively. I needed to speak up when a member of the ATTILA team asked me questions and to be seen to ask for clarification when I did not understand meeting topics. I now needed not to be seen as distancing myself from the work of my ATTILA colleagues. I wanted both to understand how ACCOMMODATE might fit within the wider ATTILA issues and investigations, and also to show that I would be actively building these connections. Over the first year of my studies, I therefore discussed my proposed study design with members of the executive team to demonstrate how I envisioned ACCOMMODATE drawing on ATTILA resources and how, in turn, ACCOMMODATE might reciprocate with contextualising data to provide me with initial insights into local practices of participants and ways they appeared to be using the interventions. I also discussed ongoing recruitment issues (common to most trials) with research workers about and as I came to gain my own knowledge of local settings, could provide them in turn with some possible suggestions for alternative routes or approaches to recruiting additional participants from community-based services.

The ACCOMMODATE design also required me to negotiate and compromise with various organisational procedures and regulations (ATTILA, social and health services, my university and ethics committees), at times potentially conflicting my own ethnographic sensibilities, and leading me to question my own and others' beliefs about living with dementia. The time invested in developing and sustaining these collaborative relationships helped me to further 'embed' ACCOMMODATE in ATTILA. The more time I spent working with people, it appeared, the more time they were likely to invest in ACCOMMODATE.

However, as I shared more information with the ATTILA team during these meetings and other exchanges, I began to realise how my relationships with them shaped ACCOMMODATE. Our arrangements appeared more than just collaborative but as shaping my work predominantly within their frameworks. I was initially using their language and concepts to articulate my ethnographic interests, so embedding not only my activities and actions, but also my intellectual focus on the practices of people with dementia and their informal carers using assistive technologies and telecare. But to properly observe as an ethnographer I could not continue to mainly embed ACCOMMODATE within ATTILA in these ways, I could not hope to describe the usual practices of people with dementia using assistive technologies or telecare. Nor should I have wanted to impose these terms within fieldwork settings. As all participants were recruited from NHS Trusts, memory clinics or social care providers, the participants represented groups of people with dementia already known to the respective social or health care systems. Instead, my journey, experienced and represented here as more transformative, needed to be enabled to illuminate – potential and conceivable practices for *any* person with dementia or informal carer and to be open to the myriad reasons for why people with dementia or informal carers use or did not use them with assistive technologies and telecare. In other words, ACCOMMODATE needed to highlight the diversity of potential practices, to reveal imaginings of how people with dementia use technologies, and to question and explore taken-for-granted assumptions about technology-enabled dementia care. Although one interpretation of my ‘embedded’ ethnographic activities might be that they limited this study with people with dementia and their informal carers, an alternative way to see this is that all studies have to define their scope, drawing boundaries, real or imagined, to define what researcher can attend to during the life of a project. My relationships with the ATTILA team, their activities, concepts, and locations, provided this basis to define the scope of ACCOMMODATE. It served as a crucial starting point for focusing my initial thoughts about living with dementia, how I understood ‘care’, and what it means to ‘live in the community’. It did not ultimately distract from the ‘life’ of my ethnographic insights nor dull my ethnographic sensibilities. It helpfully shaped my field, and direct my actions within the complex of arrangements of characters, locations and things in setting the early conditions through which I observed and the people I interacted with during this study. However, it also opened my work to enable me to raise further questions and critiques. It therefore strengthened my own interpretations of what I observed or made me re-think whatever new insights I thought I uncovered. It put my work as an ethnographer into a particular perspective and knowing I had additional obligations to the ATTILA team gave my work additional purpose.

Although embedding could be seen as constraining and limiting how I built relationships with people with dementia and informal carers, it also provided additional opportunities to learn about technology-enabled dementia care from other professionals and practitioners. My decision and active work to embed within ATTILA established and specified a methodological and analytical boundary for this study, which I was able to critically review as I built further relationships in the field. I encountered limitations to how and what I could examine during fieldwork yet I could also draw on alternative experiences and expertise to help situate what I later learned through observations and conversations with participants.

### 3.6 Chapter Summary

This chapter outlined key considerations in justifying the methodological choice of ethnography to examine how practices of people with dementia and their informal carers using assistive technologies and telecare may affect experiences of living with dementia, meanings and practices of care, and relations with the home and community. To address this research problem, I suggested ethnography as a research methodology based on its focus on the ethnographer's reflective and interpretive accounts resulting from sustained participation and observation in the everyday lives of people with dementia and their informal carers in their home, as a socially and physically bounded research field. Fieldwork will be used to produce thick descriptions where the ethnographer not only considers substantive analysis but also methodological reflections about how these analytical claims and connections are made. However, I argued that conventional approaches to ethnography were ill suited to the research context of this study. Three methodological challenges were identified for this study compared to conventional ethnographic work: geographically dispersed population of people with dementia affects how I immerse myself in a field, participants may have other obligations that may affect how long I can sustain contact with them, and how limited interactions and symptoms of a person's dementia may affect the quality of the relationships created with participants in this study. To address these methodological challenges, contemporary concepts from ethnographers in the social sciences were adapted to the key characteristics of this study: multi-sited, focused, short-term, collaborative and embedded ethnography. These adaptations contributed to a novel ethnographic approach for this study that could address complexities of contemporary settings, here specifically, to examine the practices of people with dementia and their informal carers using assistive technologies and telecare.

# Chapter 4: Data Collection and Analysis

## 4.1 Introduction

Working with a randomised controlled trial created novel experiences that shaped how I attended to these processes. This study was not the first time a qualitative study worked alongside or as part of a trial. Collaborative, interdisciplinary research is becoming a crucial requirement to investigate social, environmental and health concerns for understanding how populations and their constituent local contexts may reinforce or contradict each other. More recently, this has resulted in qualitative research being used to supplement research of complex interventions in health and social care. The process and ways that qualitative methodologies are used vary based on the requirements of the study. However, the systematic review of Lewin, Glenton and Oxman (2009) suggests eleven ways that qualitative research is included in trials by helping to develop and refine the intervention before the trial commences, unpacking the processes of implementation of the intervention during the trial, or explaining variations in effectiveness within the trial's sample. Even with the rise of qualitative methodologists working within these complex trial and evaluations, there are still few examples that use an ethnographic approach. This may be due to ethnography still being poorly understood by health and social care professionals. However, anthropologists may provide insights into health and social care processes and experiences of living with disease whilst working in a multidisciplinary team (Lambert and McKeivitt 2002).

This chapter examines key processes of the study such as: accessing participants from the ATTILA trial as an 'embedded' researcher, recruiting people with dementia and their informal carers from said trial, carrying out participant-observation as a method of ethnographic fieldwork for collecting qualitative data, and the iterative processes of analysing this qualitative dataset.

## 4.2 Negotiating access to the trial

A common practice of all qualitative research is how the researcher contacts people that inhabit or meet the criteria for their chosen area of inquiry. Using personal contacts for negotiating access or entry into a particular cultural group or location is common practice for ethnographers (Bernard 2011). In order to recruit participants with dementia and their informal carers into this study, the supervisors of the study (Professor Fiona Poland and Professor Chris Fox, University of East Anglia) suggested that

I contact the manager of the ATTILA trial to discuss how this ethnographic study may benefit the trial. The supervisors of the study were also listed as principal investigators on the trial and helped write its protocol (Leroi et al. 2013).

I suggested to the trial manager that an ethnographic approach would add a qualitative dataset to complement the interpretation of the statistical analyses from their findings, a rationale previous research also identified (Gibson et al. 2004; O’Cathain et al. 2013). Whereas the research workers of the trial collected data through a series of validated questionnaires and a ‘technology checklist’ directed to the person with dementia and his or her informal carer, an ethnographic study could observe the actual practices of whether and how people with dementia used assistive technologies and telecare. The trial team agreed nominally with this approach at first whilst

For the first year of the study, I attended quarterly ‘research worker meetings’ where all of the local ATTILA research workers discussed their ongoing travails with recruitment in local authorities and the local NHS Foundation Trust. These meetings also covered any required changes to the protocol or questionnaires the trial manager, a principal investigator or a research worker identified. These meetings were always followed by informal drinks at a local pub, these informal gatherings after a full day of discussing the work of the trial helped me create rapport with the trial manager and the local research workers as a form of ‘impression management’ (Bernard 2011). I also attended two monthly teleconferences throughout the first three years of the study: one for principal investigators and the second one for the local research workers. During the fourth year of the study, there were no longer any teleconferences for either principal investigators or the research workers. When I asked the trial manager why there were no more teleconferences, she explained they were no longer needed because they finished recruiting participants into the study. It is beyond the scope of this thesis to reflect or draw conclusions on the material discussed during these teleconferences, however, the teleconferences and quarterly ‘research worker meetings’ allowed me to have a presence with the wider ATTILA trial team.

These meetings introduced me to the concepts of ‘assistive technology’ and ‘telecare’ and also what types of technologies people with dementia received in the trial. I used these meetings with the local research workers to frame further discussions as I planned the research design for this study. The research protocol was submitted to the supervisors of this study, the trial manager, principal investigators of the ATTILA trial, and the local research workers for their comments. The supervisors of this study provided the most robust and constructive comments and critiques. After several drafts

of the protocol, the trial team members approved the study. After the trial team approved the study design, the work was submitted to the local research development office at the University of East Anglia for their approval to provide indemnity insurance. The research development team also approved the study design. After all teams approved the study design, then I applied for ethical approval from a research ethics committee of the NRES, the group of research ethics committees the NHS oversees.

Here I highlighted the initial processes for how I made contact with the ATTILA trial team and eventually received permission to conduct an ethnographic study alongside them. In particular, I described how I attended meetings and teleconferences with two subgroups of the trial team: the principal investigators and the local research workers who collected the data. I attended these teleconferences, meetings and informal gatherings after to generate rapport with the ATTILA team – especially the trial manager and local research workers with whom I intended to work with on this study. These demonstrated specific attempts to ‘embed’ the qualitative approach of this study into the processes of the ATTILA trial from the earliest design stages.

However, I did not always ‘embed’ the processes of this study within those of the ATTILA trial team. ATTILA trial team members and I often intentionally differentiated how we carried out our studies so as to address methodological, ethical or practical issues we saw as relevant to the situations we experienced during each respective study. Yet these spaces and times where we acted to disassociate were not all or always permanent nor removing the work of each study completely from the work of the other study. Rather, these observed differences in my separating my spatial and temporal relations with ATTILA tracked instances and processes of ‘disembedding’ ACCOMMODATE.

## 4.3 Ethical commitments

As with any research study, there are ethical considerations which require careful reflection as to how the researcher will ensure the dignity of research participants in their practice whilst mitigating the potential for harm. This section considers the ethical commitments and procedures for carrying out ACCOMMODATE.

### 4.3.1 Identifying and addressing ethical and safety dilemmas for ACCOMMODATE

Here I describe the ethical and safety dilemmas encountered during this study and how they were addressed. I particularly consider the legal and ethical requirements for assessing the mental capacity

of participants, processes for informed consent, methods for providing anonymity and confidentiality, plans to ensure participant safeguarding.

#### 4.3.1.1 Adults Lacking Mental Capacity

This study collected data from people with dementia who lacked mental capacity. As described in the Mental Capacity Act, research can only be justified with people who lack mental capacity if the research is directly about the condition in question. I chose to directly involve people with dementia as participants, because it is critical to understand how their practices with assistive technology and telecare can be seen to support their independence. As a person expresses more severe symptoms related to their dementia, there may be more pronounced issues with memory loss and other cognitive functions. Whether and to what extent assistive technologies continue to address these challenges needs to be understood. The exclusion of people with dementia in favour of a reliance on the perspective of carers and health professionals is also an unethical practice because it marginalises their experiences of their own health and wellbeing (Nygård 2006).

For this study, I assessed all adult participants for capacity during each visit. I began by assuming each participant had mental capacity unless they demonstrated two characteristics: 1) the presence of a mental or learning disability/long-term condition, and 2) evidence that the person with the disability or condition could not retain information long enough to make a decision *or* lacked awareness and understanding of what was expected from them if they participated in the study. I informally carried out each assessment through conversing with each participant at the start of each field visit and before I sought their informed consent. I noted the results of each person's assessment in my fieldnotes. If I decided that the person with dementia lacked mental capacity, then I asked the carer to sign privately a consultee declaration form which enabled them to act as a consultee. Having the informal carer sign the consultee declaration form allowed the person with dementia to take part in ACCOMMODATE. However, I decided to involve the person with dementia in the recruitment process even if they lacked mental capacity, by asking for their assent to take part. I took the view that relying on mental capacity as the only means to satisfy a person's ability to participate in ACCOMMODATE problematic seemed to limit autonomy and self-fulfilment to measures of cognisance. For this reason, I asked people with dementia for their assent. My decision to seek assent from people with dementia set ACCOMMODATE apart from ATTILA which relied solely on informed consent and consultee declarations when appropriate. This illustrates an early example of 'disembedding' to differentiate the ACCOMMODATE principles from those of ATTILA.

#### 4.3.1.2 Informed Consent

Tied closely to mental capacity issues, informed consent presented another ethical dilemma for ACCOMMODATE. Research in dementia care may include particular challenges to conventional informed consent processes. People with dementia experience progressive cognitive decline which challenges their ability to provide their own informed consent. Informal carers may also fear taking part in studies, since they may worry about losing access to current health or social services if they do not participate. On the other hand, they may expect additional services as a benefit of their participation. Nonetheless, informed consent is a critical process to ensure people can choose to take part voluntary in research. For ACCOMMODATE, I decided not to treat informed consent as accomplished in a single interaction at the recruitment stage. Instead, I chose informed consent parallel processes as this reflected the longitudinal design intrinsic to most ethnographies. In practice this meant that I sought informed consent from each participant during each fieldwork visit (Dewey 2007). All informal carers had to give informed consent to participate in ACCOMMODATE. However, as I mentioned above, the person with dementia may lack the mental capacity to provide informed consent. When the person with dementia lacked mental capacity, then I asked the carer to act as a consultee considering whether taking part in ACCOMMODATE reflected the best interests and wishes of the person with dementia. If either participant had difficulty with physically signing the forms, then they could provide verbal consent by stating their name and the date of the visit which I could record on a dictaphone. However, no participant required this option to give their consent I reassured people with dementia and their informal carers that choosing to or not to take part would not change the current level of health or social support that either of them received nor would it jeopardise their participation in ATTILA.

#### 4.3.1.3 Anonymity and Confidentiality

I treated all data as highly sensitive and personal information requiring high-level security measures, I was therefore the only person who handled raw data with personal information or identifiers. Whenever I discussed incidents or interactions arising from fieldwork with ATTILA investigators (including academic supervisors) I only referred to anonymised data. To ensure strictest confidence yet also attend to the nuances of each participant's life, I gave each participant in the study a pseudonym. Pseudonyms presented an opportunity to anonymise the identity of a person yet they also allowed me to present and link these assumed names with a minimal amount of personal information, such as their (former) occupation, gender, ethnic or cultural background, and location of the individual is provided to contextualise the data. Every time I wanted to present this data within a case, I justified its relevance with the supervision team (FP, CF). This approach should allow readers to

understand some of the nuanced practices and meanings of participants yet ensure readers could not identify participants from information reproduced in any written reports or publications. I stored transcribed fieldnotes and anonymised interview transcripts on a password protected PC with raw, untranscribed data stored securely in the School of Health Science (HSC)'s Postgraduate Research Office at the University of East Anglia. All data will be stored in the HSC archive for ten years after the study ends, then it will be destroyed. These processes ensured that for the 'life' of the project and the post-study period directly afterward, participants' personal data would remain secure, anonymised and confidential.

#### 4.3.1.4 Participant Safeguarding

Safeguarding is the practice of protecting vulnerable groups from potentially harmful threats to their emotional, physical, mental or spiritual wellbeing. Prior to fieldwork, I was concerned people with dementia may feel uncomfortable and agitated with my presence. As they may not have remembered who I was or why I was there. I worried that 'being there', embedding myself into their lives and practices, would distress the people I wanted to learn from, to understand. I decided that if I observed or the informal carer or person with dementia told me that either of them unhappy or uncomfortable, then I would check whether they wished to end the session. Although the maxim of 'do no harm' is enshrined as a key ethical principles in health research, I wanted to ensure participation in the study did not affect the wellbeing of participants in this study at any time. However, participating in ACCOMMODATE would likely not contribute any additional stress or trauma in the lives of either people with dementia or their informal carer. I wanted to learn from them. I hoped that my genuine interest to learn about their everyday lives and how assistive technologies and telecare fit within it promoted a greater familiarity and sense of trust. However, if research participants had any concerns or queries about the research, then they could contact my primary supervisor to discuss them. Her contact details appeared on the participant information sheets (Appendix I). Participants could also withdraw from the research at any point in time for whatever reason. If I heard or witnessed any behaviour or actions which appeared abusive or a participant disclosed an incident of abuse to me, then I would notify a member of my supervision team and contact the local ATTILA research worker. The ATTILA researchers worked with members of the local authorities and had professional clinical backgrounds in psychology or occupational therapy. The professional relationships and clinical background of the ATTILA research workers would help signpost me to the relevant person at each research site's Council with Adult Social Service Responsibility. If the abuse or situation was an immediate emergency for the person with

dementia or their carer, then I would contact the relevant local authority's abuse hotline or 999 depending on the severity of the situation.

#### 4.3.2 Applying for ethical approval and research governance

Although I previously set out the potential ethical issues I may encounter, this study also required a favourable outcome from a National Research Ethics Committee 'flagged' to handle research involving people lacking mental capacity. Applications for ethical approval are managed through a central system called the Integrated Research Application System (IRAS). The IRAS form involved answering predefined questions about the study in order to populate further questions tied to the specific design of your study, e.g. recruiting human subjects or using human tissue samples would generate different questions designed to determine the appropriateness of the study for identifying and addressing potential ethical issues. The ATTILA trial received their ethical approval prior to the start of ACCOMMODATE. Although I suggested submitting an abridged protocol of this study as a 'substantial amendment' to the initial IRAS application for ATTILA, the trial manager decided it would negatively affect the progress of the trial. Substantial amendments that alter the study design, as adding an ethnographic study would to ATTILA, meant that recruitment and data collection for the trial could not progress until the REC provided their outcome or 'opinion' on the suggested amendment. Therefore, a separate IRAS application was required for this study.

In order to gain ethical approval, a research ethics committee (REC) needed to review the relevant materials for this study: IRAS application, the study protocol, and additional supporting documents such as CVs for the investigators, topic guides, and evidence of public involvement or consultation. In the study design, I decided to include people with dementia who may lack mental capacity, which requires the evaluation of the ethical issues and how they are addressed by a 'mental capacity flagged' REC. People who lack mental capacity can only be included as research participants if their inclusion justifiably improves the rigour of the study. Current guidance suggests that people with dementia may lose their capacity to make informed decisions as their dementia progresses into later stages (Alzheimer's Society 2015a). Yet the progression of a person's dementia may also change their care needs, behaviour of the person with dementia, and affect their relationships with other people (Alzheimer's Society 2015b). This may arguably affect their practices with assistive technology and telecare especially if they are provided for supporting or addressing a specific dementia-related functional capacity or everyday task.

I attended this REC meeting in-person alone to answer any questions that the REC may have had about the study. Since the ATTILA trial team and the research and development team at the University of East Anglia already reviewed the study protocol and supporting documents, I thought the experience would be rigorous yet the REC would give me a 'favourable opinion' or suggest minor amendments. The result of the meeting was very different from what I expected. The REC asked questions about the methods, 'Is there another way you can collect data without going into their homes?' The REC also expressed concerns about whether the homes of people with dementia in the study were thoroughly 'risk assessed'; they suggested that a clinically-trained colleague should visit participants with me. They argued that I did not have enough experience working in 'dementia crises situations' as well. At the end of the meeting, they asked me to leave the room to deliberate. When I returned to the conference room, they told me the study received an 'unfavourable opinion'. However, they also said the protocol was 'one of the best academic protocols they had received'. This either suggests that very few academic studies receive ethical approval from this particular REC or, perhaps more likely, their opinion seemed based on what their assessment of me as an unsuitable researcher to carry out the study rather than the study itself. The REC appeared to imagine the research for this study as a clinician with previous work experience in dementia care. However, this undermines what I, as a non-clinically trained social scientist, may observe and the alternative interpretations or insights they may provide to understand the practices of people with dementia and their informal carers using assistive technologies and telecare. Non-clinically trained medical sociologists and anthropologists have researched a wide range of illnesses and health care delivery for decades. I reapplied with the supervisors of the study to another REC with a ten-page letter which addressed the issues the first REC identified. All three of us also attended the REC meeting this time as well. This REC approved the study (NRES East of England 15/EE/0015). Appendix IV includes copies of all REC opinion letters.

After the study received ethical approval, I thought that I could immediately start to recruit participants for this study from people already taking part in ATTILA. However, the trial manager suggested that I contact one of the NHS Foundation Trusts that identified participants for the trial about research governance and access. She was not sure whether I needed governance approval as well, since I would only recruit people from the trial rather than directly from health or care services. I spoke to one of the NHS Foundation Trusts where one of the local research workers was based. I explained that I recently received ethical approval and that I was checking to see whether I needed to have a 'letter of access' from them. I argued that I would not need to have NHS staff identify prospective participants, personally search patient databases for appropriate participants, nor would I use NHS facilities to conduct the research; the key characteristics for determining whether 'NHS

management permission' or research and development approval is required (Health Research Authority 2017). However, the research governance lead argued that I needed approval from them because the people I intended to recruit were 'patients'. I tried to persuade the research governance that they were people in dementia living in their own homes – it would be inappropriate to suggest that they were always patients in these circumstances any more than a person without dementia. Living with dementia should not mean the person was always defined by their illness. However, the research governance officer explained that I could not proceed with my study unless I received approval from the Trust. This led to applying for research governance access at four different NHS Foundation Trusts in the East and Southeast of England. Each different site required additional information even after the 'lead Trust' approved the research and issued a research passport.

The total length of time from when the initial IRAS application was submitted until the final NHS Trust provided a letter of access was twelve months.

The research ethics and governance process identified distinctions between how research development teams, RECs and I defined the study and the people taking part in it. The initial REC argued that my relative inexperience working with people with dementia made me unsuitable as the researcher for this study. The experience highlighted how RECs prioritise certain experiences when conducting research with people with dementia that require clinical training. Discussions and disagreements with research governance offices at each Trust also highlighted how they differently viewed access to people with dementia for research: they had control because they were patients at the Trust. However, I questioned the claim of people with dementia living in their own home as perpetual patients because this medicalised the everyday life of each person due to a dementia diagnosis. If we accept the role of assistive technologies as 'enabling independence' (World Health Organisation 2004), then how do people with dementia enact independence when imagined as a 'community' of patients? Each barrier that I encountered with the trial team, individual NHS Trust and R&D department exemplifies how I also began to view and understand the lives and practices of people with dementia and their informal carers in ways which did not match with these other teams and organisations. It shows how I continued to disembed my procedural activities and so disembedded my ethnographic sensibilities from the more narrowly-defined approaches of the NHS Trusts contacted for ACCOMMODATE and the ATTILA trial team. Yet I did continue without fixed aims along an established disembedded trajectory of thought and action. Recruitment provided an opportunity to discover a more nuanced form of embedding and disembedding for ACCOMMODATE.

## 4.4 Sampling strategy and recruitment

To ensure that I could learn about the meaning and practices of people with dementia and their informal carers using assistive technology and telecare, I needed to ensure that my sampling strategy could account for the potentially diverse range of practices and underlying relationships which could affect participants' practices. Yet I had to operationalise this strategy to recruit prospective participants. Here I set out my sampling strategy and process to recruit people with dementia and their informal carers taking part in the ATTILA trial into ACCOMMODATE.

### 4.4.1 Sampling strategy

For ACCOMMODATE, I selected a purposive sampling strategy informed, in part, by inclusion and exclusion criteria from ATTILA as a starting point. As all participants in ACCOMMODATE also took part in ATTILA, this meant they necessarily also fulfilled these same criteria. The inclusion and exclusion criteria are reproduced here from the published ATTILA protocol (Leroi et al. 2013) to highlight the characteristics required to participate in both studies:

#### *Inclusion criteria*

People able to take part were:

- People with dementia or evidence of cognitive difficulties significant enough to suggest the presence of dementia, both with and without capacity, and their carer who are participating in ATTILA;
- Who had been offered the opportunity to use assistive technology and telecare equipment;
- Fluent in English.

#### *Exclusion criteria*

People ineligible to take part were those who are:

- Unlikely to comply with follow-up, e.g. because of an unstable medical or psychiatric condition;
- Participating in another clinical trial (i.e. not ATTILA) involving an intervention for dementia;
- Having an urgent need for a care package due to immediate and severe risks to themselves or others.

These criteria may appear as relatively simple to determine whether a person could participate in ATTILA and ACCOMMODATE. However, I also wanted to explore the variety within these criteria as well. Although all people in the study may experience cognitive difficulties or memory problems, how

did they differ in severity or frequency? More importantly, how did this perceived range of expressed symptoms affect their everyday lives? The criteria also do not elaborate on the potential range of technologies offered to each participant. What kinds of technologies were offered? By whom? Therefore, I chose to use these categories to frame a more specifically purposive sampling strategy to inform ACCOMMODATE.

Purposive sampling strategies involve selecting participants for a study based on a set of analytically relevant concepts to explore how variation within each concept may influence the researcher's phenomena of interest. The purpose of this sampling strategy was not to focus on representative experiences. In other words, I could not use information from the participants in this study to suggest *all* people with dementia and *all* informal carers use assistive technologies in ways I later illustrate.

To constitute a contextually-diverse yet relevant study sample where I could observe potential insights into participants' practices with assistive technologies and telecare, I chose three concepts to inform the study's purposive sampling strategy based on themes identified from my literature review: 1) the level of severity of the person's dementia as described by ATTILA research workers; 2) the type of relationship between the carer and person with dementia; and 3) the different assistive technologies and telecare equipment provided as an intervention. These three concepts were chosen because they are likely to be linked to different types of participants' experiences of everyday activities.

The severity of a person's dementia (e.g. mild, moderate, severe) may impact their ability to perform every day activities, whether self-care practices, communication, mobility, or leisure. Therefore, it is conceivable that as a person experienced more frequent or severe expression of their dementia-related symptoms that it could influence their independence and daily life. The composition of different familial or social relationships may also suggest social factors which could influence participants' practices with technologies.

Whether the person with dementia lives alone and has limited support to complete activities, co-habits with a spouse who may be affected by their own age-related illnesses or disabilities when providing care, and how frequently a person with dementia has social contact with their informal carer may influence how assistive technologies and telecare 'fit' in their lives. People with dementia who have regular support from a live-in informal carer may have quite different experiences from another

person with dementia receiving informal care from a neighbour or family member who only checks in sporadically.

I chose to examine a range of different assistive technologies and telecare rather than any single piece of equipment as many products were offered across different ATTILA sites. Each product could potentially require different types of interactions from people – whether the person with dementia and/or the informal carer. Examining how people with dementia and informal carers use or opt not to use different types of assistive technologies and telecare at home will provide information about the relevance of specific technologies for supporting people with dementia. Observing individual practices with these technologies could also provide insight into the place of technology-enabled care broadly in community-based dementia care.

#### 4.4.2 Recruitment

To recruit participants into this study, I collaborated with local ATTILA research workers who collected data across three areas: ‘Metropolitan’, a major urban area in England, East ‘County’, a large county located in the East of England, and ‘Coastal Counties’, two counties with a seaside border in the East of England which share a single NHS Trust for adult mental health services. The boundaries for each site also corresponded to the geographic area for a single ATTILA research worker who bore responsibility to recruit new participants and collect data within the region. Such boundaries reflected the boundaries of a local authority or NHS Foundation Trust serving the area’s population.

Each area covered several counties or metropolitan boroughs in east and southeast England. I selected Metropolitan, East County and Coastal Counties because the each represented a mix of urban and rural populations with areas of both economic wealth and deprivation (Office of the Deputy Prime Minister 2011).

For ACCOMMODATE, I recruited prospective participants with three ATTILA research workers responsible for recruiting participants and collecting longitudinal data from them in Metropolitan, East County or Coastal Counties. This process for embedding ACCOMMODATE recruitment within ATTILA involved four steps:

1. Collaborating with an ATTILA research worker to identify prospective participants
2. Meeting prospective participants during their next planned ATTILA follow-up visit
3. Seeking informed consent or consultee declaration from carer and person with dementia

4. Continually renegotiating informed consent or consultee declaration for each subsequent visit during fieldwork

#### 4.4.2.1 Collaborating with ATTILA research workers to identify prospective participants

To identify prospective participants, I called the research workers at each of the three ATTILA sites every week from August – October 2016 to see whether they had any follow-up visits approaching soon. If they had a follow-up visit coming up soon, then we discussed how the person with dementia and carer dyad ‘fit’ with the purposive criteria for this study. Matching each new case was an iterative and evolving process, since it required recognising and distinguishing the differences between participants already taking part in ACCOMMODATE from others I invited to participate. At the beginning of recruitment, I possessed the most flexibility to recruit the first available participant from any of the ATTILA sites. Recruiting people with dementia and informal carers was most flexible at the beginning of the recruitment process as the widest possibility of variation still existed. Once I identified prospective participants with the ATTILA research worker, the ATTILA research worker asked the person with dementia and his or her carer whether they were potentially interested in taking part in ‘a small qualitative study linked to the ATTILA trial’. If the potential participants expressed interest, then the ATTILA research worker invited me to attend their next planned follow-up meeting.

#### 4.4.2.2 Meeting prospective participants during the next planned ATTILA follow-up visit

If a potential participant pair (person with dementia and their informal carer taking part in ATTILA) identified with the ATTILA research worker gave their permission for me to attend the next scheduled ATTILA follow-up, then I would travel with the research worker to the home of the person with dementia. During this visit, the ATTILA research worker would ask the informal carer and, sometimes, the person with dementia questions from a battery of validated questionnaires. After the ATTILA research worker finished their questions, then I would provide participant information sheets (Appendix I) to both participants. Note that even if the person with dementia was identified as lacking capacity by the ATTILA research workers, the information was still given to them so as to help inform their choice to consent/assent for ACCOMMODATE. I also used this initial face-to-face contact to discuss the participant information sheet with each prospective participant. This allowed each prospective participant the opportunity to ask questions directly to me rather than having to recall such information later. After I exchanged contact details with the prospective participants. I told the informal carer and the person with dementia that I would ring them in the next two days with the

number provided on the participant information sheets to set up another meeting if they were interested in participating.

The following fieldnote excerpt from the recruitment visit with the Stewarts shows an interaction between the ATTILA research worker (Sarah), the carer (Sally), persons with dementia (Michael and Mary) and I during these initial visits. It highlights the usual process for how I recruited people with dementia through accompanying the ATTILA research worker who introduced me, then talking about my study<sup>7</sup> with prospective participants after the ATTILA research worker completed the validated questionnaires with them.

*Sarah and I arrived at the Stewarts' home just before 10.30 AM. The home was an off-white, two-storey house near the centre of a small village. There were only two pubs, a community centre and small shop for amenities in the town. The front drive had two other vehicles already parked in front of the house: a large, black van and the other a red sedan. Sarah parked her car between the two other vehicles, then we gathered our bags and walked to the front door.*

*Sarah knocked on the door. A middle-aged woman opened the door. She smiled at us and extended her arm in greeting. Sarah and I took turns shaking her hand. She introduced herself as Sally, then invited us into her house.*

*Sarah and I took off our boots in the entryway of the house, then Sally led us into the front room of her home, the sitting room. There was a single leather couch and chair that faced the television in an opposite corner of the room. A large, brick fireplace was between the chair and the television. Sarah suggested that we both sit down on the couch. She sat on the chair. Sally told us that we could wait in the sitting room. Her father and mother were out of the house. She explained that every morning they left the house at 10 to walk their dog.*

*Sarah suggested that I use this time to explain my study to Sally. I gave Sally a copy of the participant information sheet for carers. Sally read over the three-page form. I explained as she peered over the paper that I was interested in spending time with her and her father to learn about how they use technology provided to them in the study.*

*Sally Stewart: 'That sounds fine. What about my mum?'*

*ML: 'What about her?'*

*SS: 'Will you include her in your study? She has Alzheimer's too. But she's not in the other study.'*

*Sarah explained to Sally and me that Mary did not meet the 'eligibility criteria' for ATTILA.*

*ML: 'Yes, I would like to include both your mother and father if they agree.'*

*Sally nodded. Sarah took the questionnaires out from a folder on her lap. This signalled to me that my time for discussing the study was over. Sarah suggested that they complete some of the questionnaires that did not require Sally's father. However, shortly after they started going over the first questionnaire, Michael and Mary Stewart came home.*

*Sally got up from her chair and helped her parents take off their coats and shoes. After she ushered her parents through the French doors into a room behind the couch. After her parents were inside the room, she closed the door and drew a curtain across the two doors. Sally sat back down in the chair. She suggested that they 'finish these questions' before including her parents. I sat in silence listening to Sally respond to Sarah's questions. This exchange between asking and answering questions took about half an hour. After they finished, Sally got up from her chair again. She beckoned us to 'follow her'. She drew the curtain open, then opened the door. The three of us each went through the entrance in turn. We entered into another sitting room. This room was brighter than the previous one due to the glass ceiling overhead. Michael and Mary sat in separate chairs next to each other. Across the room were two other chairs. Sally motioned for Sarah and me to each sit in one. Sarah and I walked across the room and sat down. Sally disappeared out of sight, then appeared around the corner with a wooden chair. She sat to side of the four of us, as if mediating whatever the two parties – researchers and people with dementia – discussed. Sarah still had her folder in her hand. She suggested that she 'go first'. She asked Michael questions about his mobility, wellbeing, and to rate his health at this moment. Michael answered each question.*

*After Sarah finished, she told me it was my 'turn'. I pulled out two copies of my study's 'Participant Information Sheets for Person with Memory Problems', and handed Michael and Mary a copy. I sat back down in the chair. I told Michael and Mary that I was interested in learning about 'their experiences living in the community' and they 'got on using the technologies' given to them. I told them that taking part was 'completely voluntary' and that if they agreed to take part I would 'spend time' with them once a month. I told them to think about it with their daughter over a few days, then I would ring them to see what they decided. They nodded. Sarah and I thanked the three of them for letting us visit, then we left.*

Here we see how I built on the working relationship Sarah, the local ATTILA research worker, previously built with the Stewarts to recruit them into ACCOMMODATE. Yet one feature which was atypical of this particular case was my decision to include Mary Stewart in ACCOMMODATE despite her having been excluded from the ATTILA sample for reasons I did not know at the time of that visit. I learned later from Sarah that Mary had been excluded because of her history of cancer that the ATTILA protocol defined as too high a risk for Mary's to be likely to stay in the trial for the full ATTILA follow-up period of 102 weeks. However, the shorter six months' commitment for this study seemed feasible for Mary as subsequently confirmed when she took part. Including Mary then also provided an opportunity to examine experiences from a family where an adult child cared for two older parents, who both lived with a dementia. Such ethnographic activity could be seen as becoming increasingly 'disembedded' from the practices of ATTILA as I decided to include people excluded from the narrower criteria of ATTILA to move my own work toward a more naturalistic inquiry, to understand, of the lived practices of people with dementia and informal carers.

#### 4.4.2.3 Seeking informed consent or consultee declaration from carer and person with dementia

If the person with dementia and their informal carer agreed to take part in the research during my follow-up phone call, then I arranged the next visit (the first data collection visit) which I carried out alone with the person with dementia and his or her informal carer. I again provided each participant with a copy of the participant information sheets and the informed consent forms (Appendices I and II). To determine the mental capacity of each participant with dementia, I discussed the details of this study with him or her and asked whether he or she could repeat some of the information. Such a conversation demonstrated mental capacity by the person with dementia evidencing their ability to understand, retain and communicate information which will allow the person with dementia to give his or her informed consent by signing the form. The outcome of the mental capacity assessment was

noted in my field journal. If they did not have capacity during this particular visit, then I asked for their assent to participate and asked his or her informal carer to act as a consultee if they felt taking part in the study represented their interests and wishes. After informed consent or consultee declaration was obtained, then the researcher could start collecting data during the visit.

#### 4.4.2.4 Continually renegotiating informed consent or consultee declaration for each subsequent visit during fieldwork

Even after informed consent was given during the initial fieldwork visit, it was continuously re-examined during each subsequent visit to account for potential changes in the ability for the person with dementia to provide informed consent as the study progressed. Each person with dementia had their capacity to provide informed consent assessed during each meeting by again discussing the research with me to ensure that the person with dementia was able to still show familiarity with the research. Informal carers were also formally re-consented during each visit. This process ensured transparency for the informed consent and consultee declaration to fulfil ethical commitments and demonstrate appropriate legal and regulatory evidence if the study was audited.

Such recruitment practices and the sampling strategy which underpinned it demonstrated how initially embedding this ethnographic study also reflected practices and language from the ATTILA trial. Yet recruitment for this study differentiated itself in a couple of ways from the ATTILA trial. There were two instances where I recruited an additional participant aside from the person with dementia and informal carer identified through collaborating with ATTILA. The above excerpt from the Stewarts' recruitment visit was one example as both Michael and Mary Stewart had dementia. While Mary was excluded from ATTILA, she was included in ACCOMMODATE to examine how using assistive technologies and telecare was realised in a household with two people living with dementia. The other case was the Clydes where I recruited Catherine Clyde, the wife of the informal carer, as I often observed her preparing meals for her father-in-law with dementia, Arthur Clyde. Therefore, ten people with dementia and ten informal carers were included in this study which represented nine ethnographic cases. Table 4 illustrates how each of the nine clusters of participants (ethnographic case) aligned with the different purposive criteria used to recruit them into ACCOMMODATE. Such ethnographic activity could be seen as becoming increasingly 'disembedded' from the practices of ATTILA so as to attend more to the naturalistic inquiry into the practices of people with dementia.

Table 4. Participants' purposive sampling characteristics

Case pseudonyms and location alias	Severity of dementia	Nature of relationship with primary carer	Categories of assistive technology
Clydes - Coastal Counties	Moderate	Father (person with dementia) with son and daughter-in-law (carers) who live in their own house but works from front office in father's home	ATTILA: Automatic falls detector (wristband model), keysafe
Drapers - Coastal Counties	Mild	Mother (person with dementia) with son (carer) who lives in his own separate home but visits for approximately six hours every day	ATTILA: Calendar-clock, bed sensors automatic falls detector, falls alarm (wrist version; replaced pendant after first visit), keysafe
Stewarts - Coastal Counties	Moderate (both parents)	Mother and father (people with dementia) who live in an annexe of the daughter' house (carer); only father takes part in ATTILA	ATTILA: Door sensors
Betty and Rose - East County	Severe	Betty (carer) is Rose's (person with dementia) neighbour; both live in their own house	ATTILA: Automatic falls detector (pendant), keysafe
Anthony and Mrs Archer - Metropolitan	Severe	Mrs Archer (person with dementia) lives in a sheltered housing flat that Anthony (carer) visits a few days per week; he lives in separate flat down the road from Mrs Archer	ATTILA: GPS tracking device, calendar-clock, automatic falls sensor (pendant), cooker-timer, calendar-clock
Campbells - Metropolitan	Severe	Son (carer) lives in mother's (person with dementia) home	ATTILA: Bed sensor, door sensor/alarm, pendant alarm
Browns –East County	Mild/MCI	Wife (carer) shares house with husband (person with dementia);	ATTILA: Door sensors, key finder

		daughter (carer) and son-in-law live in annexe	
Anansis – Metropolitan	Moderate	Father (person with dementia) lives alone in a flat; daughter (carer) visits him regularly from her home across the city.	ATTILA: Automatic falls detector (pendant), GPS ‘watch’ and pendant (Buddi)
Smiths –East County	Mild	Father lives alone in his own house. Daughter (carer) lives with her family in village from another county.	ATTILA: Wrist alarm, Automatic falls detector (waist), calendar-clock (self-purchased), door sensors, networked smoke alarm, activity monitoring sensors and software (JustChecking)

#### 4.5 Monthly, multi-sited research visits as ethnographic fieldwork

The geographically-dispersed population of people living with dementia required frequent travel through and in Metropolitan, Coastal Counties and East County. Here I provide an overview of what fieldwork entailed during these short and focused visits.

After the initial recruitment visit, I visited each case once every month for six months. Although I often scheduled follow-up visits to the day, informal carers would call me to delay my visit for a few times to suit a change in their schedule. Therefore, for most cases (8 out of the 9) I visited the corresponding group of participants, consisting of a person(s) with dementia and his or her informal carer(s), seven times comprised of the recruitment visit and the six subsequent fieldwork visits. The fieldwork in this study resulted in sixty total visits and involved 208 hours of observation with ten people with dementia and ten informal carers constructed as nine ethnographic cases. Each visit lasted an average of three and one-half hours. Only one case, Betty and Rose, did not have all seven intended visits. For weeks I attempted to call Betty but she did not return my calls. After two months with no responses, Betty one day returned my call and told me Rose had suddenly ‘got worse’ and died.

Each monthly visit to the home of a person with dementia involved observing and, at times, taking part (to greater and lesser extents) in the activities of people with dementia and their informal carers. When I scheduled each visit, I also exercised sensitivity to the participants’ needs such as the flexibility to reschedule during what they perceived as ‘bad days’, occasions where a person with dementia may

have more difficulty than normal in their everyday routine. I also tried to minimise how much I spoke, only speaking in turn when asked a question from a participant or to clarify something I did not understand. I hoped this would enable the person with dementia enough time to think and form the words they wanted to use in response to questions.

During most visits, I usually sat with the person with dementia and their informal carer(s) in the sitting room of their home. I spent most of my time listening to, and occasionally taking part in, conversations between the person with dementia and their informal carer. Informal carers often directly invited me to take part in conversations through asking questions about my life and background. Participants, especially informal carers located in rural areas, often asked me questions about my American nationality and asked me why I left the United States to study in England. When people with dementia initiated conversations with me, the topic usually centred on a story from their childhood or early adult life. Informal carers, the group of people across all cases who usually initiated and directed conversations, covered a broader range of topics, such as their own childhood, work, health, hobbies, and their care arrangements for a person with dementia. I occasionally audio-recorded these conversations with the consent of participants as indicated on the informed consent forms (Appendix II). Although I created an indicative list of potential ethnographic topics (Appendix III), participants usually had a topic in mind they wanted to talk to me about when I first arrived. These topics did not only relate to how they used assistive technologies or telecare, but they occasionally did. The range of topics underscores one of the strengths of ethnographic work – it does not seek to always structure responses to a particular schema. People can talk and respond in conversations more naturally, informal carers and people with dementia could change the topic, bring up a new idea or sit in silence. It allowed people to behave like people do in their own homes – albeit with a relative stranger interested in observing and learning about you. This relatively unstructured approach to conversations meant that I could learn what participants viewed as significant to them based on what they talked about. In these conversations, I hand-wrote key words and phrases in a physical journal along with any observable gestures, facial expressions and other physical movement taking place at the same time.

Fieldwork visits also involved considerable time spent directly observing the actions of people with dementia and their informal carers. As informal carers and people with dementia both rarely moved from their seats, I also usually stayed in one place during each visit. Informal carers usually invited me to sit in the same room as them or an adjoining one where I observed them go about their everyday routines. More rarely, participants invited me to take part in their activities during a visit. On these

occasions, a participant (usually an informal carer) asked for me to help with some everyday task like filling an electric kettle with water to make cups of tea or emptying buckets filled with water when they cleaned an aquarium. Participating in everyday activities with participants occurred with only some cases (the Stewarts and the Browns) and only during the penultimate and final visits (visits six and seven). I noted all observations in a physical journal which I used to expand into fieldnotes when I returned to the office later each day.

## 4.6 Data management and analysis

From the first note I wrote during the very first visit with participants I began to create the dataset for ACCOMMODATE. Here I found one of the most difficult tasks of this ethnography. How do you render action, purpose and meaning – the practices and understanding of an individual into text? What does movement, emotion, relations, *life* 'look' like in text? To address this problem, I drew on certain principles to guide my data management and analysis practices. For my analysis, I wanted to attend to the nuanced and, at times, unanticipated ways people with dementia and informal carers lived their everyday lives and how assistive technologies and telecare embedded into their routines. This involved a balancing act between identifying the mundane patterns that shape the broad picture of participants' lives with the extraordinary moments which may shift and reconfigure their lives and stories in often quite significant ways. As a subtle realist, I wanted to show how material reality and social reality relate. How despite each of us occupying the same physical spaces and interacting with ostensibly the same technologies, people can construct their own truths, and meanings for their relations with these objects, other people, other places, other things. Here I describe my process from constructing fieldnotes to how I iteratively analysed the data from memos to focus my observations later visits with more systematic analysis later to identify common patterns and points of divergence in participants' practices with assistive technologies and telecare. Figure 1 illustrates each step of this process and points where I iterated and returned to previous steps to inform ongoing analytical developments.

Figure 1. Data Analysis Process.



#### 4.6.1 Developing fieldnotes and familiarising myself with the data

My data first took shape as simple notes which I initially ‘jotted down’ during visits. These notes usually included any key or repeated phrases or explicit references to either assistive technologies and telecare. They also involved physical descriptions of the participants, their home and the activities I observed during the visit. I later developed these ‘jottings’ into fieldnotes and memos following each visit. Jottings were elaborated after leaving the home of the person with dementia and travelling back home or in the office. Travelling between the office and the homes of people with dementia required me to travel for extended periods lasting between one to over six hours on public transport for each visit. These extensive periods of travel gave me time to more fully elaborate and the accuracy of jottings from observations whilst the events were still fresh in my mind.

I typed up fieldnotes as soon as possible after leaving the home of a person with dementia to ensure accuracy (Emerson, Fretz and Shaw 2001). Fieldnotes included observations of participants’ activities, descriptions of participants and the environment, quotations from participants’ talk with me or others,

my personal reflections, and my decisions made during each visit. Additionally, I also audio-recorded some conversations with the permission of both the person with dementia and the carer whilst I was taking notes. I later transcribed interviews into separate Word documents from fieldnotes. Each file was organised by date and ethnographic case pseudonyms. This material represented the dataset that I generated over the nine months of fieldwork I carried out from August 2015 – June 2016.

#### 4.6.2 Memoing

As a form of initial analysis I carried out alongside fieldwork and the concurrent development of my fieldnotes, I also produced brief reflective commentaries ('memo'). Memos helped me identify common features across cases or points of divergence in how people used technologies or otherwise lived with dementia or provided care in the community. An early memo helped me reflect on how participants rarely explicitly discussed 'assistive technologies' and 'telecare' they received from their local authority or NHS Trust. Participants, usually informal carers, would mention the 'thing on your wrist' to the person they cared-for or the 'clock' next to their bed. Assistive technology may represent a helpful category for researchers and practitioners to discuss these technologies in our respective discipline. However, participants seemed to prefer to talk about objects in relation to the people and other objects in their live rather than some innately assistive component they possessed. Participants also rarely directly and observably interacted with such technologies in their everyday practices. Instead, I focused on observations and listening to participants' everyday practices and noted when and how such practices seemed to involve using assistive technologies and telecare. These observations led me to re-examine my assumptions about what I had imagined it was like to live with dementia, what constituted care practices, and participants' relations with different spaces in and outside the home that framed my analysis. Such 'eureka' moments such as the reflection on language and relations with technologies above not only directed my analysis but led me to problematise those discourses of policy makers and the ATTILA team which had informed my own initial understanding of technology-enabled dementia care. Thus carrying out independent ethnographic fieldwork as a lone researcher having to engage with participants in ACCOMMODATE not only illustrated my need to continuously 'disembed' from the practices of the ATTILA trial, but also helped refocus the direction of the study analysis. I shared anonymised memos with the ACCOMMODATE supervisors in the form of weekly fieldwork progress updates to help me consider the analytical relevance of these memos and selected fieldnotes excerpts linked to them. Sharing early analyses with supervisors offered an appropriate way of ensuring quality of the dataset and interpretation beyond just my own subjective positioning during fieldwork and later reflections (See Appendix VI for other methods for ensuring trustworthiness of qualitative research in this study).

These early memos helped direct me to examine three different broad areas which I also earlier identified in the literature as constituting technology-enabled dementia care: specific experiences of living with dementia, specific interactions between a person with dementia or informal carer which could be seen as giving and receiving care, and specific ways people with dementia and informal carers occupied and described relations with spaces in and outside the home. Early memos on these themes helped to direct how I later refined descriptive coding.

#### 4.6.3 Coding

The main themes from early memos highlighted how everyday practices of living with dementia, providing care, and occupying different spaces inside and outside the home constituted technology-enabled dementia care. Such themes appeared to constitute the problem requiring technological intervention (defining and problematizing the needs of people with dementia in their everyday lives), actions intended to address the problem (what care informal carers were providing to a person with dementia), and the spaces where these actions took place (in the home and wider community). Such themes produced from early readings of transcribed fieldnotes and audio-recordings directed analytical attention toward more focused coding (Emerson, Fretz and Shaw 2001).

Focused coding identified and examined instances of these themes across different visits for each ethnographic case and also compared them across different cases. Focused coding helped attend to particular instances of these analytical themes in context. Codes were constructed in the familiar language of participants rather than abstract concepts applied from research literature and from the ATTILA collaboration. As such, the initial memo themes shifted over time in how they were describing the analysed phenomena. As I did not want to impose or wrongly interpret actions of the person with dementia as related to his or illness, I focused analysis on particular actions which appeared to reflect a specific set of symptoms related to memory problems. Likewise, I did not want my own concepts of care to influence how participants made-sense of their own practices, so I focused on how participants understood their own practices as care or facilitating it. Finally, rather than thinking about 'space' or 'place' in a theoretical or abstracted way, my analysis attended to how people with dementia occupied rooms in the home and locations outside of it. These codes represented three 'domains' to address the research questions: memory problems, care, and the home or community (Appendix VII provides an example of descriptive coding).

#### 4.6.4 Applying key concepts to identified domains

'Domain' was selected as a descriptive term for analytical concepts, because it did not have the same connotations in qualitative research as 'themes' which often linked to a need to generate theory. Instead, the analysis of this study examined broad areas of practices relevant to understanding the research problem and addressing the research questions. However, each of these three domains was composed of diverse instances and variations. Such a range within each domain represented possible practices which reflected: memory problems people with dementia may encounter in their everyday lives, different understandings and related practices of care, and different ways of occupying the home and locations outside of it in the community. I selected these domains as relevant concepts from my literature review and embedded activities with ATTILA. In other words, they served as initial key concepts for deductive exploration throughout my fieldwork which shaped what I observed and the focus of my analysis. Yet through my fieldwork and later reflections after visits, I noted distinct and nuanced practices for each of these domains and how they mediated apparent practices of participants with assistive technologies and telecare. To represent more nuanced practices within each domain, I divided them into different instances to represent such observed variations within and across ethnographic cases. Table 5 lists the three domains and their different instances.

*Table 5. Domains and different instances*

<b>Domain</b>	<b>Instances</b>
<b>Memory problems</b>	'Forgetting' and 'Misremembering'
<b>Care</b>	'Care as concern' and 'Care as surveillance'
<b>Home and community</b>	'Reconfiguring rooms', 'Abandoning rooms' and 'Accessing communities outside the home'

#### 4.6.5 Identifying instances of each domain

After applying my key concepts to the domains I identified, I made the choice to return to the larger dataset to see how these instances fit within individual ethnographic cases. I did not want to present findings of these domains and their unique instances as themes de-contextualised from the longitudinal process through which I uncovered them. I wanted to find a way to represent the journey I experienced which moved my initial understanding of these concepts from my literature review and embedded work with the ATTILA team to how I understood them following fieldwork with ACCOMMODATE participants. This is why, in the findings chapter, I selected one ethnographic case to represent each domain's instance broken down into discrete sections to illustrate specific moments

or interactions where I noted features which shifted my understanding of memory problems, care, and living in the community and how these intersected with participants' practices using assistive technologies and telecare.

#### 4.6.6 Selecting exemplar instances as indicative and divergent ethnographic cases

As many of these instances appeared across several ethnographic cases, I chose particular cases which could highlight common mundane features yet also highlighted a more conspicuous, even divergent, representation of the case. For example, I selected Anthony and Mrs Archer as a case to highlight how people with dementia and informal carers abandon spaces in the home over time. While this was experienced in other cases, the drama surrounding the kitchen fire for Mrs Archer added a heightened sensibility to the story. It drove home how changes to physical spaces could importantly affect how people live in their homes. This enabled me to offer engaging instances and to balance the mundane with the extraordinary.

### 4.7 Presenting findings as ethnographic cases

Presenting the findings as ethnographic cases allowed the findings to follow specific instances of each domain as they developed during a single visit to a household or to span fieldwork with a particular person(s) with dementia and informal carer(s). A benefit of an ethnographic approach is attending to processes and practices of a group of people over time. Presenting the findings from ACCOMMODATE as ethnographic cases appeared to better facilitate representing changes in practices over time than representation through a conventional thematic analysis or a grounded theory approach. I selected fieldnote excerpts to frame each gradual step or shift in practices as they evolved during this study. Not all participants are presented as wholly comparable ethnographic cases. There are no findings presented from either the Browns or Clydes in this thesis. These two cases were not selected because other ethnographic cases appeared to illustrate instances of the different domains they exemplified in my analysis in finer detail.

Each case does, however, provides in-depth representations of how I found participants enacted their practices during my fieldwork with them, as a particular instance of each domain. The full implications of these instances often did not emerge until later visits with participants. Therefore, most cases consist of several discrete subsections to provide ongoing analysis as to how each respective case developed over months of prolonged contact with both the participant with dementia and their carer. However, the presentation of this ethnography distinguishes it from conventional ethnographies in another way, in selecting distinct excerpts from conversations and fieldnotes through which to focus

the analysis of distinct domains in context rather than offering a unified narrative in which my interpretive analyses have been combined and may have been more decontextualized.

Each of the following three chapters therefore contains selected fieldnotes and conversations that examines one of these corresponding areas in detail. I selected a case from the wider dataset to attend to an instance of each analytical domain. Each case represented either a common set of practices which people with dementia and their carers enacted with assistive technology and telecare which affected: their experiences of living with memory problems, their understandings about what actions count as care, and changes in the ways they occupy their home and access services, people and locations in their wider community.

The first findings chapter, Chapter 5, examines the everyday practices of 'memory problems' people with dementia enacted whilst living in the community. The chapter examines the practices of people with dementia and informal carers with assistive technologies and telecare could or could not help address the consequences of 'misremembering' or 'forgetting' for the everyday life of a person with dementia.

The next findings chapter, Chapter 6, examines practices of informal carers identified as novel forms of 'care' through their practices with assistive technologies and telecare. The chapter considers 'concern' and 'surveillance' as approaches to care that help shift social and power relations between informal carers and people with dementia based on how informal carers identify risks to the wellbeing of a person with dementia.

The final findings chapter, Chapter 7, examines how the practices of people with dementia and their informal carers with assistive technologies and telecare affects their relations with rooms in their 'home' as the actions of informal carers reconfigure the way people with dementia occupy rooms or abandon them. Practices with assistive technologies and telecare are also considered for examining how they affect the ways people with dementia occupy and access locations and services outside of their home in the 'community'.

These three chapters, therefore, address what 'care in the community' means in practice by examining the everyday life of people (person with memory problems and their informal carers), receiving and taking part in interventions (how I came to understand participants' care practices with and through assistive technologies), and where these technology-enabled practices intervened (community and

home). These findings inform a discussion of the 'imagined communities of care' policy makers and care providers construct through 'technology-enabled care services'.

## 4.8 Allocating case pseudonyms and considering fieldwork relationships

Whilst I understand the need to anonymise participant details in order to protect research participants from potential abuses by work colleagues, family members, healthcare providers, and other organisations and persons, I also felt it dehumanised the people I spent so many hours getting to know. They are not just participants in this study, since I am sometimes taking part in their lives just as much as they are taking part in this study. Some anthropologists invite their participants to select their own pseudonym. However, collaborating with the ATTILA trial made it more situationally appropriate to select pseudonyms for participants instead. Here is a brief description of my relationship with each participant to contextualise findings and discussion in the following chapters.

### 4.8.1 The Drapers

#### 4.8.1.1 Thomas (Draper)

Thomas Draper and I got along well yet I always perceived a barrier with making a real connection with him. Although he insisted that I call him by his first name, it was clear that we would maintain some emotional distance from each other maintaining a strictly professional relationship. I chose the name Draper, because draping suggests to me a veneer, a delicate covering, indicative imagery of the limited depth I felt I achieved in my relationship with him.

#### 4.8.1.2 Mrs Violet Draper

I chose the name Violet, because this participant always wore a lot of purple clothing. Violet also frequently spent time looking outside of the window in her sitting room into her garden that she used to tend but stopped following a hip replacement. I thought that naming her after a colour and flower suited both of these characteristics that I learned about during visits with her and her son.

### 4.8.2 The Stewarts

#### 4.8.2.1 Ms Sally Stewart

Sally Stewart moved across the country to co-habit with her parents. She bought a house and built an annex off the side so she could tend to both of them after her father developed stomach cancer and her mother was diagnosed with dementia. Both parents now have dementia. Sally frequently

discussed difficulty in caring for both of her parents coupled with the 'joy' of being there for them. As fieldwork continued, her father had another 'scare' for a recurrence of his stomach cancer and her mother had undiagnosed bleeding in 'her gut'. I chose the surname Stewart based on a small painted-glass thistle etched into one of the doors in her house. I once again related my fondness for a participant with my fondness for a former home. Sally is the only participant who contacted me through email during and after my fieldwork. She wanted to let me know how she and her parents were doing even after the study ended.

#### 4.8.2.2 Mr Michael Stewart

I learnt a great deal about Mr Stewart's life during World War II although he never remembered me from any of my prior visits. Most of my time spent with the Stewarts was with Sally or with Sally and her parents. I did not have many opportunities to talk one-on-one with Mr Stewart. The Stewarts are the only group which included more than one person with dementia or memory problems in this ethnography.

#### 4.8.2.3 Mrs Mary Stewart

I included Mrs Stewart in this study despite her not taking part in ATTILA. Her case seemed to be important for examining the practices of two people with dementia cohabiting in a single household, since this may affect how care and technological practices are understood and enacted. Mrs Stewart stated that she recognised me from previous visits yet she could not remember my name or why I was there during each visit so I needed to re-establish her willingness and capacity to take part during each visit.

Both Mr and Mrs Stewart's memory problems and difficulties word-finding made it difficult for me to communicate with them without Sally around to help. Our conversations together frequently turned to their dog, the weather, or their aquarium. All of these objects or animals were immediately observable and seemed to make conversation easier to initiate and maintain.

### 4.8.3 The Clydes

#### 4.8.3.1 Mark (Clyde)

Mark Clyde is the participant I developed the closest interpersonal relationship with during fieldwork. Mark always insisted that I call him by his first name, since his father was *the* 'Mr Clyde' in his family. My American accent and nationality provided a bond with Mark. Every time I visited the Clydes, Mark would regularly tell me tales about his visits to the United States and growing up in the area with an

American household in the neighbourhood. He professed loving the country and the food there. When I told him that I had lived in Scotland before moving to Norwich to start my research degree, he took the opportunity to tease both his wife, a Scottish woman, and me about the weather and what it is like living 'up there'. Mark's desire for me to call him by his first name and joking banter between him, his wife, his father and I suggested some growing familiarity and sense of mutual connection. This sense of connection was encouraged by his directness and honesty in asking me questions about his father's health and frank reflections about his role as a carer.

#### 4.8.3.2 Catherine (Clyde)/Cathy

I chose the name Catherine, then Cathy, to highlight how I became more familiar with her as I carried out more visits with the Clydes. During the first visit, she appeared markedly shy so I spent most of the visit with Mark and his father. After I recruited Cathy into this study, she talked to me more frequently, especially about Scotland and our mutual love for the country as her homeland and my first home away from the United States. I chose the surname Clyde, after one of the major rivers in Scotland, to celebrate our cherished feelings for the country.

#### 4.8.3.3 Mr Arthur Clyde/Artie

I chose the name Arthur, then Artie, in order to demonstrate how as I spent more time with Artie his name shortened to indicate a growing familiarity that was indicated by changes in the version of his real name.

### 4.8.4 Betty and Rose

#### 4.8.4.1 Betty

Betty and Rose were the first ACCOMMODATE participants who were not relatives. Betty and Rose were co-workers at a major telecommunications company for several decades before they both retired. They were neighbours during this study. They both insisted that I call them by their first names from the very beginning of recruitment, hence why no last name is given. My relationship with Betty was peculiar. My first two visits with Betty and Rose went well. Afterwards Betty went on holiday outside of the country for three weeks, then whenever I tried to call she was out golfing. Finally, when I called a month overdue for our visit I learnt that Rose had died. I still met with Betty one final time in order to learn about what happened to Rose.

#### 4.8.4.2 Rose

Rose was a retired telecommunications worker. Her sudden death made me question and reconsider what I thought I knew about living and dying with dementia.

#### 4.8.5 Anthony and Mrs Archer

##### 4.8.5.1 Anthony

Tony always smiled and spoke positively about his life despite having to move back in with his parents in his forties, his disabling disease caused by an industrial incident, and current unemployment. His optimism and love for his biological family also extended to his 'church family' where he frequently offered to help out. However, his perception of what he felt was right frequently differed from what his friend, Mrs Archer, wanted for herself. Misunderstandings between both of them consistently took place during each visit.

##### 4.8.5.2 Mrs Archer

I was less familiar with Mrs Archer compared to some of the other participants in this study. Although she told stories about her childhood in Jamaica and about how she would help her mother prepare food for dinner whilst her dad worked on a farm, she. She taught me some patois and rhyming slang from Jamaica that she and Tony could remember. Whenever Mrs Archer was not talking with Tony or me, she would watch television. I never called Mrs Archer by her first name, since even Tony called her Mrs Archer as a sign of respect to an elder of his community.

#### 4.8.6 The Campbells

##### 4.8.6.1 Kenneth (Campbell)

Kenneth Campbell faced frequent financial and social hardship as a result of poverty and substance abuse. In my first encounter with Kenneth, he joked about his past history with cocaine and other narcotics. Yet despite this uncomfortable start to our relationship, I grew to understand and sympathise with Kenneth during fieldwork. He detailed a history of physical abuse from family, drug and alcohol abuse throughout his working life, and a love for photography hindered by personal mobility issues.

##### 4.8.6.2 Mrs Lillian Campbell

Lillian is undoubtedly the participant I spent the least amount of time interacting with during fieldwork. Whenever I visited the Campbell's home, she was often out of the house at a 'day centre'

so Kenneth could do errands outside of the house or talk to me. If she came home before I finished the visit, then she was often sent into her bedroom whilst Kenneth and I stayed in the sitting room. The sitting room only had two places to sit, so it practically made sense. However, I also felt uncomfortable with Lillian always staying in her room.

#### 4.8.7 The Anansis

##### 4.8.7.1 Claire (Anansi)

Claire often discussed topics that I thought would make either one of us uncomfortable due to our different backgrounds: mine as white, American male and hers as black, British female. However, Claire always had a story to tell about race relations in schools in the United Kingdom based on her experiences as a teacher, visiting Jamaica and the United States and how being black compared there compared to the United Kingdom, and the difficulty in trying to find and keep a flexible job among others. I selected the surname Anansi, the West African and Caribbean folklore character renowned for his ability to 'spin' tales in the form of a spider, in order to pay homage to her Afro-Caribbean heritage and her ability to 'weave' a story.

##### 4.8.7.2 Mr John Anansi

John rarely could get in a word when Claire was talking. For this reason, I rarely got an opportunity to speak directly with John during fieldwork. I learned only a little bit about his life when he would interrupt his daughter with corrections. John often smiled during my short conversations with him, but most of what I learned about him was through Claire or my own observations of what he did during each visit.

#### 4.8.8 The Browns

##### 4.8.8.1 Sam (Brown)

I chose the name Brown because although it may appear basic at first appearance, I associated it with the belongings and temperament of the man they represent in this study. Sam's fingernails were often brown from working in the earth in order to maintain his garden, during fieldwork visits we frequently were in his workshop moving wooden frames and organising his stock of tools in different compartments. More rarely, we would have a cup of tea on leather sofas in his sitting room. The earth, the wood of the tools and building materials, and the leather of the sofas were all different shades of brown and the range of materials denoted a richness of character and pride whilst also

demonstrating Sam's continued desire to engage in manual labour despite a medical retirement for his knee and subsequent memory problems.

#### 4.8.8.2 Anne (Brown)

In contrast to other participants where I spent much of my time conversing directly with the informal carers, I rarely spent time with Anne, Sam's wife. Anne was frequently in the house whilst Sam and I were outside or in the workshop finishing some manual task. Anne insisted from the first meeting that I call her by her first name.

#### 4.8.9 The Smiths

##### 4.8.9.1 Lauren (Smith)

Conversations with Lauren usually discussed dogs or hill-walking before I changed the topic to her father's care arrangements. Visits with the Smiths were usually the shortest. Each visit usually lasted one and one-half hours. Lauren lived in a different county from her father and usually visited him to take him to regular doctor appointments. She only spent a limited amount of time after her father's appointment with her father in his home, so visits were scheduled around them. Nonetheless, Lauren still opened up to me eventually over the course of fieldwork even discussing unique ways of using telecare technologies for monitoring other people's activities.

##### 4.8.9.2 Mr Christopher Smith

This participant was an avid painter prior to his dementia which then made it difficult for him to concentrate long enough to progress his work. Christopher's charming demeanour, ever-ready smile and infectious laughter – when he did not fall asleep during fieldwork visits – conjured an image of a happy man pursuing an idyllic country life before his wife passed away a detail that he continuously forgot yet his daughter reminded him about to prevent his 'wandering'.

### 4.9 Chapter summary

This chapter described the methods of recruitment, data collection and analysis carried out for this study. It covered the processes of 'embedding' and 'disembedding' an ethnographic study within a national, randomised controlled trial called ATTILA and its impact on the development and day-to-day management of this study. It also considered the ethical commitments of this study through identifying and addressing potential dilemmas related to mental capacity, informed consent,

anonymity and confidentiality, and participant safeguarding during recruitment and fieldwork, in particular.

The chapter gave an overview of the fieldwork carried out as data collection and the process for developing quick notes or 'jottings' during fieldwork into elaborated more in-depth fieldnotes. An account of the inductive and deductive analytical approaches for the different modes of data described the identification and development of three domains: 'memory', 'care', and 'the home and community'. Instantiations of each domain demonstrate possible variations between people with dementia across cases and even within the same case. To represent contextualised, in-depth instances of these domains, the following chapters present findings as ethnographic cases situated within the lived context of each person with dementia and his or her informal carer.

# Chapter 5: Understanding 'memory problems' in everyday and technological practices

## 5.1 Introduction

Memory problems were frequently described in the reviewed literature as an 'impaired function' (Scherer et al. 2012) or 'symptom of the dementia syndrome' (World Health Organisation 2016). It is beyond the scope of this thesis to make claims about the appropriateness of diagnostic categories or clinical nosology related to any form of dementia. However, a definition for 'assistive technology' [commonly-used health and social services described the role of these technologies as to increase, to maintain or to improve the functional capabilities of individuals with cognitive, physical or communication disabilities (Marshall 2000). Therefore, attending to the everyday and technological practices of people with dementia and their informal carers may reveal how they may or may not have addressed 'memory problems' through using assistive technologies and telecare.

I adopted this particular focus on 'memory problems' as I also noted participants frequently referred to 'memory', 'remembering' usually accompanied with language about 'loss', 'problems', or 'changes' with these activities. My explicitly ethnographic decisions and practices with the ATTILA trial and public involvement in the research helped to further inform this focus. For although the ATTILA trial team investigated the efficacy of assistive technologies and telecare to help people with dementia remain in their own home, the team did not include 'dementia' in the acronym used to identify the study. ATTILA trial team members told me this was to prevent the experience of 're-diagnosing' a person who may have forgotten they have a dementia. ATTILA and ACCOMMODATE participant information sheets and informed consent forms for prospective participants with dementia also excluded the word 'dementia' for the same reason. However, validated questionnaires used in ATTILA explicitly identified dementia. Members of the iNSPIRE local patient and public involvement team provided feedback on early drafts of the research protocol, consent forms, and participant information sheet in this study (see Appendix V). The iNSPIRE reviewers problematised my language referring to the 'person with dementia' on the consent forms and participant information sheets for this study.

They suggested adopting ‘person with memory problems’ instead on these forms. Based on the suggestions of the iNSPIRE reviewers and the ATTLA team, I decided to adopt ‘person with memory problems’ for all study-related documents, such as the participant information sheets, consent forms and consultee declaration forms. This decision further affected the focus of my ethnographic observations during fieldwork, as I examined more carefully practices which reflected or included how participants talked about their memory problems.

This chapter presents two ethnographic cases to examine how ‘memory problems’ may or may not be identified and addressed as a practice of living with dementia. ‘Memory problems’ featured across all nine ethnographic cases of this study. Informal carers occasionally told me that they were concerned about the person they cared for ‘forgetting to take their pills’ or ‘forgetting’ how to get home. People with dementia and their informal carers often identified ‘memory problems’ as a potential sign that they may have a dementia. Signs of memory problems often prompted people with dementia in this study to personally approach or lead to family members to contact health services for a formal diagnosis.

In this study, I came to identify ‘memory problems’ in two ways: the person with dementia ‘forgetting’ a person, place, object or event, or the person with dementia recalling outdated information, i.e. ‘misremembering’. This chapter examines illustrative cases of ‘forgetting’ and ‘misremembering’, from ethnographic fieldnotes. I selected these findings to highlight how both ‘forgetting’ and ‘misremembering’ demonstrate everyday practices for a person living with a dementia different from other people in their lives, such as informal carers, without the illness. It is within the context of memory problems for people with dementia that I explore the apparent capacity for assistive technologies and telecare to address the specificity of individual memory problems ‘memory problems’.

## 5.2 Memory problems as ‘forgetting’

Most participants explicitly identified ‘forgetting’ as an example of a ‘memory problem’ that either they personally experienced or observed in the person for whom they provide care. The exact nature of what the person with dementia ‘forgot’ varied from situation to situation. However, whatever the person with dementia noticed, or was noted as forgetting, could have significant implications for sustaining their everyday practices and social relationships especially with their informal carer.

Michael and Mary Stewart were an older married couple who both had a diagnosis of dementia, and their daughter Sally, a retired businesswoman with whom they now lived. Sally moved into the neighbourhood to live closer to her parents as they got older. When Michael was first diagnosed with dementia, Mary used to help him out at home. However, after Mary was diagnosed with stomach cancer, Sally moved her father into an annex of her home. After Mary recovered from surgery in hospital, she also moved into the annex of Sally's home. Michael, Mary and Sally all lived in the same house during fieldwork for this study. Michael and Mary predominately spent their day in the annex whilst Sally usually split her time in the annex with her parents and in other rooms of the house.

This section, draws on visits with the Stewarts in their home in Southeast County to examine the place of 'forgetting' within the everyday practices of people with dementia and their effect on to embedding technologies within this context. I chose the Stewarts as the illustrative case as my time with them served as the catalyst, my 'eureka' moment, where I realised the importance of memory problems. The Stewarts also uniquely involved one of the few triads I spent time with during fieldwork. As Michael and Mary both had a dementia, it may have made 'forgetting' more prominent than in all other cases which involved only a single person living with dementia. I had noted times when other participants forgot or had trouble recalling information when either I or their informal carer asked them a question. Yet Mary and Michael allowed me to explore and brought this interest to the fore of this study. I could examine how they tried to make sense of their relationships to each other, their home and their individual biographies. Their periods of acute memory loss, here presented as forgetting, appeared to disrupt sense-making of these relations. It changed how I understood memories, now seen as mediators for us to act on in the material world. Memories have power, then to help ground us to our surroundings and relations with other people and things or disrupt and potentially harm these connections.

### 5.2.1 Michael and Mary forget the date and day of the week

To explore 'forgetting', first it is important to illustrate a precise example of it. Here I describe a particular time when Michael and Mary could not remember the date and day of the week. This case represents a relatively mundane example of 'forgetting' to illustrate the everyday scope of 'forgetting' as a practice of living with dementia and its implications for communication and shared understanding about the world around them.

Here Michael, Mary, Sally and I are seated in the sitting room of the annex which Sally built for her parents. It was my second visit with the Stewarts in just as many months. Michael and Mary sat in

two chairs beside each other facing the opposite side of the room where Sally and I sat in our chairs that faced them. Sally and I talked about the changing seasons as the brisk weather signalled winter's return to this area of England. Our talk about the weather led Sally and I to look at a nearby calendar. It was the first day of winter. Sally turned to her parents to invite them into our conversation.

*Sally Stewart: 'Dad, do you remember what day it is?'*

*Michael looked at Sally.*

*Michael Stewart: 'What was that?'*

*SS: 'Do you know what day it is?'*

*Michael turned his head away from Sally to Mary.*

*MiS: 'I don't know what she is saying.'*

*Mary Stewart: 'She wants to know today's date.'*

*MiS: 'Ah, thank you.' Michael turned to face Sally again. 'No, I don't.' He smiled and looked away from her.*

*Sally sighed.*

*SS: 'Mum, do you know what day it is?'*

*MaS: 'I'm afraid that I don't have a clue.' Mary laughed.*

*Sally turned to me.*

*SS: 'They are usually much better than this.'*

This short exchange between Sally, Michael and Mary Stewart illustrated Michael and Mary's difficulty with recalling 'the day'. Although this can be seen as exemplifying a memory problem,

miscommunication and misunderstanding may also be seen as an issue here as well. I initially considered both of these possibilities in the moment. Michael's response that he 'didn't know what she is saying' need not necessarily signify a memory problem, but it could also suggest a breakdown in understanding. Perhaps he could not conclude what Sally meant by 'day'. It is unclear from the way Sally phrased her question whether she meant 'day' as 'day of the week', e.g. Monday, or 'calendar date', e.g. 21<sup>st</sup> December. Michael understood Sally addressed him yet he could either not understand or hear what Sally said. Next we see Michael turn turned to Mary for clarification. Mary explained that Sally wanted to 'know today's date'. Mary demonstrated that she not only listened to and could hear Sally but that she also understood what Sally said well enough to repeat the words to Michael. However, when Sally asked Mary the date, Mary responded that she didn't 'have a clue'. This is what appears to signify an example of 'forgetting' in practice. Although Michael's actions and language could suggest potential miscommunication, Mary's ability to clarify Sally's intent yet respond that she 'has no clue' about the date suggests a memory problem coming to the fore in this situation. This is why I later started to interpret this scenario as an example of subtle forgetting (Michael) coupled with a more explicit admission of forgetting (Mary).

Following my interpretive reasoning, Michael and Mary's responses could both indicate that they 'forgot' the day during the visit. However, their responses also took place alongside non-verbal cues. Michael looked away from the three other people present in the room. Although I did not know why he responded in this way, Sally did not question him further. Such an action could signal his wish to withdraw from the conversation. On the other hand, Mary laughed after telling Sally that she could not remember as signified through 'not having a clue'. I did not know why Mary laughed after she admitted that she did not know the date. I know that I often laugh in tense situations – a chance to bring levity to ease difficult relationships or topics of conversations where I feel uneasy. I wonder if Sally also felt uneasy. Her words could appear to confess the practices of living with a memory problem bringing external life to her own subtle actions.

Later reflecting on this encounter, I wondered why Sally asked her parents the question in the first place. Her final aside indicated to me that she was asking her parents to name the day, but it looked to me like she asked them to perform for the benefit of the study. She appeared to think Michael and Mary could capably answer the question, signalled by her phrase, 'they are usually much better than. Michael and Mary's inability to 'perform' as Sally expected may indicate an acute of example of her parents forgetting the date and time. However, it also highlights how people can routinely expect people with dementia to answer questions as a way to determine the extent of their 'memory

problems'. Perhaps people with dementia do not perform 'forgetting' in their everyday practice. If they do so, then they may not understand they forgot some piece of information. I learned that 'forgetting as memory problem' comes to the foreground when displayed with or before other people. People with dementia may perform 'forgetting' as a distinct practice of living with a dementia, but people without the illness make it visible. They produce the person with dementia as an Other.

### 5.2.2 Practices with using 'memory aids' to help Michael and Mary know the date

If 'forgetting' potentially disorientates people with dementia, so they do not know or can no longer recall the time or date, then what can help orientate them? So-called 'memory aids' may help re-orientate people with dementia with the locally accepted definition of time and space of those around them. Returning to Michael, Mary, Sally and I. we remain seated in sitting room annexe. It's still the same December day from the previous interaction where I first identified their difficulty recalling the day of the week. Yet here we see the introduction, if not intervention, of two different 'memory aids', a wooden decorative calendar and a calendar-clocker. The local county council provided the electronic calendar-clock earlier in the month between this visit and my previous one (see Appendix IX for an indicative picture), Sally had placed it on a small table between Michael and Mary's chairs. The decorative calendar, on the other hand, had been purchased at some earlier time far before my fieldwork for ACCOMMODATE started. The following conversation starts after I noticed Sally glance at the wooden calendar on a small table between us. I had not noticed the wooden calendar before now, so I decided to ask her about it rather than fixate on Michael and Mary's difficulty recalling the date.

*ML: 'When did you get this?'*

I pointed at a long, wooden block. In the front of the block were three holes. The first and second hole were square shaped and empty. The third hole was longer and filled with a block that read 'DECEMBER'. Two smaller, cubed shaped blocks of wood were placed in front of the larger block. Each block had a number painted on one side of it: '2' and '1'.

*Sally Stewart: 'I will show you.' Sally turned her head to face her parents. 'Mum. Dad. Can you tell me the date?'*

*Michael Stewart: 'I am afraid I don't know.'*

*Mary Stewart: 'I don't know.'*

*Sally pointed to the wooden calendar.*

*SS: 'Can you see it? The month is December. What's the day?'*

*Mary squinted her eyes at the wooden blocks but did not say anything.*

*MiS: 'I can't see.' Michael picked up his glasses from the table beside him and put them on.*

*'No, I still don't know.'*

*Sally placed the wooden blocks with '2' and '1' into the two holes, so that it read '21 DECEMBER'.*

*SS: 'Can you read it now, dad?'*

*MiS: '21<sup>st</sup> December?'*

*SS: 'Yes! Well done.'*

*Mary frowned and shifted from side to side in her chair. Michael smiled at us.*

*SS: 'I also have that for them.' Sally pointed her finger at a black calendar-clock with the screen facing us on the table between Mary and Michael.*

*ML: 'Which do you prefer?'*

*MiS: 'Which what?'*

*ML: 'Of the two calendars, the one next to you.' I pointed at the electronic calendar-clock. 'Or the one next to me.' I pointed to the wooden calendar.*

*MiS: 'Those? I usually forget that they are there.' Michael turned to Mary. 'What do you think?'*

*MaS: 'About what?'*

*MiS: 'This.' Michael placed his hand on top of the calendar-clock.*

*MaS: 'It's fine. I forget that it's there sometimes.'*

My initial focus in the moment and shortly after the visit considered what appeared to me as two issues about the Stewarts' use of the memory aids: Michael required his glasses to see the object and Sally needed to maintain the wooden calendar by placing blocks of the wooden calendar in their appropriate locations so Michael can read the displayed date.

When Sally pointed at the wooden calendar set to help them answer the question Mary squinted at the wooden calendar in following Sally's pointing. However, perhaps she could not read what was displayed. Her fidgeting later in the excerpt may suggest that she felt uncomfortable with what she was being asked to do. On the other hand, Michael told Sally that he could 'not see' but did remember to put on his glasses. Yet even with his glasses on he still told her that he 'did not know'. While the glasses may have helped him see the calendar, they could not help him decipher the date since, in addition, the wooden calendar set had not been properly set up. Specifically, the blocks labelled with numbers '2' and '1' were not set into the two holes made for them. Therefore, even after Michael put on his glasses the date details were left incomplete and he would not have been able to read it. He could only read the month from his position; and Sally had already given him this information. After Michael told Sally that he still 'didn't know', this prompted her to place the blocks into their holes. Michael could then read the date after the blocks were all in their correct positions. This illustrated the importance of co-produced practices in the setting for 'remembering' or 'forgetting'. This might include maintaining simple everyday objects, especially where these were used as 'memory aids'.

Yet in contrast to their practices with the wooden calendar set, they ignored the electronic calendar-clock during this exchange except for when Sally pointed it out. However, the place of the calendar-clock may have contributed to Michael and Mary apparently ignoring it. Although the calendar-clock was physically close to hand on a table between both of their chairs, its screen, which displayed the time of day, day of the week and date, faced Sally and me in our chairs, rather than Michael or Mary. This may have prevented them from easily reading the screen. However, while they could have moved

the calendar-clock against the wall or to another place in the room they could still forget this assistive technology was there to help them recall the date or time.

Mary Stewart therefore identified the further issue with 'memory aids' like calendar-clocks: practices involving them rely on a person with dementia remembering they are there. Mary told Sally and Michael that the calendar-clock was 'fine' yet she 'forgets that is there'. The calendar-clock may tell the time, day of the week, and date. However, Michael and Mary may not have viewed this technology or may have 'forgotten' where it was located. Neither Michael nor Mary used the calendar-clock during any study visit. Although this excerpt cannot represent technological practices in my absence given the disembedded practices of this particular ethnography, it raises questions about whether Michael and Mary actually ever used the calendar-clock in their everyday practices. The excerpt also illustrated how 'forgetting' as a memory problem was not only linked to recalling information about the time, it also showed how solutions put in place, like calendar-clocks, designed to address memory problems could also be forgotten and therefore not deployed.

On later reflection I considered the relevance for this exchange and what it says about the role of assistive technologies, especially memory aids, to support people with dementia. It appeared to me that calendar-clocks, and potentially other assistive technologies, designed to aid 'memory' may not actually help with memory but aid orientation. Although the problem may arise from 'forgetting' or another problem related to memory loss or another type of cognitive decline, this does not mean that these technologies aid memory restoration or prevent memory loss. They help orientate a person to a specific time and date consistent with implicitly agreed understandings of the time in the local area. However, reorientation to a specific understanding of time and space is not the same as aiding memory. Events, time, space and people remain forgotten. Does receiving prompts from an object suddenly repair what the person with dementia forgot? I do not think so. It appears to me try to 'input' new information, it nudges a person to accept an agreed status, here, this is time. Prompts signal re-orientation, not aiding memory.

Yet these prompts may not always work in the way designers and carers expect. For example, as described above Michael and Mary could not perceive the object, or if they did then they did not seem to understand how it may help them answer Sally's question. This granular attention to the language and practices explicit and implied through this observed interaction led me to later question another aspect of these technologies – the descriptor 'assistive' which marks them as a distinct class of object. Neither Michael nor Mary included the electronic calendar-clock in what they did when trying to

answer Sally's questions about the date. Conversely, Michael did answer Sally's question by reading the relevant information from the wooden calendar after Sally placed the blocks in their correct positions to supply the answers. In this case, the wooden calendar was more 'assistive' for Michael than the formally-designated assistive technology and memory aid: the calendar-clock. The 'assistive'-ness of an object should be determined by how practices deploying it could successfully address challenges a person with dementia experienced. As well as formally-designated assistive technology objects, everyday objects may also be used to 'assist' and perhaps more easily fit with peoples' existing routines.

Such detail about individual practices of people with dementia and their informal carers using assistive technologies, such as memory aids, raises serious questions about whether practices of people with dementia using memory aids actually 'aid memory' as such. Calendar-clocks and even everyday calendars may help a person with dementia 'know' the current time. However, they do not necessarily address the 'memory problem'. A person with dementia still may not recall the date or day of the week shortly after 'using' the technology – electronic or mundane. Practices of people with dementia using calendar-clocks only 're-orientates' people with normative perceptions with time at most. 'Forgetting' persists as everyday practices for people with dementia.

### 5.2.3 Forgetting being married to each other

I continued to visit the Stewarts in their home over the winter months. Although I remained acutely aware of Michael and Mary forgetting events and the date, these became common, mundane, familiar to my sensibilities. They no longer struck me as peculiar events, they even appeared to me, an infrequent visitor to their home, as everyday. Yet they experienced other problems with their health in the meantime notably Michael's doctors suspected his cancer had returned. I returned in February to visit all three of them in their home. Sally invited me into the sitting room annexe, as she always did to start my visit. Although I expected to receive difficult news about Michael's health during the visit, I did not anticipate another emotionally difficult situation arising in its place: Michael and Mary both forgetting that they are husband and wife. Although they forgot common things, small things, this represented forgetting with more immediate and affective implications for the people involved. The conversation below plays out the scenario as it occurred.

*Mary Stewart: 'Oh hello there.'*

*I turned my head from Sally to face Mary in order to determine who she addressed. Mary was looking at Michael. Michael sat in the chair next to her. Only a small table separated the armrest of one chair from the other. Michael turned his neck to face Mary.*

*Michael Stewart: 'Hello.'*

*MaS: 'Who are you?'*

*MiS: 'My name is Michael. What is your name?'*

*MaS: 'Mary.'*

*MiS: 'That's a lovely name.'*

*MaS: 'Thank you. (10) I'm waiting for my husband.'*

*MiS: 'What's his name?'*

*MaS: 'I (5) I'm not sure.'*

*Mary looked away from Michael to the other side of the room where the French doors led house. Her gaze paused there for a moment, then she looked down at her hand. She twirled her golden wedding band around the finger. Michael wore a matching wedding band.*

*MiS: 'I am sure that he will turn up.'*

*Mary turned her neck to face Michael and they both smiled.*

*Sally Stewart: 'You are married to each other.' Sally's voice cracked.*

*I turned to look at her. Tears were running down both of her cheeks. She grabbed a tissue and wiped her eyes.*

*SS: 'You are Michael Stewart.' Sally pointed at Michael. 'You are Mary Stewart.' Sally pointed at Mary. 'And I'm your daughter, Sally.'*

*Mary and Michael looked at one another. Mary's right hand continued to twirl her wedding band. They held eye contact for a few moments then Mary turned to Sally. Mary broke the silence.*

*MaS: 'No. That can't be right.' Tears started running down Mary's face. She turned to look at Michael. 'I don't recognise him.'*

*Sally got up from her chair and walked to the doors which led to her part of the home. I followed after her.*

*We sat at the dining room table in the main part of the house. She cried for a few more minutes. 'It's so hard, watching them...' Sally ended abruptly. She wiped her face with another tissue.*

*ML: 'I will leave.'*

*SS: 'No, no. This is important.' She paused for a moment. 'It's important that you see this.'*

*We both stood up from the dining table, then walked through Sally's sitting room and back into the annex.*

This event represented a profound shift for how I understood the significance of 'forgetting'. Although I previously fixated on forgetting in everyday contexts, these seemed relatively trivial. If Michael or Mary forgot the date or time, then I knew Sally would either help orientate them. She helped to provide a routine through preparing their meals, and as I later learned taking them out to garden centres. Yet here I observed the wider possibilities of what can be forgotten and their implications for everyday living with dementia. Forgetting not only who people are but also their potentially significant social relationships to the person living with dementia.

It is only after I left the Stewarts' home and could physically and emotionally begin to distance myself from this encounter, that I was struck by how neither Michael nor Mary was initially alarmed or distressed. Was this a potential 'silver-lining' to both Michael and Mary forgetting about their marriage? It meant that neither appeared to me to experience trauma from not recognising each other as husband and wife. Perhaps, both people having dementia may have protected their feelings. They may have experienced a different outcome if one of them did not have dementia and still could recognise the other as their spouse.

In contrast, Sally, who also witnessed this conversation between her parents, knew that the two people in front of her are her married parents. Witnessing her parents equally unable to remember each other as husband and wife, led Sally to cry whilst trying to explain to her parents that *they* were married. This shows that forgetting may not only affect the person with dementia, but the people around them. In this case, Sally, the daughter and informal carer of Michael and Mary, was the person who experienced initial emotional distress from her parents forgetting.

Although Mary and Michael appeared unaware of their marriage to each other, this changed when Sally told her mother that the man next to her is her husband and Sally's father. Although Mary tried to deny Sally's claim ('that can't be true'), she still started to cry. Did this signify Mary's sudden awareness of her relationship to Michael? Perhaps she recognised some truth to Sally's words, but she still could not cognitise, could not recognise this relationship herself (she 'didn't recognise' Michael). From Mary's point of view this could appear logical: if Mary were married to Michael, then she would surely recognise her husband. Yet she did not. This may suggest that despite 'forgetting' she was married to Michael, there was still some other aspect of the sequence of events that caused her to cry. It may have been witnessing the woman in front of her, whom she may or may not have recognised as her daughter, crying. Perhaps it stemmed from Sally telling her that she was married to a man that she did not remember. Perhaps she recognised some truth in the conviction of Sally's words, yet still could not recall why the man beside her was important. While all of these questions are speculative, they illustrate the difficulty with addressing how people with dementia 'forget' not only who people are but also what their relationships were with them. To ensure I did no further harm, I did not ask questions to any of the participants during this event nor did I mention this time to them in any follow-up visit. It was enough for me to observe it once and see the toll forgetting could take on a family. I did not – I could not – as another human who felt their own small heartbreak from this interaction again discuss it with people more deeply affected by it. Experiencing it once helped to

shape my ethnographic sensibilities, but my sensitivities and ethics made sure that I did not ask others to relive it.

After I finished fieldwork with the Stewarts, I later reflected on this experience in relation to assistive technologies and telecare. It appeared to me to highlight potential limitations for the role of technological practices and interventions to address 'forgetting' as memory problems. Whereas the practices of people with dementia using calendars may help 're-orientate' them with normative relations with time, the specificity of forgetting experienced and observed here by all present could not be mitigated through assistive technologies. This highlights a potential problem for current approaches to 'technology-enabled care services': people with dementia may re-orientate themselves to specific tasks such as 'knowing' the time with assistive technologies, but practices connected with assistive technology cannot attend to other cases where people with dementia 'forget' the people in their lives. These other instances of 'forgetting' may therefore have significant, long-term consequences for the quality of the relationships people with dementia have with other people including their family and informal carers.

### 5.3 Memory problems as 'misremembering'

The second memory problem I came to identify was 'misremembering'. In this study, 'misremembering' describes any case where a person with dementia recalls information, but the information was no longer accurate or relevant for the specific situation. Misremembering in this study was observed less frequently than 'forgetting' as previously described. However, misremembering illustrates the potential complexity of memory problems people with dementia and their informal carers experienced. The information they discuss had previously been 'right' when applied in the context of their past experiences with people and places, but changing circumstances rendered the information irrelevant or 'wrong'.

This section draws on visits with Betty and Rose from East County to illustrate Rose's 'misremembering' as an everyday practice for a person with dementia living in the community. Rose was a retired professional woman in her eighties diagnosed with dementia. She lived alone in a bungalow in a small village. Betty was Rose's next door neighbour who lived with her male partner of several years. Betty used to work with Rose before they both retired. Betty acted as Rose's informal carer as Rose had no close relations living in the area. Betty visited Rose almost every day except for when she frequently travelled to Scotland for golf trips or holidays in Europe.

I selected Rose and Betty as a case to illustrate a shift in my own taken for granted assumptions about memory problems and memory loss as a particular problem. Although Rose had relatively advanced and severe dementia symptoms, my fieldwork with her and Betty led me to reconsider my own assumptions about memory problems. The broad categories of memory problems and memory loss did not quite capture what I observed with participants. People forgot information about people, places, events and even had difficulty recalling the time. Yet people also recalled information that had a truth to them. The case of Betty and Rose highlights this aspect of memory problems as 'misremembering'.

### 5.3.1 Recalling former addresses for Christmas cards

To introduce 'misremembering' as a way of enacting memory problems for people with dementia, I wanted focus on an innocuous and relatable story from my time with Betty and Rose: the annual practice of filling out Christmas cards. It was the second time that I visited Betty and Rose now in early December with frosted grass visible from the rear windows in Rose's sitting room. I sat in the chair beside the sliding glass doors just as I had on the first visit. Rose sat in her chair and Betty sat on the couch beside Rose with a stack of Christmas cards beside Betty. Rose had a small table beside her chair to lean on whilst she filled out the cards.

*Betty: 'I will fill it out. You just need to sign it, 'Love, Rose'.' Betty explained to Rose as she passed her a Christmas card with a robin covered with glitter on it. 'I'll write out the addresses.'*

Betty grabbed the envelope from the pile and placed it on the white, plastic cutting board on her lap. She picked up a pen from the settee cushion to her left. Next she looked at Rose's address book and copied the address from inside of it.

*B: 'This is for Sarah and Andrew. Do you remember them?' Betty looked up from the envelope toward Rose.*

*Rose slowly turned her head toward Betty.*

*Rose: 'No.'*

*B: 'Sarah and Andrew from Market Town? You don't remember them?' Betty asked once again, her voice becoming gentler. Silence.*

*I looked up from my jottings to find Rose staring at me. I returned her eye contact. Next she tilted her head and pulled a face at me. We both smiled.*

*B: 'No, then?' Betty persisted.*

Betty stood up and walked to the opposite side of the room. She stood in front of a large bookshelf that took up the whole wall. She pointed at a photograph on the top-centre shelf.

*B: 'This is Andrew and Sarah. Sarah is Carol, your niece's daughter, that would make her your...' Betty paused and looked at me.*

*R: 'Great-niece?'*

*ML: 'Yes, great-niece.' I agreed.*

*R: 'Oh yes, Sarah,' Rose nodded her head.*

*B: 'Andrew is Sarah's husband. I think that he is pastor in the church or something,' Betty suggested.*

*R: 'I don't know. (10) I thought Sarah lived in East Village.'*

*B: 'No. She hasn't lived there for years. Since 2010?'*

*Rose did not respond. Betty walked back over to the settee and sat down.*

*B: 'Have you written, 'Love, Rose' yet?' Betty asked as she closer to Rose in her chair.*

*R: 'No.'*

*B: 'Well, go ahead.'*

Rose picked up a ballpoint pen on the wood and metal desk in front of her and wrote something inside the card. She handed the card to Betty who, then, placed it in the addressed envelope and folded the flap into it.

At the time of this interaction, I did not appreciate its relevance for understanding memory problems. I noted the interaction down in my journal, but only after reflecting on this interaction over the following days did I begin to consider what this exchange represented for Rose's memory problems arising from her dementia. To me it illustrated the specificity of information people with dementia may not correctly recall rather than categorising the information as memory loss. Rose could remember a village where Sarah, her great-niece, previously lived, however, it was not the village where she currently lived. Although I did not know what prompted Rose to ask where her great-niece lived. Betty did not mention the current address of Rose's great-niece. Yet the previous village still helped Rose orientate herself and recall details about her great-niece. Misremembering may not present accurate or current information such as where a relative of Rose currently lived in this case. But categorising this practice as 'forgetting' or 'memory loss' would misrepresent the ability to recall partial information even it appeared outdated to other people. Despite this apparent functional limitation to recall information, the 'wrong' information Rose remembered, still helped her identify and remember who her great-niece was in this interaction. Perhaps misremembering can still help a person with dementia make valid connections about other interrelated information.

Later reflecting on my time with Betty and Rose signified the first time where I focused on more than just forgetting as a sign of a memory problem or dementia. I began to see that people with dementia knew partial information, incomplete information or outdated information. This did not signify a complete loss of memory, but a memory problem which becomes more important through socialisation with other people. Misremembering became apparent only when informal carers or other people corrected the person with dementia.

For this ethnographic case, assistive technologies appeared ill-fitted to address misremembering. Betty only received an automatic falls detector from the local council that served her village in East County. Therefore, the assistive technology could not attend to her experiences of misremembering. However, this raises the question of whether any current generation assistive technology can address misremembering for people with dementia. Practices of misremembering appeared to me as tied to the specificity of the information recalled at any particular point in time. How could assistive technology predict what information Rose might misremember in a specific interaction with Rose or

another person? Yet Rose was able to remember her great-niece through the intervention of a fully-informed carer like Betty. Informal carers may have an important role for helping address the specific instances of misremembering people with dementia experience in everyday life in ways that assistive technologies did not appear to do.

### 5.3.2 'Don't lose your memory'

A month later I returned to East County to visit Betty and Rose. Rose no longer remembered my name as she had during previous visits, but she still smiled and nodded along when I re-introduced myself and told her about my study. During this visit I had a brief interaction with Rose after Betty left the room to answer the door. The moment stayed with me as it represented to me a moment where Rose, for the first and last time during this study, articulated her feelings about living with memory problems.

*Betty: 'I wonder who that is,' Betty looked to me then turned to Rose.*

*I also heard someone knock on the door. Betty looked at her watch.*

*Betty: 'It's too early for the carer.'*

Betty got up and crossed the length of the sitting room before she disappeared out of my sight. I heard her open a door, then the sound of her talking to another woman. I heard both of them laugh but I could not make out any words. I swivelled my head to look at Rose only to find her looking straight at me. Her face looked suddenly serious.

*Rose: 'Don't lose your memory.' She paused for a moment. 'Not remembering who you are, what you are, if you are...' her voice trailed off before she finished the sentence. She closed her eyes, raised her left hand then rubbed her temple. The tip of her tongue poked out of the right corner of her mouth. I looked away as Betty and another woman entered the sitting room.*

The exchange reflected a rare moment when Rose and I spent time together without Betty present. The moment lasted only a minute or two, but the interaction raised several questions about how Rose made sense of her memory problems as part of her everyday life in the community. Rose told me 'not

to lose my memory'. I did not know whether she believed people could control their memory loss. However, the words she continued to choose may suggest that if she had control of her memory loss she would not have chosen it. She presented several ways that memory loss affected how she viewed her own existence: 'Not remembering who you are, what you are, if you are...'. These appeared to represent different ways that her memory problems affected her sense of self.

'Not remembering who you are' suggests her memories were no longer clarifying for herself who she was. This was not an uncommon experience for people with dementia nor was forgetting other people. 'Not remembering what you are' suggests that memory loss may have led her to question what she was although it was unclear what she meant by 'what'. Was she questioning her humanity, identity with a particular gender, race, class, or religion? The phrase may suggest that she can no longer identify how she associates or differentiates herself from other people or things in the world. The final fragment ends abruptly, 'if you are...', yet it could suggest that Rose's memory problems led her to question her very existence in the world. Were her memory problems acute enough to make her no longer recognise her practices and engagements with people, places and things around here as substantive and real? How can assistive technologies, current or imagined, address memory problems when they problematise a person's very existence, their very being? I did not have any answers for Rose then and even now I am at a loss for how to understand what appeared as a profound existential concern arising from living with dementia. However, the questions presented here arose in the context of showing the interactional challenges people face when their memory problems. They appeared to disrupt the connections people with dementia have with the world around them and their place within it. This raises additional questions about the role of assistive technologies in helping people with dementia overcome functional loss such as memory problems. When a person with dementia questions their presence in the world as part of their everyday experience, then assistive technologies may have limited appeal or capabilities to address these serious concerns and meaning about life with and beyond dementia.

## 5.4 Chapter summary

This chapter conceptualised 'memory problems' as specific and emergent everyday practices for people with dementia that differentiated them from their informal carer. Two particular cases were selected from the wider data set to illustrate two particular instances of 'memory problems' that were experienced by several participants: 'misremembering' and 'forgetting'. These experiences also helped to frame a functional problem that assistive technologies were designed to address, therefore,

examining the practices of people with dementia in the community with these technologies revealed how they used them and allowed for discussions to explore why they used them as well. Interactions highlighted the apparent taken-for-granted practice of people without dementia expecting people with dementia to 'perform' memory problems when they are asked to demonstrate they have dementia. It also problematized the inherent 'assistiveness' of formally provided technologies from social care providers. Instead, it appeared that 'assistiveness' was co-constructed and negotiated through interactions between people with dementia and their informal carers. Specific types of assistive technologies such as memory aids were also problematised, since the technologies did not address the 'memory problem' but only helped a person with dementia with reorientation. They would still continue to forget events, things, and even close relationships to people around them. 'Assistive' technologies may help a person with dementia re-orientate with time yet they may not attend to the more socially orientated implications and consequences of forgetting and misremembering. These suggest that everyday experiences of living with dementia must be understood in a wider context rather than a narrow focus functional activities. Through examining everyday experiences of living with dementia in the community, we can better understand why assistive technology or everyday objects may help re-orientate a person with dementia yet also appreciate how the specificity of how people with dementia enact memory problems as everyday practices may also make these technologies impractical or ineffective for addressing 'memory problems'.

A recurring element highlighted in this chapter was the role of the informal carer helping the person with dementia engage in everyday activities and maintaining assistive technologies. The next chapter, therefore, explicitly examines how care practices were understood and enacted through the everyday and technological practices of informal carers *on* or *to* people with dementia.

# Chapter 6: Understanding 'care' through everyday and technological practices

## 6.1 Introduction

How can technologies support care? This question stuck with me during my fieldwork. To answer this question, I examined additional literature to review how other scholars defined 'care' to help situate my own observations of participants' activities in the field. Berenice Fisher and Joan Tronto (1990), one of the most highly cited definitions for care in academic scholarship, defined 'care' as:

a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web.

This broad definition let me consider 'care' as any activity that could support a person with dementia. I came to identify two specific sets of practices as distinct domains of care: 'care as concern' and 'care as surveillance'. This chapter examines how I came to see different groups of participants as constructing care practices with and without assistive technologies and telecare as providing 'care in the community'. In this chapter the first domain of care, 'care as concern', is illustrated through fieldnotes relating to the Smiths. While fieldnotes from some cases described the common experience of informal carers telling me about their concerns for the wellbeing of a friend or relative living with dementia. This affective practice of caring about a person is key to understanding why people seek support from assistive technologies and telecare to give them 'peace of mind'. People may also become anxious when technological practices threaten how well they imagine a friend or family member lives. The case of the Smiths was selected as illustrating the importance of expressing concern as a catalyst for seeking support from formal care services. The second domain of care examined here is 'care as surveillance'. To illustrate this second domain, fieldnotes describe the Campbells' practices in using two monitoring technologies: a privately purchased CCTV system and telecare sensors provided by Metro Borough Council. Although both technologies are designed to monitor people, the findings seek to show how people with dementia, informal carers and

representatives from a local authority define what they see as appropriate monitoring of people with dementia.

## 6.2 Care as concern: Caring for people's happiness and wellbeing

Here I consider the practice I identified as 'care as concern'. Informal carers frequently stated that they were 'concerned' about the happiness or wellbeing of a friend or family member with dementia. Informal carers in this study explained to me that their concerns arose from a previous incident or emergency they experienced with the person with dementia.

Each visit with the Smiths usually lasted an hour and a half. The Smiths always invited me to visit at the same time during each visit, between 10 AM and 12 PM., around the same time of day as the recruitment visit. During each of the six visits with the Smiths from November 2015 to June 2016, we occupied the same positions that we did during that first encounter when I invited them to take part in this study. Christopher sat in his chair in the corner of the room by a window facing the back garden. I sat on the couch. Lauren sat on a second chair in the middle of the sitting room only occasionally getting up to make us all cups of tea. These short visits provided glimpses into the lives of the Smiths, which however, emerged through talking with Lauren and Christopher rather than direct observation.

### 6.2.1 Lauren's concerns about her father's wellbeing

Lauren and I usually spent our time talking about her dog walks in Coastal County or about her father's overall health. Yet this visit was different. It was my third visit to Christopher's home in Doeham. Christopher, Lauren and I sat in the sitting room on the cold winter morning. Christopher and Lauren sat on two chairs opposite from each other. I sat on the couch adjacent to both of them. I sat on the cushion closest to Lauren while her father slept in the chair. Here she spoke to me for the first time about her concern for her father.

*Lauren Smith: 'I worry about him.' [She turned her face to look briefly at her father before returning to meet my gaze.]*

*ML: 'Why is that? Is there something in particular?'*

LS: 'He hasn't been sleeping well at night. He [she waves her hand to indicate her father in his chair] gets confused about where mum is. He forgets that she died years ago. He called the police a couple of weeks ago to report his wife left him and took the children with her.'

ML: 'That must be very difficult.'

LS: 'He even recently started leaving the house at night. (7) His neighbours have my mobile number, so when they saw him leave the house alone one evening they rang me. I was at home, so I did not know what to do. I asked them to help him inside. Thankfully, these were the nice neighbours so they did.'

ML: 'Yes, things may have gone differently if the other neighbours were involved.' [I point behind me to indicate the 'other' neighbours.]

LS: 'Yes. [Lauren nods] I asked the local council if there was anything they could do to help. They sent a woman over to look at the house and talk to me and dad. A man came by a week later and put little sensors on all of the doors that lead out of the house. They [the door sensors] alert [East County Care Services] if he tries to leave in the evening.'

ML: 'That sounds like a good solution. How long have you had them for?'

LS: 'I think he has had them in place for about three weeks. (10) [She looks down at her foot for a moment before looking at me again.] They worked fine for a while. But one day when one of the carers came in the morning to dress dad and make breakfast, she found the door open and dad lying on the floor. She had to call another person to come and help him up. I came to visit him in the evening after I finished work. He was very shaken and confused.' [Lauren and I both turn our heads away from each other and look at her father, who is still sleeping in his chair.] I am waiting to see what if anything [East County Care Services] can do now. I don't want to move him into a home yet.'

Here Lauren explained to me that she was worried about her father's lack of sleep as it appeared to illustrate Christopher continuing to leave the house at night to search for his long-deceased wife. Yet Christopher apparently believed that his wife was still alive and had left him and took the children with her. This suggests that he not only thought his wife was alive but that she was still young enough

for their now adult children to live with them. Therefore, Christopher appeared to confuse memories of his family life with present expectations who ought to live with him. Such confusion even appeared to affect his wellbeing.

Lauren explained to me that her concern about her father's confusion intensified when one of the neighbours rang Lauren after they found Christopher outside his house one evening and helped him back inside. This event prompted Lauren to seek assistance from her father's local county council, East County Care Services. An occupational therapist from East County Care Services following a home assessment she undertook at Christopher's home with Christopher and Lauren had another member of East County Care Services install door sensor alarms (see Appendix IX for an indicative picture). Lauren explained to me that the purpose of the door sensors was to 'alert East County Care Services' if her father tried to leave in the evening again. However, in Lauren's next comments, they did not work at least one time: a paid carer from East County Care Services came by for her morning visit to Christopher's home only to find the door open and him lying on the floor of the house. The paid carer contacted Lauren who again contacted East County Care Services to investigate other potential solutions for her father's confusion and raise her ongoing concerns about his safety and wellbeing.

Christopher had been fortunate that the paid carer found him inside the house. If he had fallen or passed out outside of his house in January when the incident occurred, then he may have died from exposure. This highlights how 'concern' emerges through imagined and real risks to the wellbeing or happiness of a person with dementia. Lauren was told her father left his home by her father's neighbour and her father's paid carers informed her that they found him lying on the floor passed out. These experiences identified a potential risk to Lauren: her father could try to leave the house again. Since she did not live near her father, so there was no way she could monitor her father to ensure his safety in his house. To address the potential risk of Christopher leaving his home, Lauren articulated this perceived risk as 'care as concern'.

This conversation illustrated how Lauren presented 'concern' for her father as an impetus for her to seek professional care solutions to support her father in common with many carers motivated to seek additional approaches to providing alternative, and perhaps more formal types of care. In other words, Lauren deployed 'concern' when discussing her father's habits with formal care services to illustrate how she 'cared about' her father through taking responsibility for his wellbeing. She spoke of wanting him to be safe in his own home rather than moved to a residential care home. Therefore, Lauren's practices of 'care as concern' were expressed as being 'worried' for her father and led to her

then searching for additional formal support to help her in 'giving care' to her father. In Lauren's case, it was through using telecare technologies that she sought to address her concerns and then help support her father. Lauren sought professional help to mediate new practices to 'care for' her father. Lauren expected the door sensors provided by East County Care Services to serve this purpose. However, they did not here. This subsection suggested that 'concern' was a practice of care that emerged through informal carers identifying practices of people with dementia as 'risk'. The informal carer discussing her concern, therefore, led her to identify a new need that she could not meet within her current care practices for her father so leading to the informal carer to seek support from formal care providers.

### 6.2.2 Telecare practices to provide 'peace of mind'

During the fourth visit with the Smiths, I had the opportunity to learn more about how and why Lauren used the new telecare technology, an activity monitoring system (see Appendix IX for an indicative picture) that East County Care Services had installed since the previous ethnographic visit. I asked Lauren 'how she and her father are getting on with the technologies?' She smiled widely before she explained that she received a new 'kit' since my last visit [in February].

She got up from her chair and walks over to a small chest of drawers directly across the room from me. The height of the chest of drawers came up to her waist, however, above the chest of drawers Lauren pointed to a round, opaque and plastic object mounted on the wall. I asked her what it was. She told me that it's called 'JustChecking' and it is 'used to detect motion'.

*Lauren Smith: 'This way I know how often dad gets up or if he does not get up, then I can ring him,' she explained.*

I asked her how she can know 'how often' her dad moves around. Lauren took two steps back to her chair and picked up her rucksack. She pulled out her iPad from inside it and waved me to come over to her. I got up from the couch and stood beside her. Both of us looked at the screen of her tablet. She explained to me that when she is home, then she can check to see 'how active he is' based on when the motion sensors in different rooms are activated on the 'app' for the device. Lauren told me that the current position was selected because the motion sensor captured activity in a 'wide area'. She moved her arm from side to side indicating an arc of the areas of the sitting room that the device monitored. I asked her how many sensors are in the house. She asked me to follow her into the corridor. We walked out of the sitting room and into the corridor.

*LS: 'There is one in there.' She pointed to the left into the kitchen. 'One in the loo.' She pointed straight ahead to a room with tiling exposed behind a door left slightly ajar. 'There is one here too.' She pointed to the wall just to the left of the entrance to the bathroom door about a meter off of the floor. 'Finally, there is one in his bedroom. We placed this one just off of the floor so it would pick up the motion of his feet when he gets up rather than him moving in bed at night.' I nodded in agreement with the logic behind her choice for placing the bedroom sensor. 'We didn't place a sensor in the spare room, because dad never goes in there. We also have sensors on the front door and the door to the garden.' She explained that these sensors can 'tell me if the door is left open'. 'That's all of them though.'*

She led me back into the sitting room where she sat down in her chair. She replaced the tablet in her rucksack. I took my seat on the couch and asked her what she thought about the new system. Lauren smiled again. She told me that she 'likes it' that it was 'invaluable' for giving her 'peace of mind about my dad'. I asked if her father had any more emergencies lately. She responded that she has not had any alerts since she installed JustChecking.

Here we see how telecare may address aspects of the concerns for her father's wellbeing Lauren previously described, particularly now because he thought his wife and children left him. In Christopher's confusion, he left the home but was brought back by his neighbours. Although Lauren imagined future risks to Christopher's wellbeing, she was not ready to move her father into a residential care home. Such concerns, as she expressed them to me, led her to seek support from professional care providers. The door sensors that East County Care Services had originally provided ineffective for an unstated reason as shown by the paid carer finding Christopher's front door open and him lying on the floor. Lauren contacted East County Care Services who provided the telecare system. Lauren was happy to show me the new system including how she can monitor her fathers' activities in every room of the house except the spare bedroom because Christopher 'never goes in there'. However, Lauren had no way to guarantee that her father would not go into the room in confusion. Lauren's previous account illustrated concern about her father's whereabouts and wellbeing before the activity monitoring system was installed. If the spare bedroom was not monitored, then it was possible there was activity that she dismissed due to how she imagined her father lived at home.

I noted that Lauren, Christopher and I all came to be located in the sitting room together. The accompanying fieldnote excerpt illustrated Lauren's practices with the telecare system, but it also illustrated Christopher's bodily absence from Lauren's new care practices. In the second subsection, her gaze would drift to her father as she discussed her concerns about his walks at night. However, the selected fieldnotes above focused exclusively on Lauren's particular and sustained focus on the new telecare system. Even when Lauren explained to me how the system worked, she never indicated to or invited her father to join in the conversation. Much of her language and practices with telecare appeared to have the effect of objectifying her father, i.e. Christopher became an object of technologically-enabled monitoring rather than a subject of his daughter's co-located and personal concern. Lauren spoke of her father, but she did not speak to him. She monitored her father's depersonalised movements, but she did not see or locate *him* in her dislocated, monitoring practices. This suggests telecare may shift how care is practiced. When informal carers and people with dementia are no longer co-located during care, then technological practices objectify care. Technologies do not objectify care nor constitute 'cold care' (Pols and Moser 2009), instead, it is practices with these telecare technologies that objectify care through decontextualising people from situated living practices and locations.

Lauren also affirmed that the telecare system gave her 'peace of mind', precisely identifying this as because she could monitor her father's movements on her app whenever she liked. This illustrates why Lauren chose to use practices with telecare as her method for 'care giving'. However, Lauren's practices with telecare shift her 'care as concern' about her father's wellbeing from 'caring about' to attending to data analytics of her father's movement generated by telecare sensors. However, even using telecare technologies as they are designed to be used cannot remove the risk of Christopher leaving his house at night that initially led to Lauren's expressing concern about her father's wellbeing. Christopher was still free to leave the house at any time of day. The activity monitoring system could not prevent Christopher from leaving his home, it could only collect data about when he opened the doors and whether movement was detected in his house. If Christopher left at night or during another period when Lauren could not look at the app, then Christopher could still face the same potential risks to his wellbeing as he was effectively unmonitored. This means that the 'peace of mind' telecare provided to Lauren may be fragile, temporary and contingent. Lauren's 'peace of mind' may disappear if confronted with information that her father still enacted walking practices she viewed as risky.

### 6.2.3 Telecare practices create distress

It was my fourth visit with the Smiths. We were all sitting in our usual seats: Christopher and Lauren on their chairs and I on the couch. We were drinking tea and discussing dogs when Lucky entered the sitting room. Another actor that I had previously excluded up until this point from accounts of fieldwork with the Smiths was Christopher's little terrier, Lucky.

Lauren sipped her tea and placed the mug on the small table beside her chair. I heard the jingling of a bell at my feet. I immediately recognised the sound as the bell around Lucky's collar. I bent over and stroked the back of his ear. He leaned into my hand until he toppled over onto his side. He quickly rolled onto all four legs, then jumped up onto the couch beside me.

*LS: 'He shouldn't be up there,' Lauren told me. 'He knows better,' she continued. 'Lucky! Get down from there!' she yelled to the dog.*

Lucky walked along the length of the couch until he laid down beside. I asked Lauren if she wanted me to put him on the floor.

*LS: 'No, it's fine. Dad must be letting him up there now,' she suggested with a grimace. I tried to hide my smile as I stroked Lucky. I looked up from Lucky and noticed that we both sat right in front of the motion sensor in the sitting room.*

*ML: 'Lauren, how long do you think Lucky has gotten up on the couch?' I asked.*

She told me that she didn't know and asked 'why?' I pointed to the motion sensor on the wall. She looked at the sensor for the moment with raised eyebrows, then looked back to me wide-eyed.

*LS: 'You don't think?' she started to ask.*

I cut her off mid-sentence and asked whether the sensor may pick up the dog's movement rather than her father's.

*LS: 'Possibly. I never thought of that though.' She paused for a moment. 'Does this mean when I think my dad is getting out of his chair and walking across the room that it's actually Lucky?' she asked me. Her eyes still wide in what I interpreted as shock and distress*

*ML: 'I don't know,' I confessed. 'Is it possible?'*

*LS: 'I don't know either. I..I think it is though.'* She slumped back in her chair. Neither one of us said anything.

This illustrated how potential alternative interpretations may contest what carers previously imagined as an appropriate care solution. When I suggested to Lauren that the sensor may monitor Lucky, the dog, instead of or in addition to her father's movements, Lauren again seemed concerned. She questioned me about whether it was possible she monitored the dog instead of her father, but I did not know the answer. She did not anticipate what other people or animals the sensors may also monitor nor whether the app could differentiate between them from her father.

Here we see a further shift in Lauren's care practices with telecare. The 'peace of mind' she claimed to have during my last visit was apparently replaced with confusion and distress when she and I both suspected she was not monitoring her father with the telecare as she originally believed. Lauren envisaged that she 'cared for' her father through monitoring his movement at home and ensuring he did not leave the house unintended. However, when I suggested that her practices may instead monitor the dog rather than her father, it shifted her 'caring for' back to a form of 'care as concern' for her father. She wondered aloud whether she misinterpreted the frequent movement on the system's app as her father when it was actually the dog. I had neither the knowledge about the technology's capabilities nor did it fit my role as observer to confirm or alleviate her concerns. The effect of telecare, rather than reducing Lauren's concerns was actually to amplify them. Lauren still remains uncertain about what her practices with telecare actually achieve when she uses the app ostensibly to monitor her father. Therefore, telecare may serve to address carers' concerns for people with dementia. Moreover, telecare can also create novel forms of distress or concern when the capabilities of the technology are unknown and carers are unsure about whether they are using the device appropriately. Furthermore, the increased emphasis on 'caring for' a person *through* telecare technologies may actually decrease involving people with dementia in their own care choices and as direct participants in shaping the care they receive.

Social relationships between people with dementia and informal carers, represented through social and familial roles, may become further disrupted rather than being re-connected through technological care practices. In other words, technological practices with telecare may exacerbate how informal carers relate to people with dementia when they 'care for' and 'give care' to them. When people with dementia and informal carers no longer co-located and co-produced care practices,

informal carers appeared to have the power to decide what constituted care based on how they viewed the actions and needs of people with dementia. This allowed for 'care as concern' to emerge as informal carers identified potentially risky activities which they imagined people with dementia would enact. Therefore, it should not come as a surprise that the technology offered by formal care services addressed the concerns of informal carers rather than directly attending to the needs of people with dementia. Monitoring is designed to give 'peace of mind' not necessarily stop or address the actions of a person with dementia.

### 6.3 Care as surveillance: Contested interpretations of using CCTV and telecare

'Care as surveillance' was another practice which identified an alternative type of 'care' for people with dementia their informal carers taking part in ATTILA. In this study, health and social care providers frequently provided people with dementia and their informal carers with telecare and other technologies that help monitor the whereabouts and activities of people with dementia, e.g. worn GPS tracking devices. Seven of the ten people with dementia taking part in this study wore some form of monitoring technology or had it installed in their home. Violet Draper had a bed occupancy sensor to determine whether she returned to bed. Michael and Mary Stewart had door sensors on all exits of the house they shared with their daughter, Claire. John Anansi and Mrs Archer both had a GPS tracker they were supposed to wear whenever they left the house. The Smiths, as I described earlier in this chapter, had an activity monitoring system to check whether Christopher got up from bed or left the house at night. The final person with dementia that had monitoring technology was Lillian Campbell.

#### 6.3.1 Kenneth installing CCTV to monitor Lillian's location in the home

During my second visit with the Campbells, I spent the whole time with Kenneth in the downstairs sitting room. Lillian was at a day centre for the afternoon. I asked Kenneth if he had any 'technologies that helped him care' for Lillian. He nodded and took another drag from his cigarette. His head continued to bob up and down as he exhaled.

*Kenneth Campbell: 'Yeah, I have something upstairs' he replied. I asked what type of technology it was. 'A set of cameras,' he replied. '*

*ML: 'What kind of cameras?' I probed.*

Kenneth took another drag from his cigarette. He shook the ashes off into a large crystalline ashtray on top of the worktop. He told me that he bought and set up cameras in the house in order to make sure that his mother was 'safe' and 'didn't get into any trouble downstairs when I am not down here.'

*ML: 'What kind of trouble?' I asked.*

*KC: 'Falling down the stairs to the kitchen and sitting room. Wandering around downstairs. Messing around with clean bed linens.' He pointed up with his head. 'There's one.'*

I turned around in my chair. Above the three stairs that lead down from the front of the ground floor to the sitting room was a grey and black metal camera. It looked like a security camera that I usually see in shops.

*KC: 'There's one on the other side of the stairs too.' He paused for a moment to take another drag from his cigarette. 'They cost me £200. But I think it is worth it so I can watch a film or play guitar upstairs. I can watch for mum on the screens in the other room to make sure she is fine.'*

When I first asked Kenneth about whether he had any technologies that helped him care for Lillian, I meant to imply assistive technologies or telecare provided by the local council or NHS Trust. However, Kenneth inferred that I actually meant *any technologies* that he used to help him care for his mother. Kenneth told me that he purchased 'cameras' that helped him care for his mother. I was surprised that he considered cameras as a technology that could help him provide care for his mother, but I probed him for more information. He told me that the cameras allowed him to keep his mother 'out of trouble'. Kenneth defined trouble as common activities other older people with dementia experience such as 'wandering' or 'falling'. This suggests that Kenneth also viewed the role of practices with technologies for people with dementia was to address risks like Lauren did with her father in the previous section. However, Kenneth explicitly defined his reason for using the cameras as a means for keeping Lillian 'safe' when he was not also downstairs. Although he did not explain why he needed to be downstairs, the activities he identified, 'wandering' and 'falling' suggest that he would either attempt to prevent or help Lillian with either of these 'troubles'. Therefore, cameras allowed Kenneth to monitor Lillian in order to make sure that she did not take part in practices or actions that he thought would endanger her safety. This suggests that Kenneth views monitoring and

surveillance through a CCTV system as methods for 'giving care' to Lillian. In other words, Kenneth constructed his practices with a CCTV system as 'care as surveillance'.

### 6.3.2 Metro Borough Council provided telecare

Later during the second visit with the Campbells, the return of Lillian with one of her paid care workers prompted Kenneth to tell me the story about how Metro Borough Council provided telecare products (see Appendix IX for indicative pictures) to Lillian and Kenneth as a replacement for the CCTV system Kenneth used to monitor Lillian. The event still takes place in the downstairs sitting room where I sat on a wooden chair in the middle of the room and Kenneth sat on a stool in the downstairs kitchen about five feet from me.

*Kenneth Campbell: 'Sorry about that. I had to let mum's carer in,' Kenneth said in a quiet voice.*

He stomped past the chair where I sat and into the kitchen. I heard a female voice come from behind me followed by a knock on a door. Silence for a moment, then I heard the sound of a door opening and closing followed by muffled voices in another room. Kenneth pulled a mint box with the Cross of St Andrew emblazoned on its top from his trouser pocket. He opened the lid and pulled out a cigarette. Next he picked up his lighter from the worktop, placed the butt in his mouth, and lit the other end. He sat down on the stool and faced me again. He took a long drag and exhaled.

*KC: 'Sorry, I'm not very happy with them at the moment.' Kenneth pointed toward the front of the house with his cigarette. 'I am currently fighting with the Council,' he explained.*

*ML: 'Why?'*

*KC: 'I will make mum meals, but I won't help her wash. There are some things that a son shouldn't do.' During one visit 'about two months ago', she confided in Kenneth that other carers 'bullied' her in the office. 'I told her: 'Don't get involved in office drama. Just keep your head down', he told me. The carer told Kenneth a couple of weeks later that 'it worked'. Kenneth told me that he thought they were 'friends'.*

*KC: 'Three weeks ago, she comes over to visit mum in the morning, then we started talking about photography'. I led her upstairs and showed her my photography equipment – different lenses, my DLR, you know?'*

*Kenneth explained that she saw the monitor for the cameras in the room too and she asked him what they were for.*

*KC: "I use them to watch mum when I'm up here," I told her. I didn't think anything of it.'*

Kenneth explained that the next day the paid carer's supervisor rang him. 'She told me, 'I can't believe that you are using cameras to watch your mum. That's borderline abuse. Cameras are too invasive in a person's own home.' Can you fucking believe it?' Kenneth's voice rose as he cursed. His face was flushed. Kenneth told me that 'maybe a week later' another person from the Council came to the home. 'She looked around, talked to me, talked to mum, then she left.' He paused for a moment and took another drag from his cigarette. 'Some bloke come by late last week with some new things for me to try out with mum.'

*ML: 'What were they?'*

Kenneth explained that the man put a 'box on the door' and a 'pad under mum's bed'. 'And what do they do?' I asked. Kenneth took a drag from his cigarette. His back raised and lowered. He told me that the 'box' notifies Metro Borough Council if the door is opened at night and the 'pad' detects if Lillian is out of bed 'for longer than half an hour at night'. I asked Kenneth how and his mother liked using them. 'I don't know. I haven't tried them yet.'

After the paid carer confided her struggles at work to Kenneth, he reciprocated this honesty by confiding his personal interests to her so as to show how he trusted her. He believed that they were friends. This story's description sounded like Kenneth's manner when we, too, spoke together. He always spoke candidly about his life even deeply personal or troubling experience, such as homelessness and substance abuse. Kenneth easily trusted people. Therefore, I was not surprised when he told me that he 'didn't think anything of' telling the paid carer how he used CCTV to watch Lillian.

This suggests some informal carers may place personal trust and value in their relationships with paid carers as lines between professional care and friend appeared to blur. Kenneth regularly saw this young woman when she visited to attend to Lillian's personal care. When they both shared personal experiences, i.e. struggles at work and hobbies, Kenneth interpreted sharing these experiences as

relationship-building practices. As Kenneth described himself, he believed that they 'were friends'. Therefore, when she told her supervisor about Kenneth's practices with a CCTV system to watch Lillian, he was angry. He had trusted her and she betrayed that trust. On the other hand, the paid carer may have felt an ethical obligation to report a practice that she thought was inappropriate. If she did not think that Kenneth's use of cameras was inappropriate, then she probably would not have told her line manager. Perhaps the line manager could have found an alternative approach or language to discussing Kenneth's CCTV system that did not treat his practices as nearly criminal, i.e. 'borderline abuse'. Both Kenneth and the paid carers from Metro Borough Council engaged in practices they defined as care. Kenneth still made Lillian's meals, washed her clothes and bed linens, and brought her to doctor's appointments. The paid carers from Metro Borough Council helped Lillian with personal care. Nonetheless, the paid carer's report to her supervisor created a disruption in Lillian's care network. Kenneth's sense of betrayal contradicted the paid carer's sense of duty to report Kenneth for what she perceived as an unethical practice. However, Kenneth felt betrayed by Metro Borough Council. This may explain why Kenneth did not 'use' the technologies Metro Borough Council provided him. I identified these technologies with two common types of telecare objects based on how Kenneth described the technologies: the 'box on the door' was a door sensor and the 'pad under mum's bed' was a bed occupancy sensor. However, they may also have represented an interaction with a paid carer he perceived as betrayal and a supervisor at the council suggesting that how he cared for Lillian was borderline abuse. This has important implications for Lillian's continued wellbeing. After all, when informal carers and paid carers disagree about appropriate care practices, then how does the 'cared for' prosper? Of course, the contested issue was not 'activities of daily living' practices. Metro Borough Council and Kenneth disagreed that CCTV was an unobtrusive way to monitor Lillian when depersonalised technologies like telecare were available. The issue was about determining what technologies were appropriate for monitoring a person with dementia living in their own home.

Metro Borough Council made their beliefs about appropriate monitoring technologies clear in their strong rebuke of Kenneth's choice of technology stating that CCTV was not appropriate. Technological practices with CCTV were 'borderline abuse' and 'too invasive' for watching a person in 'their own home'. Metro Borough Council's indictment did not describe or Kenneth did not wish to disclose to me what makes monitoring through CCTV 'borderline abuse' or 'too invasive'. However, the line manager who spoke with Kenneth qualified her statement with in 'their own home'. This suggests that CCTV may be an appropriate monitoring technology in other settings aside from someone's personal home. Despite the criticism from the line manager at Metro Borough Council that CCTV was

an inappropriate technology to monitor Lillian from of CCTV as a monitoring technology, we learned from Kenneth that they provided their own monitoring technologies for Kenneth to enact alternative 'care as surveillance' practices. This suggests that the line manager and care workers at Metro Borough Council did not view monitoring and surveillance as inherently 'borderline abuse' or inappropriate, it was something about the approach to surveillance of the CCTV system that made it so. In other words, surveillance could be a care practice with appropriate technologies in place. Metro Borough Council provided a door sensor and a bed occupancy sensor, two telecare technologies that also appeared to monitor the person with dementia as well. However, what they were designed to monitor differed from the CCTV system. Doors sensors detect whether a door is left home for a prolonged period of time. If the door is left open, then an alert is sent to a call centre to check and see if the person living there is home or whether they may face a personal emergency, e.g. 'wandering' or 'fallen over'. On the other hand, a bed occupancy sensor detects whether pressure exerted on the pad sensor indicates 'enough weight' to represent a human occupying the bed. Metro Borough Council may have problematised Kenneth's use of CCTV, because of what monitoring practices it enabled. Monitoring practices through telecare are focused on measuring a specific phenomenon. Is a door open? Is the pressure on the pad equivalent to the weight of a person? Kenneth's practices with CCTV captured less specific phenomena: *anything* that passed into the field of view of the camera was recorded. Rather than relying on sensors to interpret and prompt a response, such as alerting the call centre about an open door, practices with CCTV require human agency to interpret what the cameras record. One interpretation for the disapproval of line manager at Metro Borough Council about Kenneth using CCTV was the lack of specificity about what phenomena the CCTV system recorded. Cameras could record something sexually or grossly inappropriate. The paid carers had no way of knowing what Kenneth recorded with his own personal equipment. On the other hand, telecare's narrowly defined parameters prevent such safeguarding problems with the types of data they collect and measure. However, this also means that any challenges a person with dementia or informal carer encounter in everyday life must be reducible to leaving bed or opening a door based on predefined criteria about how people interpret acceptable times for a person to go to bed and stay in bed until morning.

The line manager from Metro Borough Council may also have challenged Kenneth's 'care as surveillance' practices with CCTV on the grounds of governance over the data and technologies he used. Kenneth privately purchased the CCTV system. Therefore, he owned the technologies and any recordings he made through the system in his house. Metro Borough Council, on the other hand, provided their own monitoring technologies for Kenneth to monitor his mum. A call centre had to link to these telecare technologies in order for monitoring and any alerts they initiated to prompt an

appropriate response. For example, calling the home to investigate whether the door was left open on accident. If the call centre was owned and operated by Metro Borough Council, then they could be described as having a vested business interest and providing their own technologies rather than promoting technologies informal carers purchase independently. When Kenneth's uncertainty about whether the technologies worked may suggest a form of resistance. He may have decided to delay using the telecare devices as a way of subverting Metro Borough Council's authority to define what practices constitute appropriate 'care as surveillance'.

Metro Borough Council seemed to assume that their technologies by providing depersonalised data through sensors that did not potentially intrude or record sensitive information about the person with dementia were, therefore, the better solution for monitoring Lillian's actions as a means to ensure her safety. However, as the next subsection illustrates technologies provided may not always 'fit' with how people live their everyday lives.

### 6.3.3 Challenges with fitting telecare into everyday life

During the third visit with the Campbells, I noticed I observed with assistive technologies and telecare that formal care services provided: the lack of 'fit' between technologies and the practices and everyday experiences of people with dementia and their informal carers. After Kenneth's passionate account describing his disagreement with Metro Borough Council about appropriate technologies for monitoring Lillian, I expected he would update me on this when I visited the Campbells for my scheduled follow up visit a month later. I spent almost four hours talking with Kenneth about photography and his other hobbies that he neglected now 'because I need to care for mum'. I waited for Kenneth to initiate conversation about the forms of telecare available to him and whether and how he used them. When he left to give his mother his dinner, I noticed a small cable buried under bed linens on the couch in the downstairs sitting room where we also spent this visit. I could only just make out the word 'bed' on a piece swaddled under a duvet. I decided to use this discovery to direct my conversation with Kenneth to learn about how he used telecare.

*ML: 'What's that?' I pointed at the pile of bed linens and duvet on the couch that helped divide the open plan kitchen and sitting room on the ground floor.*

*Kenneth Campbell: 'What's what?' Kenneth responded. He walked up to the couch.*

*ML: 'There is cable under the bed linens,' I explained.*

*KC: 'Ah that! That is...was the thing for mum's bed.*

*ML: 'Why is it there?'*

*KC: 'Mum broke it. She must've found the cable one day and decided to see what it was. She must've either given it a hard pull or tried to pull it up from the bed a few too many times.' He laughed. He picked up the device from under the blankets. The pad was still in one piece, however, the cable that connected it to its power source revealed frayed wires.*

*ML: 'I see. Do you know why she pulled on it?' Kenneth placed the pad and cable on top of the bed linens.*

*KC: 'No, and in her craziness I doubt she does,' he replied as he walked around the couch and into the kitchen.*

*ML: 'What about the other one? The one on the door?' I asked.*

*He told me that he 'couldn't get it to work' because it 'didn't connect to [his] phone'.*

Neither Kenneth nor I know why Lillian broke the device or why she wanted to look at me, whether through curiosity or even anxiety about what the object was doing under her bed. This illustrates a subtle approach to examining how monitoring or other 'care technologies' fit into social practices of people with dementia and their carers. According to Kenneth, neither he nor Lillian knew her reasons for her breaking the device. Although Kenneth provided no insights into Lillian's reasons for breaking the bed occupancy sensor, this particular type of technology did not seem to fit. If someone tried to explain what the technology did, why it was installed, or how it worked to Lillian, then she may have understood. However, neither Kenneth nor paid carers from Metro Borough Council explained the technology to her, so Lillian appeared to investigate the device by herself. There is no guarantee that explaining what the technology was to Lillian would have prevented her from breaking the device anyway. However, it would allow Lillian to have some potential involvement role in understanding care that was decided for her rather than dismissing her lack of insight as part of her 'craziness'. Lillian may have recognised the bed occupancy sensor as a new device that was out of place, otherwise why only destroy that object in her bedroom. This suggests that Lillian could still differentiate between

what was 'normal' for objects located in her room and what was newly introduced. This discernment and subsequent destruction of the telecare technology under her mattress suggests that it did not 'fit' into how Lillian wanted to have her bed even if she could not articulate this rationale to other people.

Kenneth's inability to make the door sensor work due to it not connecting to the phone line misplaces the responsibility he had for maintaining the house to a failure of the technology. The number that the local ATTILA research worker gave me to contact Kenneth was a mobile number, because his landline was no longer connected after he did not pay the bill. Therefore, the problem Kenneth had with the technology was not due to its connection with the phone line rather it was Kenneth not having an available phone line to which he could connect it. However, this still illustrates that the technology does not 'fit' into the Campbells' home or care practices. If Kenneth was unable to afford a phone line for the house instead preferring to use a mobile phone, then a technology that relies on a phone line would not fit into how he and Lillian live their lives or the resources available to them. The paid carers at Metro Borough Council may not have known that Kenneth no longer had a phone line, however, even if they insisted he get a phone line this would not make paying for one feasible. This suggests that it is not just the relations of technology in the built environment that people with dementia and informal carers occupy that determine what technologies 'fit', it is also the available resources that make these technologies 'fit' in these relations. In the case of the Campbells, the telecare technologies provided by Metro Borough Council did not fit into the lives of Lillian and Kenneth.

#### 6.3.4 Caring through CCTV?

The final visit differed from all of the preceding visits I spent at the Campbell house because it took place on the first floor instead of the ground floor. I would also later learn that I would see how Kenneth enacted his particular 'care as surveillance' practices with his CCTV system for monitoring his mother, Lillian.

When I arrived at 2.30 PM, Kenneth ushered me upstairs. He wanted to show me his guitar collection and the CCTV system that he described during previous visits. Light came in from a single window in the far side of the room. Kenneth never turned on the light. The space was cluttered with litter – empty bottles of fizzy drink, food wrappers, old newspapers and other things that I could not identify in the faint lighting.

He brought me over to a flat screen television situated against the wall adjacent to where we came. He sat down at an office chair perpendicular to the television where one might expect a desk was a grey, metallic book shelf. Monitors were displayed on a screen at his eye level. He explained to me this was the CCTV system that he installed about a year ago. There was one old CRT monitor that was divided into quarters like a Cartesian plane. Each of the four parts was streaming footage. He told me that he had one above the front door, so he could make sure no one stole his car. He picked up a small, plastic box with a joystick fixed atop it.

*Kenneth Campbell: 'I can see what else is going on the street too.'*

He explained that he had one camera downstairs in the corridor just above the step down to the downstairs sitting room facing the front door.

*KC: 'This gives me a clear view of my mum's bedroom door, the door to the bathroom and the laundry room so I can see if she tries to get up.'*

The third screen displayed the downstairs sitting room and kitchen. The fourth screen was black. Kenneth explained that he did not have any reason for a fourth camera yet. He was not sure where he would place it. He told me that these three cameras were always on and could record if he wanted them to do so. On a lower shelf, there was another screen that was black.

*ML: 'What's that?' I asked.*

*KC: 'This is for a camera in my mum's bedroom. It can't record anything and I usually keep it off. However, if I hear a bang downstairs then I can switch it on and see if she fell or what not. If I see she is fine, then I don't have to bother her. I'll show you.'*

He flipped on a switch just below the black screen. The video was black in white compared to the colour images of the other cameras. Lillian was sitting up in bed. Her arms stretched out before her with palms facing down. She began to move her arms back and forth over her patterned duvet. 'What's she up to?' he wondered aloud before turning off the screen.

We see how Kenneth did not consider installing a camera on the first floor and only monitored the ground floor of the house. Therefore, the only area that Kenneth surveyed was the spaces that Lillian may occupy. This distinction highlights the different everyday lives Kenneth and his mother experienced: Kenneth could remain upstairs where he could observe whether her mother left her bedroom at any moment. Whereas Lillian could not see her son unless she saw him face-to-face. This highlights an inequality between how Kenneth gave 'care' and Lillian received 'care'. Kenneth had the power to choose when and who can see whom. Lillian could only act in a limited capacity with the implied consent of her son to engage in activities he approved as a means to prevent her from taking part in practices Kenneth viewed as 'getting into trouble'. This is further illustrated when Kenneth demonstrated how he used a black and white camera so as to monitor Lillian in her bedroom. He explained that this small camera 'did not record anything', but if he heard a noise from downstairs in the middle of the night he could check to see whether Lillian was the cause. If she was not, then he did not need to wake her up needlessly. The camera was meant to benefit both of them through Kenneth's covert practices. Yet this device also illustrated further differences between the power of the 'carer' and the 'cared for' in 'care as surveillance' practices. I felt deeply uncomfortable as I was watching alongside Kenneth, when Lillian was rubbing the patterns on her duvet. Here was a woman whom I hardly spent time with anywhere, yet I was watching her in the privacy of her bedroom.

Kenneth's practices with CCTV illustrated the relative inequality exemplified by who can monitor whom with monitoring technologies. However, Kenneth's practices with the CCTV were sustained more consistently than his practices with the telecare products. Lillian never destroyed a CCTV camera during fieldwork. Kenneth also understood how and why he used the CCTV to provide 'care as surveillance' whereas he never got the door alarm to work. CCTV was the better monitoring technologies for Kenneth's practices of 'care as surveillance'. If, therefore, we define telecare as 'care at a distance', then we must also recognise other monitoring technologies, such as CCTV, as objects for also providing 'care as surveillance'. However, we need to examine how 'care as surveillance' affects the sociality of care. I argue that 'care as surveillance' as commonly practiced through monitoring technologies like telecare shifts care relationships from equivocating 'caring for' to 'watching a person'. Informal carers' practices with monitoring technologies are inherently 'anti-social'. They cannot allow carers to use the technologies in order to attend to other people as embodied, agentic social actors (Poland and Birt 2016). Practices of informal carers with monitoring technologies identify people as visual data for CCTV screens, pressure for occupancy sensors, or a fixed point on a satellite map for GPS tracking devices. In this case, current practices with telecare systems

cannot be person-centred, since these practices must de-personalise and de-contextualise human activity from the very social relationships that define us as people.

### 6.3.5 The ethics of care as an ethnographer

This chapter's conceptual and analytical focus to care and its examination of multiple, sometimes deeply contested, forms and practices of care raises: how I, as an active ethnographer, consequently came to understand my role and responsibilities, enacting ethics of care, to the study participants. The term 'ethics of care' derives from feminist ethical critiques (Tronto 2017) to include a focus on relationships and compassion (Fisher and Tronto 1990), which fit my concerns as a care ethnographer to emphasise the importance of building and sustaining relationships with participants. This can both help socially understand and 'care about' how other groups live. This means the ethnographer not only feeling compassion for participants, but enacting it through how we research their lives and practices. Research protocols set out how we may anticipate specific ethical problems arising from or within our ethnographic relationships. Subsequently, our active decision-making situated within the field and reflected upon after we leave the field helps us understand how we realise these commitments to participants in practice. The Campbells' case highlights a specific set of ethical challenges for me as an ethnographer to relate to a care professional's second-hand statement from Kenneth that he allegedly committed 'borderline abuse'. To understand my own ethnographic care ethics, I attempt here to clearly describe and consider how I managed my own ethical commitments to both Kenneth and Lillian Campbell in this particular situation.

This ethnographic case already introduced how Lillian Campbell, her son, Kenneth, and at least one care professional at Metro Borough Council appeared to view the role of service-provided telecare technologies and independently purchased CCTV cameras repurposed as care technologies. When Kenneth described how a senior member of staff from Metro Borough Council called his use of CCTV to monitor his mother within their home, instead of bed and door sensors they provided, 'borderline abusive'. The Social Care Institute of Excellence (2018) identify ten types of abuse: physical, domestic, sexual, psychological, financial, modern slavery, discriminatory, organizational, neglect, and self-neglect. I ruled out organisational abuse, neglect and self-neglect as they did not fit within this familial care arrangement. Modern slavery or financial abuse were not present as the arrangement did not include any expected exchange of money for labour. Yet Kenneth's practices may still be seen as forms of physical, domestic, sexual or psychological abuse which I realised I

needed to investigate. I noted these words in my field journal to follow-up after I left the Campbells' home.

In my study protocol, I identified the local ATTILA research worker as my first contact if I thought I observed or heard potential abuse or safeguarding issues. As it was after 5pm when I left the Campbells home on this particular occasion, I decided to email the local ATTILA research worker. I recounted Kenneth's account of misplaced trust in a visiting care worker who helped bath and dress Lillian in the morning and that visiting care worker eventually told a senior member of her team about Kenneth's use of CCTV to monitor Lillian. I saw this as providing context for my reference to the phone call Kenneth received from the senior team member at Metro Borough Council and her allegation of 'borderline abusive' practices based on how he used CCTV to help monitor his mother. As I wrote the email, I felt sympathy for Kenneth who had previously told me about his difficulty keeping a job and home whilst he was estranged from his own adult children and ex-wives. His caring roles were now limited to his care for his mother in his childhood home. However, I also noted the decision of the care professional team decision to highlight a potential threat to Lillian's safety and dignity through Kenneth's practices with the CCTV. I sent the email, aware that safeguarding one person (Lillian) from potentially harmful behavior from an informal carer's (her son's) practice could mean exposing another person to potential harm— in this case, losing a home and benefits for Kenneth. However, I knew my ethical commitment and process outlined in my protocol had to determine what I did in handling such dilemmas; it justified my email to the local ATTILA research worker. Still, I did not sleep well that night.

The next morning, I nervously phoned the local ATTILA research worker who covered the Metro Borough area. She told me that she had read my email, and that she 'already knew' that Kenneth used CCTV in his home. She told me that she reported it to Metro Borough Council, and that Metro Borough Council said that they were 'aware' of the CCTV but did not 'plan to take any further action'. This completed my ethical duties as outlined in my research protocol: I had confirmed that the ATTILA team knew about Kenneth's use of CCTV cameras to monitor Lillian. I felt vindicated that they also decided to contact someone from Metro Borough Council about the situation. All external parties were aware of the issue and the person with overall safeguarding responsibility for Lillian, Metro Borough Council, decided not to act on it despite members of the organization stating their previous discomfort with CCTV in Lillian's home. I cannot comment on why no one from Metro Borough Council decided not to act further in this case nor why the local ATTILA research worker did

not pursue any further actions. They, like me, may have come to understand how Kenneth used CCTV that did not appear to cause harm or impinge on Lillian's autonomy.

During my next visit Kenneth showed me specifically how he used the CCTV cameras installed outside and within the house. He installed cameras downstairs only in shared areas of the home: one in the hallway facing the front door and the other in the sitting room facing the kitchen in the back. He also had one camera outside and above the front door to watch his car to make sure no one tried to steal it. Kenneth kept these cameras switched on at all times. However, he also had one camera installed in his mother's bedroom and this he accessed through a separate console. The screen was much smaller than the other three. Initially, no image appeared on the screen, only the tell-tale black mirrored reflection from a screen switched-off. Kenneth explained that he only turned on this screen if he heard a noise downstairs in the middle of the night. He could use it to check to see if Lillian had fallen down without going into her room and 'waking her up for nothing'. Kenneth's explanation and practices with CCTV demonstrate a clear rationale for his having the CCTV. He could use them to monitor his mother from a distance, albeit a short distance from upstairs and downstairs in the same house, without waking her up or bothering her unnecessarily. His monitoring practices could ensure that Lillian could maintain her own independence and routine with minimal intrusion from Kenneth except for when he visually verified whether there had been an accident which required him to intervene. With this information, Kenneth's actions did not appear as 'borderline abusive' practices, but as thoughtful actions of a son trying to help his mother stay safe and independent in their shared home. I felt reassured that Kenneth had not engaged in any abusive behavior.

After I completed my fieldwork with the Campbells, the local ATTILA research worker recounted during a research meeting that Metro Borough Council never took any further actions toward Kenneth. Although it may be possible for people to abuse people living with dementia through how they monitor them with CCTV, my own observations and conversations with the ATTILA team and their own investigations with Metro Borough Council confirmed that Kenneth's actions did not reflect a form of abuse.

Kenneth's individual practices with CCTV actually suggest a particular technology-related practice of caring for a person with dementia. I offer my own conceptual insights learned through my visits to the Campbells' home to reconsider the place for CCTV in individual care arrangements. When I first started fieldwork for this study, I was clear with my definitions and distinctions between not only assistive technology and telecare, but also how these categories differed from everyday

technologies. Although, as highlighted in Chapter 2, scholars, practitioners and policy makers disagreed about what constitutes technologies as 'assistive', my initial embedding work with ATTILA narrowed the definition to electronic technologies delivered by formal care services. However, listening to the stories of participants like Kenneth Campbell led me to question the assumption about what distinguishes assistive technologies from other 'things' also placed in their home. The previous subsection's heading asked a question: 'caring through CCTV?' Is such a practice possible? Can people care through the use of surveillance devices? Who has the authority to decide? Metro Borough Council initially decided that Kenneth's use of CCTV was an ethically-problematic method of monitoring Lillian. However, when the local ATTILA research worker raised the issue of Kenneth's further use of the technology with them, they decided not to act further at least by the end of the study in August 2016. However, Kenneth told me using CCTV gave him 'peace of mind'. It was a system that he purchased and managed himself. He understood how to use it. He preferred to use it. He chose to use it.

Metro Borough Council, on the other hand, provided door sensors and a bed occupancy sensor to counter Kenneth's monitoring activities with CCTV that they viewed as problematic. However, Metro Borough Council may not have fully appreciated how these technologies fit into the lives of Lillian and Kenneth. Nobody knows why Lillian decided to break the bed occupancy sensor. Yet I can understand how a person with dementia may curiously tug on cables under their mattress. I think that any person would investigate the sudden appearance of such cables. Yet the outcome of her interaction with the bed occupancy sensor suggested Lillian may not have accepted its presence in her life and bedroom. This suggests that although authorities like local authorities and councils may see their products as less 'ethically problematic', this does not mean that they will enable people with dementia or informal carers to realise meaningful care practices and relations when they use them.

Kenneth's practices with the CCTV system, on the other hand, allowed Kenneth to monitor his mother, observe the images he saw on the screens, and respond to them based on what he saw. The telecare could not provide this level of data even if the devices worked in their lives and home as intended. Therefore, the CCTV allowed Kenneth to respond to accidents with a fuller understanding of whatever occurred. It also meant that Kenneth could identify any false alarms from the device by looking at the monitors rather than having to potentially rouse his mother from bed to check on her. Kenneth's use of CCTV to monitor his mother could be viewed as a potential safeguarding issue as he could inappropriately watch his mother. It was also unclear whether she

consented to Kenneth's observations. On the other hand, it could also be interpreted as a practice which facilitated better care for Lillian in her own home. Kenneth's ethical duty to care for his mother and prevent harm or respond to an accident as soon as possible was facilitated more through CCTV than the formally provided technologies from Metro Borough Council. This suggests that CCTV could be used both to potentially safeguard people with dementia like Lillian rather than perpetuate different psychological or physical harm.

My ethnographic intentions and actions identified a potential case of abuse in relation to Lillian Campbell's. This example showed how my own procedural ethics and in the moment decision making led me to contact the ATTILA team who had already identified similar concerns to Metro Borough Council. When Metro Borough Council told the ATTILA research worker, then this discharged me of my own procedural ethical responsibilities. However, my own ethnographic care ethics required me to investigate the situation further based on the concern and empathy I developed for the Campbells over the course of my fieldwork. Through my relationship with Kenneth Campbell, I learned how he used the CCTV in ways that appeared to mitigate potential for abuse through limiting most cameras to common spaces in the home, and using only one other camera as a means to check his mother when he suspected she had an accident which caused her physical harm. This complex ethnographic and ethical case exemplified for me the strength and relevance of ethnographic relationships not only for producing analytical insights but power to illuminate contextualised understandings before making judgements that might be problematic if rushed or under-analysed.

## 6.5 Chapter summary

The findings in this chapter have provided analytical insight to how the ways informal carers practiced and understood care were affected by their use of assistive technologies and telecare. 'Care as concern' and 'care as surveillance' appeared as two instances of care practices informal carers adopted with and through technologies to support their caring roles for people with dementia. 'Concern' allowed carers to articulate what they viewed as a risk to formal care providers which may lead to the provision of assistive technologies and telecare. Technological practices of informal carers may give them 'peace of mind' if they imagine that the technology allows them to predict or address any of their concerns. However, telecare did not appear to either prevent or address the actual risks to the person with dementia. A person with dementia may still leave the house even if they are remotely-monitored. Practices with telecare appeared to only help informal carers believe that they

were more actively involved in the care of a person with dementia when they were not co-located. Informal carers may also misattribute what telecare systems record through their motion sensors. This may increase the stress of informal carers when they realised that the safety of the person with dementia was still uncertain. In other words, informal carers appeared to select telecare to improve their 'peace of mind' rather than directly address the needs of a person with dementia. 'Care as surveillance' suggests that watching a person can be an acceptable practice of care to make sure people with dementia are safe. Yet practices with monitoring technologies revealed potential inequalities with informal carers enabled through their dislocated technological 'care as surveillance' arrangements to watch the person with dementia or 'detect' their presence through telecare devices, whilst a person with dementia cannot watch or interact with informal carers whenever they like. Monitoring technologies appeared to require an examination of human activity as de-personalised and de-contextualised from those very relationships that define us and the ways we engage with the wider community. This raises further questions for understanding and supporting appropriate relationships of people with dementia with their community. When informal carers and people with dementia were not co-located it appeared to make sense to adopt monitoring technologies to help provide 'care' over whatever distance. Telecare technologies facilitated informal carers to monitor people with dementia yet the range of the sensors appeared to limit such activities to the home of the person with dementia. If assistive technologies and telecare were designed to promote independent living in the community, then this calls into question how practices with these technologies mediate such relations.

The next chapter attends to how people with dementia occupy the home in greater depth to examine how technological practices with assistive technologies and telecare mediate their access to these spaces and links with their communities.

# Chapter 7: Understanding 'home' and 'community' through everyday and technological practices

## 7.1 Introduction

The emergence of surveillance as a new care practice of informal carers through telecare raised further questions to me about the importance of the home as a location where they could now observe people with dementia only if they remained there. I decided to attend to the ways in which people with dementia and informal carers occupied rooms in the 'home' and people, services and areas located in the 'community'. Given the emphasis of people with dementia 'living in the community' in both policy and practitioner-related discourses, I decided to also examine how practices with assistive technologies and telecare affects access to the wider community for people with dementia when technological practices appear to constrain everyday life to the home. This decision also built on the logical progression of previous findings. Having already attended to participants' technological practices in relation to memory problems and caring, I wanted to emplace these activities in relation to the spaces where people with dementia and informal carers enacted these practices: their homes and communities. To examine different ways people with dementia and informal carers occupied and interacted with their home and community, I selected three cases to illustrate differently evolving relations with spaces – both domestic and communal – and how participants' practices with assistive technologies and telecare also appeared to affect these relations. The first two cases examine how people with dementia occupy the home in differing ways. The first shows how informal carers reconfigured the previous function of rooms in the home as the physical functioning of people with dementia deteriorated so that they became less mobile. Reconfiguring the function of the room also meant that people with dementia abandoned other rooms in the home as they shifted practices formally associated with them to a new space. The second case follows a variation on this practice of abandoning rooms in the home. The third and final case illustrates how informal carers' technological practices may affect the ability of people with dementia to access locations outside their home and to interact with their wider community.

## 7.2 Reconfiguring rooms in the home

People with dementia experienced changing care needs as their illness progressed to more advanced stages expressed through more frequent or severe symptoms. These changes affected the relationships of people with dementia with how they perceived their surroundings in this study and how informal carers provided support to them. Such changes also led people with dementia to occupy rooms in their homes in different ways as their ability to enact everyday practices changed. Informal carers would add objects into rooms and alter the layout which also change how people with dementia occupied these rooms. To illustrate how informal carers 'reconfigured rooms in the home', I selected the Draper ethnographic case. This ethnographic case included Violet and Thomas Draper with visits taking place in Violet's home in City Village. Violet Draper was a woman diagnosed with a relatively mild form of dementia who took part in ATTILA. She lived in City Village outside of the suburbs of a large city in the region. Violet was a retired school teacher who lived alone in a two-storey house after her husband died. She had two adult sons who live in neighbouring villages, but one of them rarely visited or spoke to her. The other adult son was Thomas. Thomas Draper was the informal carer and son of Violet. He was in his early sixties when fieldwork was carried out. He used to work as a salesman prior to fieldwork and started caring for Violet part-time after she broke her hip. However, after Violet was diagnosed with dementia whilst she still recovered from her hip replacement surgery, Thomas quit work in order to care for Violet seven days each week.

Although the Drapers represents an atypical example compared to other cases in ACCOMMODATE, I wanted to show the degree of change possible for just a single room over time. The Drapers case illustrates the ongoing work of an informal carer to continuously accommodate the changing care needs of the person with dementia and its consequences for the layout of just one single room and how both participants came to change the ways they occupied it.

### 7.2.1 The sitting room as bedroom

To consider practices which may 'reconfigure rooms in the home', I begin here with my first visit with the Drapers on one morning in September 2015. This visit was my first time I spent any time with the Drapers after the recruitment visit and later served as a benchmark for me to examine how the sitting room, the room where I spent all of my time with Violet and Thomas, changed over time. I had visited them at Violet's home earlier in the month with the ATTILA research worker, but now I had the opportunity to start generating data with them for ACCOMMODATE. Thomas greeted me at the door, then he invited me inside and guided me into the sitting room. To my immediate surprise, I saw Violet laying on a bed at the far side of the room (see Figure 2 for a map of the room with relevant objects

and people). After I sat down at a chair near the foot of the bed, I also noticed a new calendar-clock. I used the following conversation about the nearby assistive technology to explore why someone placed a bed in the sitting room of Violet's home and how adding it may change how Violet and Thomas occupy it. during this visit.

*ML: 'Tell me about that clock next to you.' I extended my hand to point to the calendar-clock on the small table beside Violet's bed. 'Just there.'*

*Violet Draper: 'Oh this? I love it. It's great. I find it so useful.' She picked up the calendar-clock with both hands and placed the device on the duvet covering her lap.*

*Thomas Draper: 'It is great.' He said facing me, then he turns his body to face Violet. 'It's really great. Isn't it, mum? I almost wish that I had one myself.' He spoke loudly. We all laughed.*

*I turned to face Violet.*

*ML: 'Violet, does it have an alarm in it to wake you up in the morning?'*

*VD: 'I'm sorry. I can't hear you.'*

*TD: 'Matthew asked whether your clock as an alarm,' Thomas shouted to Violet. Thomas turned to face me. 'It doesn't have one though. Or if it does we never set it up,' he said in a lower voice. 'I usually wake her up when I arrive in the morning.'*

*VD: 'I can't hear you!' Violet exclaimed her voice slightly raised in frustration.*

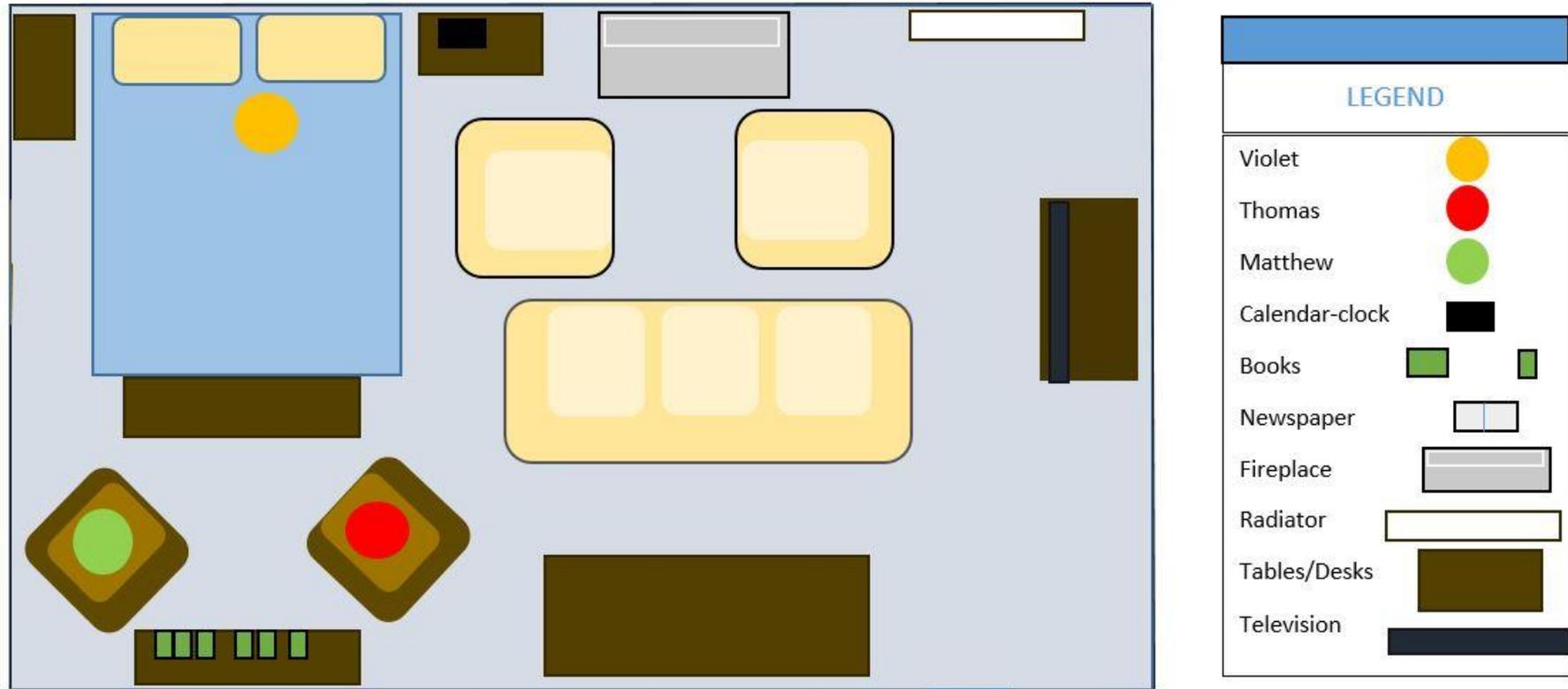
*TD: 'I just told Matthew that I usually wake you up when I arrive,' Thomas yelled to Violet.*

*ML: 'So she sleeps down here?' I asked Thomas for clarification.*

*TD: 'Yes. (5) After she had her hip replaced, I brought in the bed from the guest bedroom to down her so she didn't have to go up and downstairs every day. She's still recovering, so she just sleeps down here for the moment.'*

My initial thoughts about the bed immediately led me to question whether it was ethically appropriate to be in that room. I had agreed with the ethics committee that I would not go into any participant's bedroom as a way to safeguard both participants and also mitigate potential harm to myself. Here it could be argued though that Thomas adding a bed and Violet changing the place where she slept to the sitting room suggests that the role and function of the sitting room also changed. Most of the furniture located in the room included objects the Drapers originally placed there when the room functioned as only a sitting room. Yet now that a bed also occupied some of the space in the sitting room and Violet slept there at night, the room took on additional meaning and purpose. I did not know how initially make sense of how I perceived distinctions between what I considered a bedroom and a sitting room. Did a bedroom necessarily exclude other furnishings (e.g. chairs and couches) and everyday practices (e.g. socialising together, completing puzzles, entertaining guests)? Did the presence of a bed constitute the room as a bedroom? Later reflecting on how Thomas, Violet and I differently occupied the room, I decided the room now represented a hybrid that functioned as a sitting room or bedroom based on how people occupied it at any given time. Thomas and I constituted it as a sitting room during my daytime visits, since they took place during the later morning or early afternoon when Violet was awake and taking part in conversations. Meanwhile, in the evening and overnight when Violet sleeps is alone and sleeps in the bed the room becomes a bedroom. This illustrates how rooms are not only physical locations, but that people produce, or co-produce in this case, the function of rooms based on what they do inside of them with other people and objects co-located in the same space. If the sitting room was contingently co-produced through the practices we enacted during my visits, then when I was not in the room that Thomas and Violet may have co-produced the room in different ways. This analytical distinction also allowed me to continue carrying out fieldwork with the Drapers in the sitting room despite Thomas placing a bed in the room. Whilst I was located in the room, we maintained the function of the room as a sitting room.

Figure 2. Map of Violet Draper's sitting room from September 2015 visit



## 7.2.2 The sitting room as bathroom

Violet eventually experienced a bad fall late one evening in December. The fall resulted in a broken bone in each leg. She spent a month in hospital before she was released back home for her son to resume caring for her. When I visited in early January for my fifth visit with the Drapers, Violet had gone to stay at a care home for a few days whilst occupational therapists fitted out her home with additional adjustments. Despite Violet's absence, Thomas still agreed to meet at his mother's house to update me on his mother's condition. The accompanying map, Figure 3, locates Thomas and I in relation to each other and the objects in the sitting room, the only place where I spent any time in Violet's home during this visit. After we sat down, I started small talk with him to find out how he was doing. The following extract of this conversation with Thomas highlights his plans to move things out of Violet's sitting room to make caring for her easier for himself and paid carers from a local agency.

*ML: 'How are you doing?'*

*Thomas sighed. His shoulders sank down.*

*Thomas Draper: 'Tired. There is so much to do to get ready for mum to come back.'*

*ML: 'What do you have to do?'*

*Thomas looked around the room, then looked back at me.*

*TD: 'I need to get rid of the lamps in here. The local authority is going to provide some lamps that turn on and off with a touch. I also need to remove one of the couches [Thomas pointed down at the couch we sat on] and both chairs to make room for carers and other people who are going to visit. There is too much in the way now.'*

*ML: 'Where are you going to put the furniture?'*

*TD: 'I'm not sure. My home probably. But I need the space, she needs to walk across the room to get to that as it is. It needs to be closer.'*

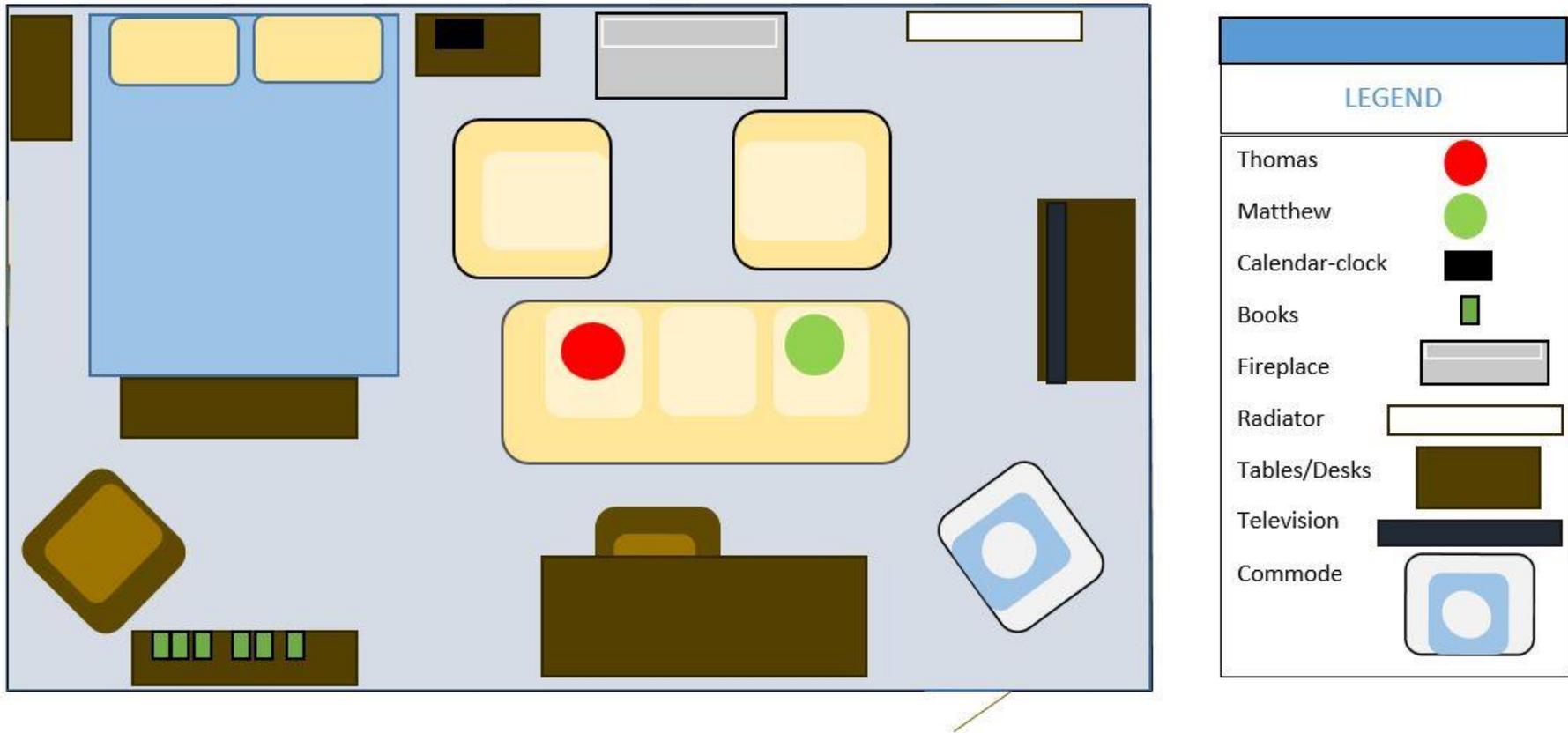
Thomas pointed at a white chair made of moulded plastic with a metal frame. The chair had four legs that each ended with a wheel. A small bucket protruded from under the seat of the chair. It was a commode.

*TD: 'She shouldn't need to walk across the room to use it.'*

Although I intended my question to allow Thomas and I to gradually work toward Violet's wellbeing and his care arrangements, it appeared that these matters weighed on Thomas as he immediately discussed what he needed to change in his mother's home. Prominent to me in this discussion was the revelation of the commode now also located in the sitting room. Much like my discovery of the bed in the sitting room during my first visit, the presence of the commode also made me think about what this meant for this room. Was the sitting room now also a bathroom in addition to a sitting room and a bedroom? I understood practically that if Violet could no longer manage walking around by herself in the home following her fall, then she needed to have everything she needed to manage her everyday routine accessible in a single room. For her it appeared this now meant that she had to use a commode in her sitting-room-cum-bedroom for toileting. After coming to terms with the bed in the bedroom, I was less surprised with the addition of a commode and the implications for Violet's everyday routine. To me it meant that the sitting room continued to operate as a multifunctional domestic space. Now Violet also toileted in the same space where she also slept and entertained guests. Yet I could still identify the individual objects that shaped the room in its state during this visit. The couches, chairs and desk - all furniture that defined the room as it was originally occupied as a sitting room. When Thomas added a bed into the same room, it also allowed for sleeping to take place in the room. Social care providers from the local authority providing Violet a commode for her to use for toileting only represented the most recent attempt at reconfiguring the room. Although we might consider these objects and practices as disparate and located in different rooms where we enact appropriately situated practices with them, in this case the co-location of these objects in the same room suggests that how we imagine the function of a room is again contingently co-produced based on the objects located and the practices people with dementia and informal carers enacted in them. For Violet, this meant that her sitting room was not only a sitting room, but it also fluctuated between acting as her bedroom or bathroom whenever she slept in the bed or used the commode located in the room. Again it demonstrates how people's practices contingently constitute the function of the room at any given time.

This conversation also demonstrated the difficulty Thomas had between providing a space for care practices *and* living for Violet. After Violet's fall and subsequent return home, he needed paid carers to help him provide care for Violet. However, paid carers potentially experienced difficulty navigating the room because the current layout included furniture which blocked easy access to Violet's bed. Thomas explained to me that he needed to remove the furniture in the room to make it not only easier for paid carers to help Violet but also so he could move the commode closer to Violet's bed to improve her ability to use it. The map in Figure 3 illustrates the relatively limited space which Violet with her limited mobility and a busy team of paid carers may have difficulty navigating. Thomas did not suggest that Violet ever had trouble using the toilet, but he seemed to suggest that he carefully considered how the room and objects placed within it could enhance or inhibit care practices, whether paid carers enacted them or Violet enacted practices of self-care, such as toileting. Perhaps Thomas understood a relationship between care practices and where they took place.

Figure 3. Map of Violet Draper's sitting room from January 2016 visit



### 7.2.3 The sitting room becoming an institution

The Drapers continued to shift their practices in the sitting room as additional objects continued to alter the role of the room in Violet's everyday life. After a month delay to our scheduled final visit, I again met with Thomas at his mother, Violet's home in April 2016. When I called to arrange the final visit with Thomas, he told me that Violet had already moved permanently into a care home since my previous visit. Her move actually precipitated the delay, he later confided to me. Yet before her move into a residential care home further objects from social care were added in the sitting room. The accompanying map in Figure 4 illustrates the placement of these new objects in the sitting room during my final visit to Violet's home.

*Thomas Draper: 'I'm sorry. I'm trying to move all of mum's items out. Chairs. We need chairs.'*

Thomas left the room and crossed the hall into the sitting room. I followed after him. The room was different from my last visit. All of the bookcases, the television, chairs, couches and even his mother's bed were gone. However, the room was not empty. There were ten lamps beside their boxes on the ground. The commode, the only object I recognised from my prior visits was located where Violet's bed used to be. In the middle of the room was a new bed that had large grey side rails. The calendar clock rested on top of the mattress with an infusion pump at the foot of the bed.

*ML: 'What's all of this? When did it get here?'*

*TD: 'It must have been since your last visit. We tried one more time to have her stay home. She lasted less than a week on her own home. She's staying in the care home now. This wasn't much better anyway.'*

Here we see the result of what a room looks like when it is devoid of the décor I came to associate with the sitting room, all of the domestic furnishings that helped me identify the room as a sitting room or bedroom, now removed. The only objects that remained from my previous visits which I recognised were the commode and calendar clock. However, several new assistive and care technologies now occupied the room, including a bed that looked like it came from a hospital. There was now nothing that told a person who walked into the room that this space *was* a sitting room. It was no longer a room that I expected to find in a home at all. In my mind, the room now resembled a room in a hospital more than one in a person's house. It looked like it belonged in an institution. The trappings that made the space a sitting room, bedroom and even a bathroom had been based on

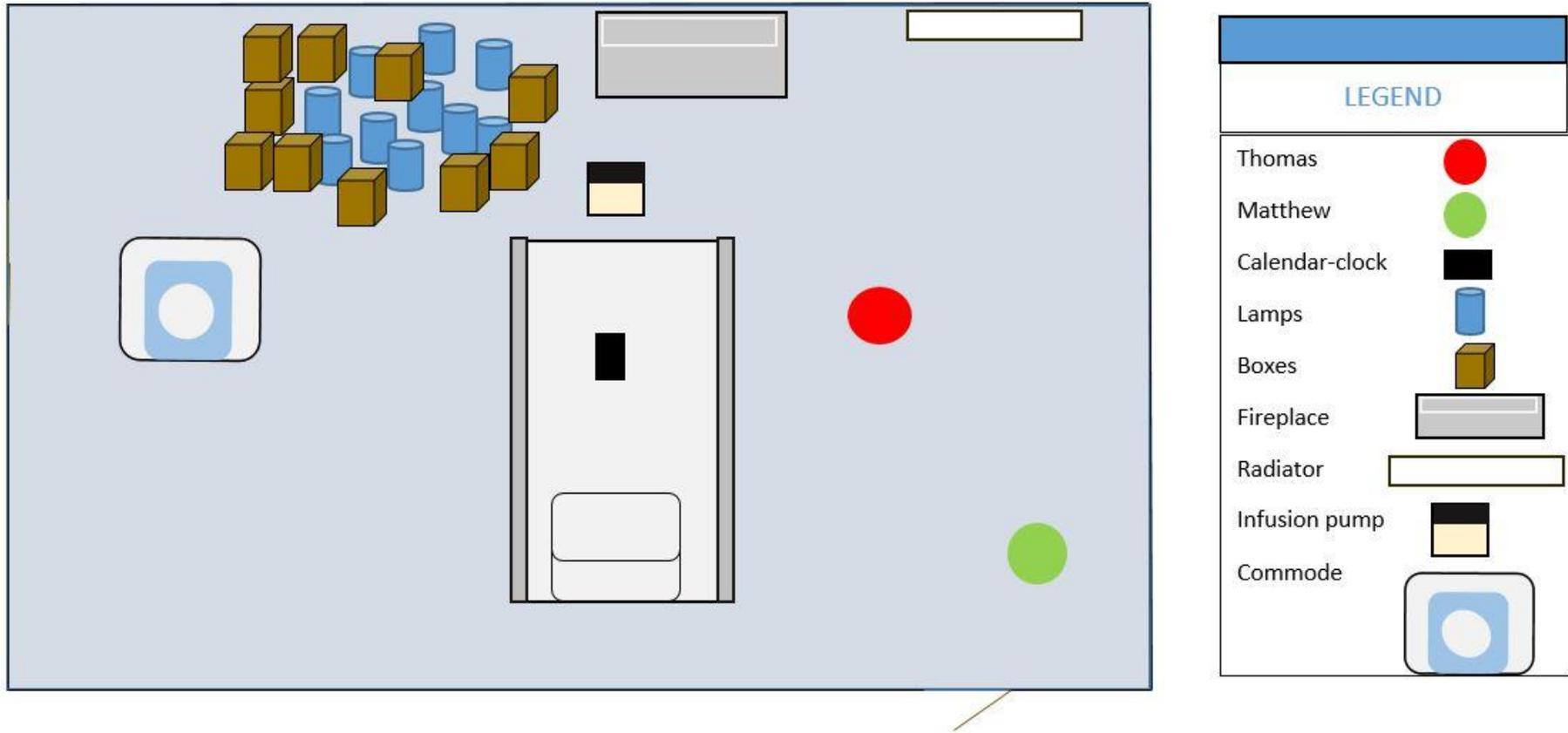
the personal preferences of Violet and Thomas. Although Violet encountered changing and more intensive health challenges, Thomas and Violet managed to keep the room largely intact for several months with an only subtle changes in objects and practices at first. However, when Thomas removed all of Violet's furniture and other personal objects to accommodate new technologies and give paid carers enough space to easily reach Violet, the room then changed from a domestic one into an institution where Violet received care. Here, her care needs may have undermined how she wanted to live her life and inhabit her home.

The changing objects and practices in Violet's sitting room reconfigured the room with Thomas' introduction of each new object. The addition of a bed meant that Violet could now sleep downstairs, this resulted in the sitting room also functioning as a bedroom. The addition of a commode meant Violet then also toileted in her sitting room. Violet's practices that previously occurred in other rooms in the house became restricted, confined perhaps, to only the sitting room. The sitting room became the only location that Violet experienced everyday living. The sitting room became the whole of her home; life now seemingly reduced to the space of her sitting room. Violet and Thomas reconfigured the sitting room into Violet's home and health services reconfigured the room into an institution.

If people with dementia commonly identify and relate to rooms in their home based on how they occupy them and the practices they enact there, then adopting or crafting new practices may contradict previously-shared expectations for how people *ought* or wish to act and occupy these rooms. Misunderstandings or negotiations may then follow between people who receive and people who provide care, both informal and paid. This has implications for how informal carers routinely alter rooms located in the home to suit the care needs of people with dementia based on how informal carers *imagine* them. This may also affect how people with dementia can experience their everyday 'life in the community'. This means that 'community' may not even be an appropriate concept for understanding care practices for people with dementia outside of residential care settings but living in their own homes.

The Draper case illustrated how Thomas reconfiguring the sitting room accommodated Violet to take part in everyday practices previously located in other rooms. Yet it also meant *she no longer occupied all of the rooms within her own home*. Violet's occupation of her home was focused and centralised rather than dispersed.

Figure 4. Map of Violet Draper's sitting room from April 2016 visit



### 7.3 Abandoning rooms in the home

The Draper ethnographic case illustrated how people with dementia and informal carers occupied and reconfigured rooms in the home and its implications for how they lived their lives. Now I examine what happens to spaces when participants abandoned them. To examine how spaces in the home become abandoned and their implications, I selected the ethnographic case with Mrs Archer and Anthony.

Mrs Archer was a woman diagnosed with dementia and an ATTILA participant. She was in her late eighties at the time of fieldwork. Mrs Archer was a first generation immigrant who migrated from Jamaica to England as an adult. She was an active member of her church throughout her life in England. Mrs Archer's involvement with her community church in Metropolitan introduced her to Anthony's parents. Following repeated cases of Mrs Archer's family allegedly stealing money from her, Anthony stepped in to act as Mrs Archer's informal carer with legal power of attorney rights and responsibilities.

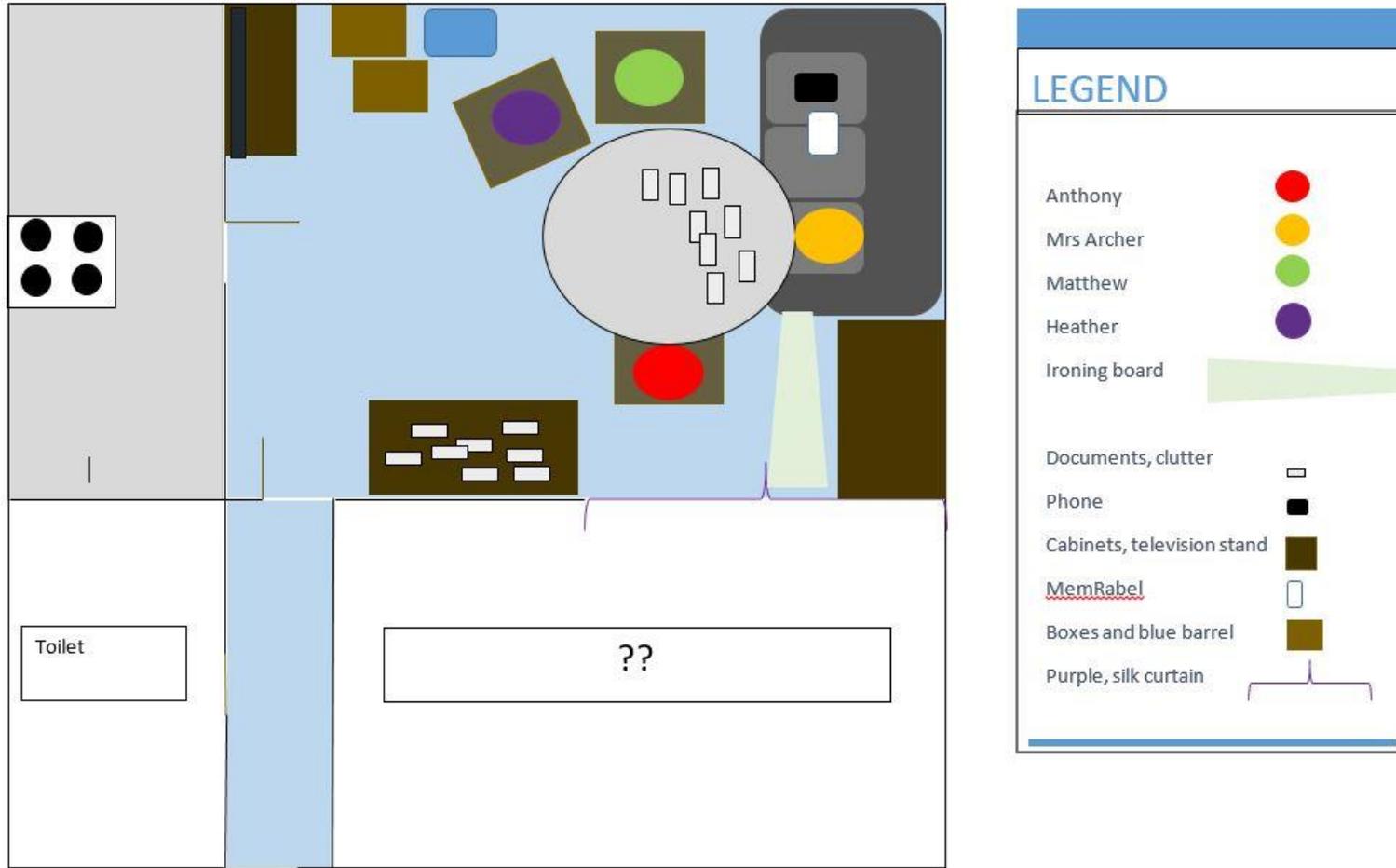
Anthony was the informal carer for Mrs Archer. Anthony was in his late forties while fieldwork took place. He was a second generation immigrant as the son of two Jamaican parents who both also resided in Metropolitan. Anthony retired from a job in government office after he was exposed to toxic fumes disabled him. He had difficulty breathing and only could walk for short distances with the aid of walking stick.

The locations Mrs Archer, Anthony and I occupied during the recruitment visit remained the same for all six subsequent fieldwork visits for this study. Anthony and Mrs Archer occasionally got up from their seats in order to use the toilet, make a cup of tea, or attend to another household chore. However, Anthony always returned to 'his' seat at the table and Mrs Archer returned to the couch. The flat was very small, typical for flats located in Metropolitan. There was a separate bathroom and kitchen, but the sitting room was also combined being used as a dining room. The bedroom was in a small room of the flat behind where I sat. However, a drawn curtain usually obscured my view of the bedroom.

I selected this case as it represented an alternative to the gradual abandonment of domestic spaces through gradual changes to spaces in the home as illustrated with the Drapers doing this. Thomas added a bedroom, commode and other objects in the Violet Draper's sitting room over time which

suggested the bedroom and bathroom became abandoned just as gradually. Mrs Archer and Anthony, on the other hand, illustrate how one crisis can impact on the everyday routine of a person living with dementia and the extent of assistive technologies to mitigate these consequences. The accompanying map in Figure 5 indicates the layout of the flat and the positions of Anthony, Mrs Archer and I during all of my visits. The importance of this map is to illustrate the layout of the flat during earlier visits as a benchmark to highlight future changes.

Figure 5. Map of Mrs Archer's flat from recruitment visit



### 7.3.1 Fire in the kitchen

It was February 2015 in Metro Borough. The afternoon had thawed out the frost from the sparse vegetation in the neighbourhood. I had already met Mrs Archer and Anthony four previous times. This is now my fifth time to Mrs Archer's flat in a sheltered housing unit. When I called Anthony to arrange this visit, he told me about a kitchen fire that happened a few days ago in Mrs Archer's flat. I rang the buzzer at the entrance to the building. Anthony answered and unlocked the door. After I walked upstairs to Mrs Archer's flat, Anthony invited me inside and led me to the sitting room where I usually spent my visits with Mrs Archer and Anthony. Almost as soon as I sat down I looked up to Anthony sitting next to me (Figure 6 illustrates the layout of the flat and the positions of Anthony, Mrs Archer and I during this visit).

*Anthony: 'Do you want to see it?' he asked me.*

*ML: 'The fire?'*

*A: 'Where it happened.'*

He used his walking stick to stand up from the table in the sitting room. He motioned me to follow him into the kitchen. It only took a couple of steps, then we were inside Mrs Archer's small kitchen. I looked at the oven first at the entryway. There was no damage nor signs of fire. Anthony walked over to the left side of the kitchen. My gaze traced his movements.

*A: 'Here.'*

Anthony moved to in front of the sink for me to get a better view. Next to the cooker was a worktop that ran down the length of the left half of the kitchen. On the far left side of the worktop and next to the sink, there was a round crater in the worktop. The outer edges were amber that darkened to brown to black as I gazed toward the middle. The walls and cupboards above the worktop were charred and smoke-damaged. The air still smelt acrid.

*ML: 'Wow. What happened? Why was the fire on the worktop?'*

Anthony did not answer immediately me. He motioned for me to follow him back to the sitting room where Mrs Archer still sat on the couch. We took our seats at the table once again.

Anthony explained that Mrs Archer was cooking something last night when her ‘fourteen-year-old granddaughter’ visited. They both ‘fell asleep’ watching ‘telly’ though. The granddaughter woke up to ‘smoke’ coming from the kitchen. She went to the kitchen and moved the ‘pan’ from the cooker to the worktop, then she went back to sleep. They both slept until the smoke alarm went off because the walls and cupboards were on fire. The fire brigade came over and put on the fire.

*Mrs Archer: ‘That’s not what I said. I was sleeping the whole time.’ She moved forward from her slumped back position on the couch until her arms were on the table. ‘[The granddaughter] fried chicken by herself. She fell asleep again. When she woke again, she took the pan off of the cooker.’*

*A: ‘So you were sleeping until the alarm?’ he asked Mrs Archer.*

*Mrs Archer nodded. Anthony asked why the granddaughter was cooking by herself. Mrs Archer did not respond.*

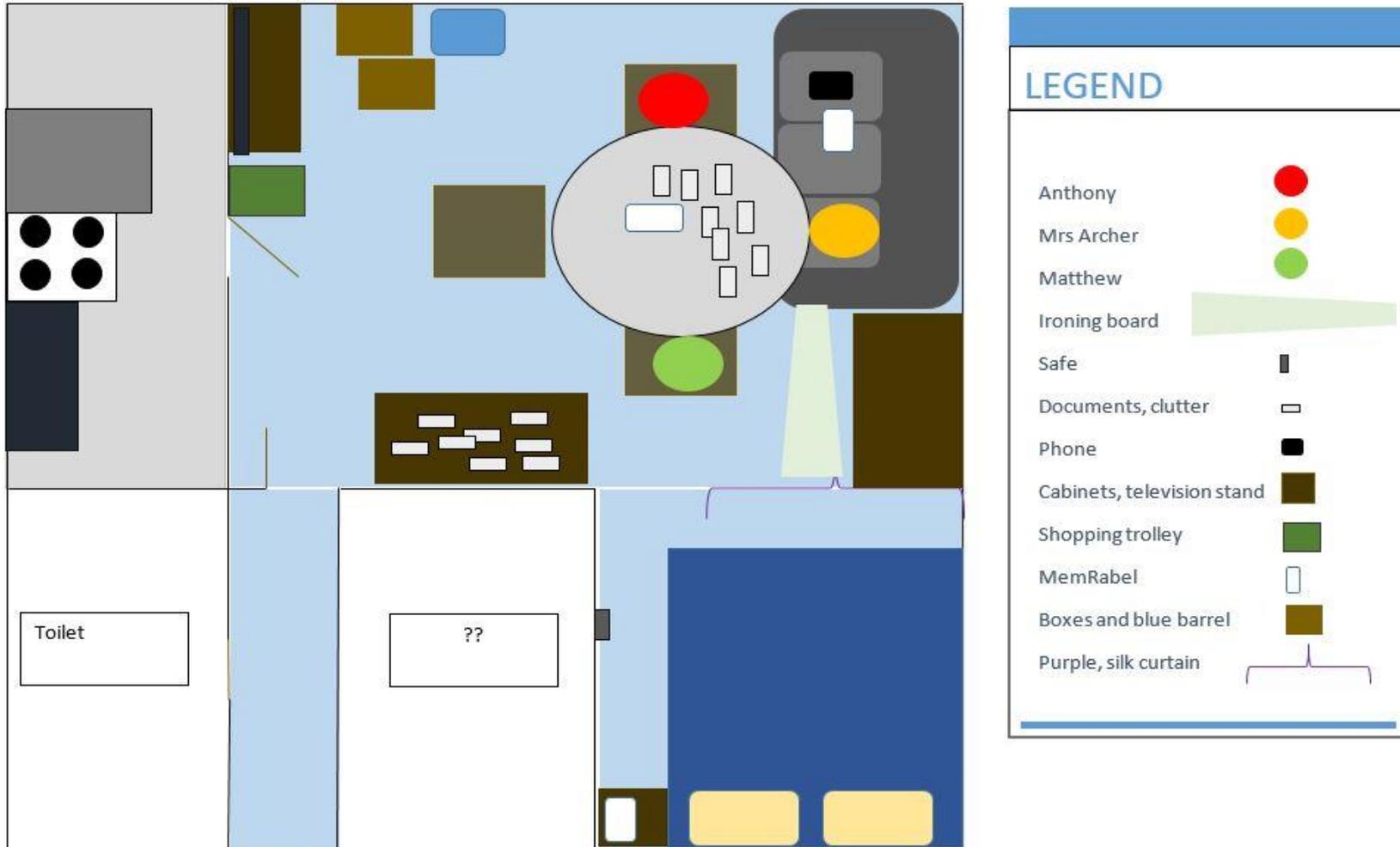
Mrs Archer’s clarification exposed what I considered an important consideration for how the building manager and Anthony should determine responsibility for causing the kitchen fire. If Mrs Archer was sleeping at the same time that her teenaged granddaughter started cooking food, then she should not be blamed for the kitchen fire. However, Mrs Archer was the only adult in the flat at the time and rents the place from the private care agency. Ironically, the fire may not have occurred if the granddaughter left the pan on the cooker. The pan was hot enough to burn a crater onto the plastic-coated worktop, however, there was no fire or smoke damage around the cooker.

The care agency which serviced Mrs Archer’s flat also provided her with assistive technologies and telecare systems. Mrs Archer’s kitchen was fitted with an ‘automatic cooker shut off device’ (see Appendix IX for an indicative picture). This device was designed to turn off cookers if left unattended for a pre-set amount of time. The automatic cooker shut off device would shut the cooker ring off so that the pan no longer had additional heat applied to it. However, Mrs Archer’s granddaughter may not have understood how the automatic cooker shut off device worked. Indeed, she may not have known that it was there. Instead of leaving the pan on the cooker, the granddaughter placed the hot pan on the worktop which caused the residual heat to burn a large hole on to the worktop and eventually the walls to catch fire. This highlights how technologies like automatic cooker shut off devices only ‘work’ when people with dementia and other people also present understand how to

them in emergency situations. People with dementia and informal carers need to act in very specific ways for assistive technologies and telecare to function as designed. Here this meant the technology was useless for preventing the kitchen fire in Mrs Archer's flat.

Later reflecting on this information, I also began to problematise the possible roles for Mrs Archer and her granddaughter in the events which led to a kitchen fire in Mrs Archer's flat. The unsafe kitchen practices of Mrs Archer's granddaughter called into question who should bear responsibility. Mrs Archer was the only adult present during the fire. However, she was asleep at the time the fire occurred. Her granddaughter started the fire, however, her young age means that Anthony and the building manager may not view her as responsible for the fire. It was also unclear who was meant to care for whom in this situation. We do not know whether the granddaughter was preparing food for herself or for her and Mrs Archer. I initially assumed that the granddaughter was there to provide care for her grandmother with dementia or to spend social time with her. Yet, when I later reflected on the incident I wondered whether Mrs Archer was caring for her granddaughter so her daughter did not need to find a child minder. Perhaps how the building manager, Anthony and I initially viewed the relationship between Mrs Archer as the 'cared-for' and her granddaughter as the 'carer' may not actually reflect the practices of either person during the evening of the fire. Only after I concluded fieldwork did I begin to piece together this alternative idea about caring roles for that evening. For me it raised additional questions about why Anthony and the building would not believe Mrs Archer's story. If she was responsible due to being the only adult present during the fire, then her story appeared as a plausible explanation for how the fire occurred. It appeared that the building manager and Anthony may decide that Mrs Archer can be blamed for the fire as an adult yet ignore her account and judgement as a significant adult actor, perhaps, because of her diagnosis with dementia.

Figure 6. Map of Mrs Archer's flat from February 2016 visit



### 7.3.2 Deciding on new practices with food for Mrs Archer

A couple of hours later during this same visit, the building manager visited Mrs Archer and Anthony to discuss with Anthony how to continue supporting Mrs Archer after the fire. Anthony briefly talked to the building manager in the kitchen. Mrs Archer and I spent these few moments sitting in her sitting room in silence. Anthony came over to me and told me that the building manager wanted me to leave the flat so he could talk with Mrs Archer in confidence. I spent half an hour in a chair in the stairwell waiting for Anthony to come get me. Although I left the room for this conversation, Anthony later told me that they decided to remove the cooker from Mrs Archer's flat. Here I present a brief account from this conversation when Anthony and I discussed the potential implications for his joint decision with the building manager to remove the cooker from Mrs Archer's flat for Mrs Archer's cooking and eating habits.

*Anthony: 'Sorry for making you wait outside. I thought he wanted to have a private word.'*

*ML: 'I understand. What was decided?'*

*A: 'We decided that we are going to remove Mrs Archer's oven and cooker. They are hers so she can sell them. But (5) we just feel that it's too risky for her to continue to have it.'*

*ML: 'How will she make food instead?'*

*A: 'I am not sure yet. I am thinking about getting her a microwave or meals on wheels.' He looked at Mrs Archer. 'What do you think about that, chook? Have your food brought her?'*

*Mrs Archer: 'Why?'*

*A: 'We're getting rid of your cooker. We don't want any more fires.'*

*ML: 'Do meals on wheels' cook Caribbean and Jamaican food?'*

*A: 'I'm not sure. They must in Metropolitan. There are so many of us here.'*

*MA: 'I can't cook?'*

*Anthony turned to face Mrs Archer.*

*A: 'No, Sister Archer. The [building] manager and I don't want you to have another kitchen fire. It's temporary until we can move you into a home.'*

*Mrs Archer slowly nodded her head. Anthony turned back to me.*

*A: 'You should see these homes. They all have their own chefs that can cook you anything you like. Mrs Archer will also be safer there.'*

*MA: 'I will show them to cook my food my way.'*

*A: 'No, chook. You can't go in the kitchen there. Each family makes food their own way. Every family has their own recipe in Jamaica.'*

Here, Anthony justifies his choice as a method to prevent future kitchen fires. Yet if we believe the testimony of Mrs Archer earlier that day, then her granddaughter was the person who started the fire. Removing the cooker will prevent any further kitchen fires from happening with the cooker, but it also appeared to me to disproportionately affect Mrs Archer. This seems to suggest that the building manager and Anthony blamed Mrs Archer for the kitchen fire despite her account. It also implies that Mrs Archer's granddaughter will not bear any responsibility for causing the fire.

To allow Mrs Archer to continue eating food in her home after the building manager removed the cooker, Anthony suggested two potential solutions: microwave and meals on wheels. However, in the moment I realised that these options may not allow Mrs Archer to eat food that she likes. The food that Mrs Archer cooked or helped the paid carer cook in the evenings always involved using the cooker. Yams and plantains needed to stew slowly. Microwaves may not allow Mrs Archer to cook the food she likes, since the design of microwaves will limit the settings and cooking style that she can practice. Anthony also suggested 'meals on wheels' as a solution. However, as he admitted in the final line of this excerpt, each family had their own recipe for Jamaican dishes. Therefore, how one person prepares chicken and rice may differ from how another family does as well. 'Meal on wheels' may provide Jamaican food as Anthony suggested based on the number of Jamaican people living in Metropolitan. However, he could not know whether any of the food delivered to Mrs Archer would taste right to her own sensibilities. Anthony's decision to remove the cooker may prevent any kitchen

fires from occurring in the future, however, this decision creates a new obstacle for providing care to Mrs Archer: making or procuring Jamaican food without a cooker. Anthony may need to decide whether it is more important for Mrs Archer to eat food in a reduced risk environment or eat food she enjoys with the risk of another kitchen fire.

The concluding lines in this excerpt depict Mrs Archer as not arguing about having her cooker taken away nor as questioning the decision to move her into a care home. However, when Anthony told me about each care home having a chef that will 'cook anything you like', Mrs Archer interjected that she would show them how to cook the food she wanted. Anthony clarified that she could not go into the kitchen. Here is a potential disconnect between what Anthony imagined as what 'anything you like' entails from Mrs Archer's interpretation. First, Anthony told me it was 'anything you liked' which I interpreted as a general 'you' used to signify inclusion of everyone. Here he appeared to assume that people can always communicate whatever food they want prepared. However, if people do not memorise recipes with specific measurements but actively cook food to their own taste, cooking what people want may not be so straightforward in practice. Therefore, when Mrs Archer suggested that she show the kitchen staff how to make the food she wants, it is perhaps to transfer the practices leading to expected tastes and cooking methods rather than a formally-prescribed recipe.

This discussion illustrates what I observed as tension between how informal carers identify and manage appropriate risks for the person with dementia to take part in everyday practices that are personally meaningful. However, the person with dementia may be prevented from continuing to take part in these activities if informal carers determine that the risk is too great. In other words, informal carers may determine when enacting everyday practices are no longer safe or prevent them from providing care in whatever practice or form they imagine. This may mean that people with dementia may not only abandon or at least take a diminished part in their own everyday practices, but they may also abandon the locations where these practices are situated. Technological practices of people with dementia and informal carers with assistive technologies and telecare may only help people with dementia continue to take part in meaningful activities if practices of people with dementia also matches the intended use of such technologies. Otherwise, assistive technology and telecare may not 'fit' into the built environment of the home or how people with dementia live their lives in the community.

### 7.3.3 Empty kitchen

During my final visit with Mrs Archer and Anthony in early May, I could observe the new arrangements for making her meals. I had spent most of my final visit learning a few phrases of Jamaican patois from Mrs Archer and Anthony and learning about Anthony's plans to rent a new place. Just as I prepared to leave Mrs Archer's flat for the final time, a paid carer arrived as she did every evening. The following brief conversation between the paid carer, Anthony and I took place in the final minutes of my visit w. Figure 7 illustrates the layout of the flat and our relative positions to each other during this visit.

*Anthony: 'What is she having tonight?' Anthony turned his body to the paid carer in the kitchen.*

She told him, 'yams and fish'. I heard the crinkle of a plastic bag from in the kitchen followed by repeated beeping sounds. A moment later I heard the hum of a microwave.

*ML: 'How is she cooking fish without a cooker?' Anthony turned to face me.*

*A: 'It's already cooked. She brings the food her to heat it up.'*

*ML: 'Where does she prepare it?'*

*A: 'She prepares the food at her home. Before the [building] manager removed the cooker, we had Mrs Archer show her how to make some meals.' He pointed back to the paid carer. 'It's worked great.'*

The paid carer was in the kitchen for only a few minutes to heat up Mrs Archer's meal. She brought out a small fillet of white fish with some yams on a large white plate. She placed the plate in front of Mrs Archer on the table with a fork. She asked Anthony if there was anything else she could do. He shook his head.

*A: 'No, it looks clean. I think we're all set.'*

While this new practice described here for making food appeared to allow Mrs Archer to continue to eat food she liked even after she lost her cooker, this solution may be temporary. While Anthony told me that day that Mrs Archer taught one carer to cook her meals, he did not indicate what care

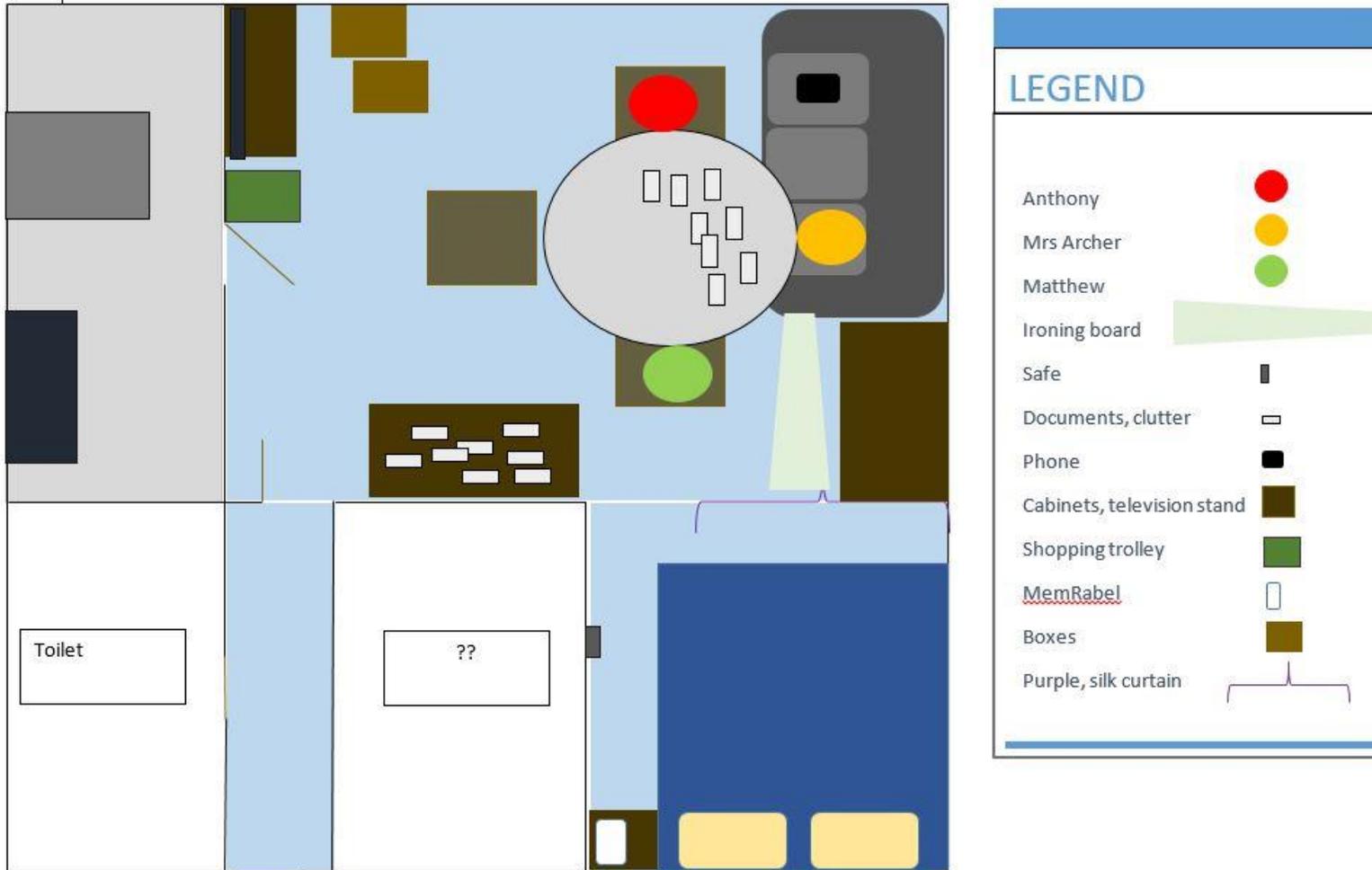
arrangements might be put in place if this carer fell ill, quit her job, or if another carer covered her visit. During this visit, Anthony again told me about his plan to move Mrs Archer into a care home. Yet when she moves to this new location, she would still probably need to instruct the staff how to make food she likes or otherwise have to eat whatever food they prepare for her. Whilst the paid carer making Mrs Archer's meals appeared to ensure Mrs Archer ate food she liked as my fieldwork ended, this also highlighted the limited and context-contingent scope of this solution.

When I later reflected on this interaction to construct ethnographic cases as indicative of these instances, I wondered whose role it was and also whose role it should be to prepare food for Mrs Archer. Mrs Archer indicated from my first recruitment visit the importance of food and Jamaican cuisine in particular to her. Her past experiences as a woman from Jamaica appeared to connect her closely with the food culture of her homeland, and a woman's role in preparing food based on a traditional division of domestic labour. When I first started fieldwork with Mrs Archer, she cooked for herself although my visits never coincided with her lunchtimes nor her dinner times, for me to observe these. The kitchen fire, however, eventually led to a change in her practices. Anthony and the building manager both knew that Mrs Archer did not cause the kitchen fire. However, they still took the decision to remove the cooker citing as a reason to 'prevent future fires'. This explanation may have been based on their anticipating future likely changes in Mrs Archer's capacity to cook for herself and not being able to cook in the future. Having experienced one kitchen fire in her flat they decided to prevent any repeat of this hazard by removing the cooker. However, this 'imagined future' affected how Mrs Archer then gained access to meals. She still had the capability to cook her own meals yet she now was having to rely on an alternative practice because the sheltered housing staff and Anthony removed her cooker in order to reduce the risk of another kitchen fire. Anthony and the building manager did not consider supporting Mrs Archer to cook her own meals to be more acceptable than running the potential risk of another kitchen fire. Mrs Archer took active steps to ensure she could have meals she still liked by teaching a paid carer how to cook meals based on her own cooking practices. Despite Mrs Archer's capacity and the strong links food had for her identity, because of a household emergency she did not create the building manager and Anthony now denied her the opportunity to cook her own food, which she found ways to counter by teaching her paid carer to do the cooking she herself had done.

Changes in the practices of making food could also be seen to affect where food is made. During my fieldwork, Mrs Archer and Anthony regularly went into the kitchen to make a cup of tea or a snack. Anthony and Mrs Archer also noted that she cooked her own meals some evenings as well. Both

Anthony and Mrs Archer would talk from the kitchen during my visits at this time. Oddly, I only went into the kitchen once which was to see the property damage from the kitchen fire. This was also the last time that I saw Mrs Archer or Anthony in the kitchen. At the end of fieldwork, a paid carer started to use the kitchen to reheat meals for Mrs Archer in a new microwave. There was a marked shift from Mrs Archer making her own meals to a paid carer spending no more than five minutes reheating a meal. The kitchen was no longer a place for everyday practices such as food preparation or allowing Mrs Archer to reminisce about her earlier years spent living in Jamaica. The informal carer's decision to remove the cooker left to not only Mrs Archer abandoning her food preparation practices but also abandoning her occupation and use of the kitchen. This highlights the tension between informal carers providing care and people with dementia living their lives as they want to in their own homes. In this case, the potential for a future fire outweighed what the informal carer and building manager thought were acceptable risks for allowing Mrs Archer to continue making her own food.

Figure 7. Map of Mrs Archer's flat from May 2016 visit



## 7.4 Accessing communities outside the home

The previous two cases illustrated how people with dementia and informal carers differently occupied rooms in their home through reconfiguring these spaces or abandoning them with implications for how they lived their lives. 'Home' figured prominently in my analytical focus, shaped by my methodological constraints to observe only practices within the homes of people with dementia. This limitation spurred me to explore how people with dementia spent time outside of their homes. I previously mentioned we have already seen how Sally Stewart brought her parents to garden centres in East County to get her parents outside of their annexe. Other people with dementia, such as Rose, rarely left their home except to attend doctor's appointments. Here I want to look at one particular ethnographic case, the Anansis, to examine how people with dementia access locations outside the home such as neighbourhoods and their wider community.

The Anansi case included William and Claire Anansi. William Anansi was a man in his late eighties diagnosed with moderate dementia. William was a first generation immigrant who moved to England from Jamaica in his forties. He lived alone in his own flat after he separated from his wife. He worked in the financial sector before he retired two decades ago. He has three adult children. Claire acted as the primary carer for taking part in ATTILA and supporting him at home. Claire Anansi was the youngest daughter of William Anansi. She was a second generation immigrant who moved to England as a teenager with the rest of her family. She worked in further education at colleges in Metropolitan where she taught classes related to the hospitality industry. Claire lived on the opposite side of Metropolitan from her father. However, she travelled two hours' roundtrip several times each week to check on him.

I spent most of my time with the Anansis in William's sitting room usually immersed in conversation with Claire. Claire spoke the most out of the three of us whilst William rarely spoke at all during my visits. When he did speak it was almost always to Claire rather than me. He rarely interacted with me beyond when I assessed his mental capacity at the beginning of each visit.

I learned from Claire during my initial visit with the Anansis from that William liked to go to Metropolitan Market. Although William never told me about going to Metropolitan Market, Claire told me during a later visit that it was a place where he could get 'good Caribbean takeaway'. According to her he also 'knew most of the shop owners' in the market too. William could still travel to Metropolitan Market by himself on the bus. He did not need anyone to help him get there or back

to his flat. Yet his visits to Metropolitan Market began before he received a GPS tracking device (see Appendix IX for an indicative picture) to where when he left the house to make sure Claire and her siblings could quickly locate him if he became lost in Metropolitan. I selected this ethnographic case to illustrate possible interactions and tensions when access to community spaces for the person with dementia become mediated through assistive technologies.

#### 7.4.1 Claire locating William with a GPS device

I had already visited the Anansis four times, when I arrived at their place one day in April 2016. I did not know at the time I arrived, but I would finally see how a participant in ACCOMMODATE used their assistive technology. I had already noticed the GPS tracking device hanging from the door handle of William's sitting room during previous visits. After I arrived for my fifth visit, Claire told me that she arranged my visit for this particular day because she needed to bring her father to a dentist appointment later that afternoon. Approximately two hours into the visit, William left the sitting and told Claire that he was going to the kitchen. Unbeknownst to her and I at the time, William also left the flat without telling Claire. Claire rang her father's mobile when she realised he left his flat. He did not respond. To locate her father, Claire decided to phone the call centre linked to her father's GPS tracking device on her father's landline phone whilst she continued to dial his mobile number on her own mobile (Figure 8 reflects the approximate positions of Claire and I during this scene).

*Claire Anansi: 'Where is he? He knows that he has an appointment.'*

Claire picked up her mobile from the armrest of the couch. She scrolled through her contacts until she found her father's number. She rang the number the number, but he did not answer. She got up from the couch and walked over to charging base unit for her father's phone. She picked up the phone and checked for a dial tone. She stopped trying to ring her father. She searched for something on the phone, then dialled a number into her father's landline phone.

*CA: 'Want to hear too?' she smiled as she asked. I nodded. She put the phone on speaker. The phone rang a couple of times before a male voice picked up on the other side. Claire introduced herself as William Anansi's daughter and carer. She explained that her father 'left the flat without saying a word'. However, she needs to 'get him back home because he has a dentist appoint at 2'. The male voice on the other line asked her to 'please wait'. While Claire was on hold she used her mobile to try to phone her father on his mobile.*

*'Hello?' A voice asked on the other line. Claire told him that she was 'still here'. He told Claire that they found her father in Metropolitan close to the market.*

*CA: 'Great. Can you get him to come back? He's not answering his mobile.'*

*The voice told her they would contact William through the speaker on the GPS tracking device.*

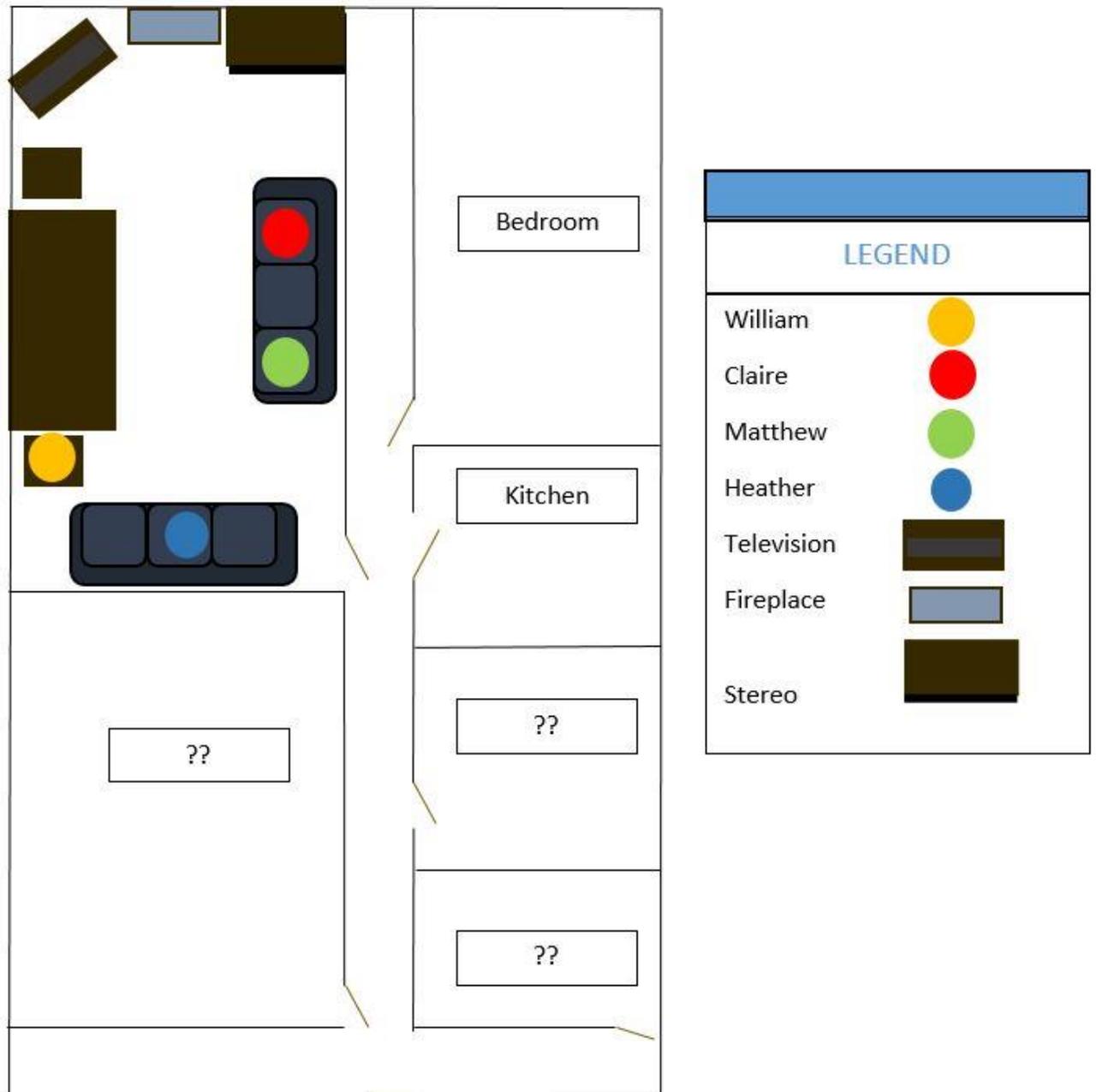
I noticed that Claire cleverly made use of both phones in the flat to continue calling her father whilst also contacting the call centre as an additional method to locate her father. Although she initially tried to call her father directly on his mobile she ultimately relied on new technological practices with her father's GPS tracking device to locate him in Metropolitan. Although Claire and I were surprised that he left the flat without telling Claire, we should have expected him to go to Metropolitan Market. Claire previously told me that enjoyed visiting Metropolitan Market as it provided him opportunities to speak with other people and also eat food he enjoyed.

This brief interaction also highlights Claire's apparent frustration with William. She told me the reason why she visited her father, and also scheduled my visit, for this particular was to bring William to a dentist appointment later that afternoon. I never learned William's reason for leaving the house at the time. Perhaps he forgot about his dentist appointment. What I understood in that moment was that William made a decision about how he wanted to spend his afternoon – visiting Metropolitan Market. Claire decided in that moment that she needed to locate him and bring him back home so he could go to the dentist.

On later reflection after this visit ended, it appeared that neither Claire nor William appeared to consider why the other person prioritised accessing different activities and resources in the community that day. What if William would rather spend a spring day in the market than in a seat at the dentist's office? William could still make decisions for himself about how he lived his life. He did not, however, appear to articulate why he left to Claire. Yet this situation demonstrated to Claire that she could locate William in Metropolitan with a single phone call with the assistance of the GPS tracking device and assistance from the call centre operator. However, this did not mean William continued to allow Claire to seemingly prioritise how he engaged with his community. William leaving his flat without telling Claire and Claire's subsequent attempt to track him with the aid of call centre appeared to reflect William and Claire contesting the relative importance of how and in what

ways William links with his community. Such insights develop 'care as surveillance' discussed in the previous chapter to a point where it extends beyond surveillance in the home. Now informal carers, in this case here represented as Claire, could create practices with assistive technologies that appeared to limit how people with dementia, William in this case, engaged with spaces and people outside of his home. Yet what I observed during this visit with the Anansis differentiated surveillance here from its practice within the Campbells' home. Here, William appeared to find ways to subvert this external control from Claire and the GPS tracking device.

Figure 8. Map of Mr Anansi's flat from recruitment visit



#### 7.4.2 William subverting tracking through technologies in the community

Despite Claire's use of the GPS tracking system to locate William, the call centre operator and Claire could not contact William at first. However, a few minutes after both Claire and the call centre operator attempted to contact William he answered his mobile phone.

*William Anansi: 'Yes.' I heard William groan through Claire's mobile. I could just barely hear him.*

*Claire Anansi: 'Dad, you need to come home now. Where are you? You have to be at the dentist in forty minutes and it takes thirty to get there.'*

*William groaned again. I could not understand any words though. Next I heard the dial tone. William had ended the call.*

*CA: 'He hung up on me!' Claire exclaimed. She re-dialled the number. He answered the phone. 'Dad, I need you home now. I've tried to find you for almost the last hour. Where are you?'*

*WA: 'I know. I'm coming.' He ended the call again.*

*'Mrs Anansi?' a voice asked from the other phone. The call with the call centre was still engaged. 'I can see that he is moving towards you.'*

*CA: 'Great. Thank you.' She ended the call with the call centre, then she turned to face me. 'I need to go now. I will have to pick dad up at another stop to avoid traffic.'*

*We both gathered our belongings and left the flat.*

Here, Claire told her father that she needed him home in order to bring him to an appointment with the dentist. Yet William did not sound concerned about his dentist appointment from what I heard during the call. He had decided to go to Metropolitan Market for the afternoon which he did. I did

not see William again that day since Claire and I both needed to travel to different sides of Metropolitan to get to our destinations. However, I learned during my next visit that William made it on time to his dentist appointment.

William's actions on the phone with Claire appeared to me as a way to subvert recent attempted changes to how he himself lived and maintained control over his life. Although he agreed to wear the GPS tracking device, he still managed to find ways of subverting Claire's monitoring practices through the device. William's tone and repeated sighs on this brief phone call seemed to indicate his annoyance with the conversation or perhaps the repeated attempts from the call centre and Claire to contact him in the first place. When Claire explained to William that she had tried to contact him, he told her that he knew and was 'coming'. William did not explain why he ignored her calls nor why he hung up. However, given the new technological practices Claire performed to locate her father it is possible that he subverted her practices in order to maintain control over his own life and to make choices about how he wanted to live it.

This case highlighted a peculiar instance for how a person with dementia accessed different aspects of their community. Most people with dementia spent every day at home. They usually only left home to go to a doctor's appointment. William not only still walked around Metropolitan, he could also still independently navigate his way to Metropolitan Market as well. However, his family – especially his daughter, Claire – worried that he would one day get lost, hence the presence of a GPS tracking device. Although they seemed to understand why he wanted to go to Metropolitan Market they worried about him losing his way home at some imagined future time. This illustrates potential tensions arising between how informal carers and people with dementia differently imagined and acted on how they could access the community outside of their home. People with dementia like William still enjoyed taking part in activities outside of his home, however, he and his family appeared to weigh up his preferences with potential risks to his wellbeing. Claire included assistive technologies to help her monitor William, but the kinds of monitoring these enabled, appeared to undermine his capacity to manage his own affairs. For this reason, I came to see practices with assistive technologies and telecare reflective of and constituting often disparate views of how informal carers differently imagined people with dementia living in the community from how people with dementia actually chose to or wished lived in their communities.

## 7.5 Chapter Summary

This chapter examined how people with dementia occupy and mediate relations with and within domestic and community spaces through their everyday and technological practices. It considered diverse relations with home or community that people with dementia experienced in this study through three cases: 'reconfiguring rooms in the home', 'abandoning rooms in the home', and 'accessing communities outside the home'.

These cases illustrated how everyday and technological practices of people with dementia and their informal carers led them to reconfigure or even abandon rooms in their home. This in turn was seen to constrain how people could experience their everyday lives with dementia, how 'care in the community' could conflate care in the 'community' with practices actually located in the 'home'. This suggests that 'home care' and 'living at home' may sometimes be more useful and precise ways of describing the reality of where people live and receive care than a more 'imagined' concept of 'community'. However, even within 'home care', the 'home' can be seen to be a contingent and flexible concept, since people with dementia and their informal carers may reconfigure rooms so as to locate a newly-relevant set of practices within fewer or even one location whilst also abandoning the use of other rooms in the home. This is not to say that enabling people with dementia to live independently in the community should be excluded as a goal of practice or policy for health or social services care provision. However, current practices with assistive technology and telecare appear potentially to constrain people within their homes while providing little support to help them maintain their current relations with the spaces in their home, let alone the wider community. For people with dementia, maintaining familiar relations, practices and spaces may be particularly important for maintaining their relative independence, participation and wellbeing.

# Chapter 8: Discussion

## 8.1 Introduction

I previously described health research literature presents using assistive technologies and telecare as a tool to help people with dementia live independently as a form of 'good clinical practice' (Hughes and Louw 2002). Critiques from the medical humanities and social sciences described using telecare and assistive technologies as challenges to a person's autonomy that may undermine how people want to live their lives and receive care. This set up a novel place for this study in the field of medical social science research. I could perhaps give a fuller account, a critical counter-narrative, about technology-enabled dementia care services informed by my observations of the practices of people with dementia and informal carers using assistive technologies and telecare. Now I return to the theoretical concept of 'imagined communities' to place the findings within the wider field of sociology, anthropology, and science and technology studies. Drawing on this theory allowed me to examine how providers and commissioners of 'technology-enabled care services' may envision 'care in the community' for people with dementia in ways that de-contextualised them from their everyday social reality and therefore also from how people with dementia and their informal carers and the services which interact with them, realised such care in divergent ways.

First, I will evaluate the appropriateness of the 'imagined communities' to discuss the findings from ACCOMMODATE and how it sits within or opposed to alternative approaches of understanding care in the community. I noticed three imagined communities that illustrate the conceptual and methodological development of ACCOMMODATE: the 'imagined care communities' of policy makers and care professionals; the 'imagined diagnostic communities' of health researchers; and the 'realised ethnographic communities' constructed through the activities of this study.

## 8.2 'Imagined communities' of dementia care and research

I previously attended to how I came to see memory problems, care, and the home and community as they related to the practices of people with dementia and informal carers using assistive technologies and telecare. However, my realisations did not occur all at once. I gradually recognised differences between how social policy, health research, and, finally, my own decisions about technology-enabled care influenced differed. I spent time with participants which challenged my preconceived ideas about living with dementia in the community and providing care. These appeared to me as marked differences between how social groups - including health services, local authorities, policy makers,

and industry - constructed dementia, reconfigured practices and meanings of care, and re-shaped what community means to form 'imagined communities of care'. Here I draw attention to dissonances and contradictions between how policymakers, care professionals and I, informed by ethnographic activities with people with dementia and their carers, envisioned 'care in the community', 'technology-enabled care services' and the practical realities of providing and experiencing care mediated through technologies. I call these divergent understandings 'imagined communities of care'.

Anderson coined 'imagined communities' as a theory to explain the formation of nations as a social construct, 'an imagined political community', and to differentiate a shared 'commune' of individuals from other groups (Anderson 1983). He argued that nations were socially constructed because individuals drew on shared images, iconography, and texts that marked their national identity as distinct from how they 'imagined' others (Anderson 1983).

During my fieldwork and early analytical phases of this research, I noticed that the concept of 'imagined communities' appeared increasingly important as a way to make sense of my experiences. It also helped me to understand the dynamics and discourses of different stakeholder groups either directly observed and reported to me throughout fieldwork. Whilst anthropologists conventionally carried out ethnography based on spending extended periods of times in the field with a geographically bounded and situated group of people, what once might call an 'ethnographically-imagined community'. ACCOMMODATE, however, included a group of people initially categorised based on a medical history of memory problems or dementia and unmet social care needs, to take part in a wider study called ATTILA. Although I did not create these initial categories based on the severity of person's dementia, they still shaped my own ethnographic imaginings informed by my relationships and work within the ATTILA trial. Yet I later came to challenge these categories. Health researchers and care service providers imagined communities as well, however, they imagined communities based on 'living in the community' and collectivising people around the single illness category of 'dementia'.

The concept of imagined communities therefore extends the relevance of discussing this study's findings to highlight the claims of diverse groups, including those of the ethnographer, as differently imagined and realised 'dementia', 'care' and 'community' to exist as distinct practices and as appropriate objects of policy, practice, and research. Health researchers, care service providers and I have also constructed imagined communities of 'technology-enabled dementia care' through specific types of work: we all identified, categorised and differentiated people with dementia and informal

carers through what we expected and perceived as shared commonalities. Policy makers and care providers appeared to imagine 'care communities' based on the types of care people with dementia received and from whom they received it. Health researchers may have imagined 'diagnostic communities' from research where the key focus was on the diagnosis of participants. I constructed an 'ethnographic community' which arose through adopting concepts from 'imagined care communities' and 'imagined diagnostic communities' to build my ethnographic approach before then observing practices of people with dementia and informal carers that appeared to challenge these imaginings.

### 8.2.1 Imagined care communities

'Imagined care communities' have helped here to represent how policy makers and care providers have envisioned 'community-based care' and 'living in the community' for people with dementia. Following the closure of asylums, 'care in the community' was the primary form of care for people with mental health problems and older people. During the latter period of Thatcher's Prime Ministership, she commissioned Sir Roy Griffith to evaluate current 'care in the community' (King's Fund 2006). Griffith's report (1988) concluded that 'care in the community' was ineffective due to poor leadership. He suggested: local authorities hold budgets and determine appropriate care packages for recipients living in the community and residential care, and social care should have the responsibility for providing long-term care (Griffiths 1988). The government responded to the Griffith's report with the *Caring for People* white paper which suggested a needs-based approach to 'promote independence' for people who wished to live in their own home instead of residential care (Renwick 1996). To me this suggested that 'community care' was designed to help older people live in their own homes for as long as they wished.

More recently policy makers identified the potential for increased social and health care costs as populations in Europe and North America lived longer. Ageing populations now became viewed as a social cost rather than source of capital as people considered the effect of a 'silver tsunami' that will 'swamp' health and social care systems (Fried and Hall 2008; Roehr 2012; Schwartz 2012; Bartels and Naslund 2013). The expected increase in older people living to over 85 years old also suggested an increased incidence of people living with dementia. Current research estimated between 670,000 (Mathews et al. 2013) and 685,000 people live with dementia in England (Alzheimer's Society 2014c). Reports from the Alzheimer's Society estimated that two-thirds of people living with dementia 'live in the community' (Alzheimer's Society 2007; Alzheimer's Society 2014c). In response to an ageing

population, policy makers and care providers decided to search for solutions to help people with dementia continue to 'live in the community'.

Here we notice a shift in language. Previously policy makers characterised 'community care' as support that helped people live in their own homes. Now 'community care' helped people live in the community. However, I noticed that both living at home and living in the community appeared to be used interchangeably. Yet as the findings from this study illustrated 'home' and 'community' refer to different spaces, groups and practices than the spaces, people and practices located at home. Community could therefore be seen as encompassing the familial relationships and domestic spaces yet also include services, people, and organisations located in a specific bounded area outside the home. 'Community care' in the Griffith Report and the *Caring for People* white paper appeared to refer to members of the community, who worked as volunteers or for a local authority, providing care or support to people. In other words, the community provided care. However, current use for 'community-based care' appeared to suggest that care was provided *in* the community just as people lived in the community too. Here I purposively leave this sentence as a passive construct as community appears to refer to a specific space or location rather than denoting the people who inhabit these areas. Instead, the actors providing care, whether paid or informal carers, become invisible.

In 2015, the NHS Commissioning Assembly published *Technology Enabled Care Service Resource for Commissioners* that promoted 'technology-enabled care service' as using 'telecare, telehealth, telemedicine/teleconsultation and self-care apps' that help people manage chronic illness and sustain independence (NHS Commissioning Assembly 2015). Technology-enabled care services were expected to make primary care more efficient, help provide care seven days a week, improve access to services for people living in rural areas, and personalise care (NHS Commissioning Assembly 2015). This document illustrated the centrality of 'care' for technology-enabled care services: care will be more efficient, available every day of the week regardless of whether a person lives in a rural or urban area yet personalised to address their individual care needs. Yet what remained unclear was how technologies would help 'enable' services to achieve these ambitious goals. Technology-enabled care services may represent a new form of community care yet 'community' is no longer explicitly stated as a feature of these care services. If community is no longer a central feature of new policy, then we must consider *who* will provide this new approach to care and who the imagined recipients of this care will be. Instead, 'technologies' are the central feature which enable care. Such a reduced scope in policies related to technology-enabled care services abstracts how the ideas of policy makers and

commissioners relate to the actual services and people providing them they describe. Policy exists in a bizarre position where it not only describes current procedures but also sets out these same procedures as goals for which service providers should strive to achieve. However, policy cannot fully attend to either present practices nor envision actual future practices. Instead, it continues to exist as an imagined ideal yet now devoid of people to deliver care. Policy makers reified technology as caregiving subjects to care recipients outside of social relations and spatial boundaries.

### 8.2.2 Imagined diagnostic communities

In contrast to policy makers, I noticed that health researchers appeared to imagine communities more explicitly through how they constructed first populations and then samples for their studies. They include and exclude people from their studies based on whether they identified with specific criteria. In the case of ATTILA (Leroi et al. 2013), this meant that the local research workers only recruited people into the study who had:

1. a diagnosis of a dementia,
2. a 'significant need' based on 'Fair Access to Care Services' criteria,
3. a working telephone line connected in their home.

ATTILA trial investigators imagined and then enacted a particular type of people living with dementia who may 'need' and 'receive' technology-enabled 'care' to make recruitment for the study possible. People with dementia recruited into this study had to have a diagnosis of dementia, yet only approximately 40% of people living with dementia received a diagnosis (Alzheimer's Society 2011). Although the Fair Access to Care Services was phased out with introduction of the Care Act 2014, the replacement eligibility criteria defined eligibility based on a person experiencing 'significant impact' if they experienced difficulty with predefined 'eligibility outcomes' related to nutrition, personal hygiene, toileting, dressing, 'maintaining a habitable home environment', making use of local services like public transport, amongst others. However, local authorities must know of a person with dementia in order to refer them for an assessment. In addition, people with dementia may not display officially recognised 'difficulties' that demonstrate a 'significant impact' based on their living circumstances, availability of private funds, and other care they have in place. Finally, the absence of a working telephone line may exclude people who are already vulnerable and isolated from the research and capturing their experiences with the technology. Such narrow parameters suggest that the people with dementia included in ATTILA and, therefore, ACCOMMODATE, were people with relatively high awareness and access to local services which may not reflect the experiences of most people living with dementia.

Conversely, people who met these criteria were excluded if they had:

1. an 'unstable medical condition' and/or
2. previously received or abandoned assistive technology or telecare from local authority. (Leroi et al. 2013)

The exclusion criteria further constructed a particular imagined community of people living with dementia. Such a person with dementia must not experience an 'unstable medical condition'. This may exclude people from taking part in the study who live with dementia and other illnesses that make everyday life difficult. Previous medical research suggested that 61% of people living with Alzheimer's disease, the most common cause of the dementia syndrome, have 'three or more comorbid diagnoses' (Scutton and Brancatti 2016) with a person's progress into later stages of the disease resulting in additional comorbidities (Doraiswamy et al. 2002). Therefore, this study excludes the most potentially vulnerable population from the study. The final exclusion criteria prevented people with dementia who previously received an assistive technology or telecare device from taking part in the study. This suggests that people taking part in this study will have shared the belief that assistive technology or telecare may help them personally or help them provide care to a person with dementia. The trial results, therefore, cannot account for how people with dementia or their carers opposed to assistive technologies or telecare may or may not take up these devices as a component of their care.

This work suggested a cluster of criteria for imagining dementia to identify people who would be acceptable for taking part in the ATTILA trial. However, the ATTILA trial team further constructed less-commonly-shared ideas about dementia when they included people with only an official dementia diagnosis who are required to have 'significant impact' based on formal care support assessment along with a working telephone line whilst not having any other debilitating illnesses or previous history of using assistive technology or telecare. These criteria could not capture the full range of how people experienced dementia nor even the most common ones.

Health researchers will construct imagined communities of populations to test the efficacy of an intervention. In the case of the ATTILA clinical trial, the team constructed a narrowly-defined group of people living with dementia in the community who might receive assistive technologies or telecare. The need to control for specific diagnostics may mean that otherwise statistically significant findings may require further work for implementing the intervention in *actual and specific* clinical or domestic care settings and practices.

### 8.2.3 Imagined ethnographic communities

The imagined ethnographic community attempted to relate the practices of people with dementia and their informal carers living in their homes in 'the community' identified as using assistive technologies and telecare and therefore to be connected through the fieldwork visits of the ethnographer. Observing people with dementia and their informal carers carrying out everyday routines revealed when (or whether) and how they may also have used the technological interventions provided by statutory services within those routines. The study, therefore, differed from how health researchers and policy makers appeared to engage over time with the everyday practices and experiences of people with dementia and their informal carers using assistive technologies and telecare. I could modify the imagined ethnographic community as I learned more from participants in the moment and later still when I reflected on individual visits and compared them across the ethnographic cases. Nonetheless, the imagined ethnographic community was also limited as its findings could not represent these practices in terms of a whole population of people with dementia. I can only describe and attempt to represent practices from particular cases of people with dementia and their informal carers taking part not only in this study, but also in a randomised controlled trial. In realising an ethnographic approach, the framing and activities of this study will have created its own 'ethnographic community' based on the very diagnostic criteria critiqued in the imagined diagnostic community promoted in health research in dementia, and reproduced through the visits, connections and relationships built through the ethnographic fieldwork.

My imagined ethnographic community could not apply to or represent *all* people with dementia and informal carers using assistive technologies or telecare. Instead, it was able to come to highlight granular details about how *some* people with dementia and *some* informal carers did use these technologies to inform further imaginings to realise as new care practices. My imagined ethnographic community could also illuminate the distinct ways people differently imagined community-based dementia care and visions for technology-enabled care as a specific set of practices for it. My dis/embedded ethnographic activities moved me across different disciplinary and organisational boundaries that shifted how I understood technology-enabled dementia care. I came to realise that no single 'imagined community of care' in isolation encompasses any definitive 'truth' about the role of technologies in supporting people with dementia and their informal carers. Revealing and combining the different imagined communities of care helped reveal the dynamics at play.

### 8.3 Appropriateness of the research design

For this study, I set out to examine the practices of people with dementia and their informal carers living in the community using assistive technologies and telecare to understand how 'technology-enabled care services' as a component of 'care in the community' became realised in everyday life. After I framed the research problem, I identified three core concepts as relevant to understanding 'dementia care in the community': everyday practices of living with dementia, how care is understood and performed, and how people with dementia access and occupy the community. I refined these concepts into four research questions to consider how assistive technologies and telecare may affect the associated practices of people with dementia and informal carers:

1. How do people with dementia experience everyday life in the community?
2. How do carers provide 'community-based care' and through what activities?
3. How and why do people with dementia and their informal carers use, or choose not to use, assistive technologies and/or telecare in the community?
4. How do assistive technologies and telecare fit into the communities of people with dementia?

To answer these four research questions, I selected ethnography as an appropriate methodological approach to understand how and why people with dementia and their informal carers used assistive technologies and telecare. As an ethnographer I directly observed, and at times took part in, enacting practices with participants using these technologies. Here I want to evaluate the appropriateness of this research design for ACCOMMODATE.

I considered alternative methods, such as interviews and focus groups, to allow people with dementia to discuss their practices. However, people with dementia may have communication difficulties, like aphasia, that make articulating their experiences difficult. Sabat (2001) noted that even people with dementia who can speak may still change the structure of their sentences and the speed in which they can speak. Taking part in interviews and focus groups may also require people with dementia to recall information that their memory problems may make difficult. Ethnography, on the other hand, could focus on observing phenomena in 'real life' often as it occurs. The immediacy of my observations helped me discuss what and why people with dementia did particular practices as they performed them.

Social scientists conventionally approached ethnography predicated on situated, immersive and long-term fieldwork commitments that often entailed spending a year or longer in one particular location or 'field'. Therefore, to make an ethnographic approach relevant to this study, I needed to rethink how fieldwork could be understood and carried out with people with dementia living in the community, a

group that lived in geographically dispersed areas around England. Before fieldwork started, I began considering alternative ethnographic approaches that would allow me to draw on the sensibilities of ethnography I learnt from previous training in social anthropology with the practical requirements for this study. I adapted ethnographic approaches from scholars in global studies, communication studies, and political anthropology to achieve this goal with the result of a multi-sited, focused/short term, and collaborative approach described previously in this thesis. I turn to each of these adaptations to evaluate how they affected the robustness of this study and whether it is, therefore, appropriate to call this study 'ethnographic'.

### 8.3.1 Multi-siting fieldwork to examine multiplicity of practices

As discussed in Sections 3.4 and 3.5 of this thesis, one methodological challenge to carrying out ethnographic fieldwork was how 'field' was conventionally envisaged in ethnographic studies from the practical requirements of this study involving people with dementia living in the community. Although previous health and care literature often presented 'living in the community' as a singular place or group, people with dementia occupied multiple communities definable at different levels from nations down to neighbourhoods and homes. However, all people with dementia do not reside in a single community whether defined by geographic location or their social network and services that occupy these locations. Ethnographies from social anthropologists, sociologists and more recently public health and development studies, often identified their research with a particular location and a group of people that inhabit that area. This point is exemplified from classic anthropological ethnographic texts like Evans-Pritchard's ethnographies of the Nuer (1951) and Azande (1937) people from the Nile basin to more contemporary examples from sociology such as Goffman's (2014) research on how black Americans are institutionally criminalised in Philadelphia. Both examples clearly identify a group of people with a particular location. However, these ethnographic examples studied accounts that were based on people that were relatively co-located geographically.

Increasingly, in our fluidly-organised and globalised world, not all people occupy only a single location nor do they continue to live in only that one location for their entire lives. People with dementia living in the community reflect a group of people that occupy and live in diverse range of locations in England and globally. To carry out an ethnographic study with people with dementia, this study, therefore, had to adopt a multi-sited approach. I previously described in Section 3.5 a specific concept of a multi-sited ethnography emerging from the work of George Marcus (1995) designed to understand experiences of migrating people, from journalists to members of ethnic Diasporas. Marcus' work was

an example of what he called 'following the people' because he was interested in the processes involved in people moving from one location to another one. The approach for the ACCOMMODATE study differed from that of Marcus, because the people with dementia taking part in this rarely left their homes. Therefore, this study did not 'follow people' in movement, but the researcher had to travel themselves because of the nature of the wider ATTILA study in which ACCOMMODATE was embedded. As the goal of this study was to examine how practices of people with dementia and their informal carers using assistive technologies and telecare, may affect experiences of living with dementia, meanings and practices of care, and relations with home and community. This study could be seen as constructed as multi-sited so as to understand the policies of 'technology-enabled care services' as a component of a diverse 'care in the community' which varied according to location and therefore required multiple locations. This study, therefore, 'followed' these local policies as 'metaphors' (Marcus 1995: 108). 'Technology-enabled care services' and 'care in the community' are not 'things', they are ideas that are realised in local practices and which therefore help account for how policy makers and practitioners imagined services and practices to support people with dementia.

In practice, multi-siting this ethnography meant this study examined the practices of ten people with dementia and their informal carers using assistive technologies and telecare from East County, Coastal Counties and Metropolitan. Each person with dementia and their carer was presented as a case initially based on three purposive sampling criteria: the severity of the person's dementia, the type of social relationship between informal carer and person with dementia, and the assistive technologies and/or telecare they received from their local authority. Multi-siting, therefore, enabled this study to examine a diverse range of assistive technologies and telecare products and how people with dementia with different care needs arising from their dementia and a variety of carer relationships constructed practices with these technologies. This meant that the findings presented here not only attended to subtle differences between cases but also similarities despite the variety across the three purposive criteria.

On the other hand, the multi-sited ethnographic approach also came with costs such as time constraints for each visit which limited the descriptive depth or 'thickness' of ethnographic fieldnotes. Participants in this study lived in three different counties and one major urban area in England. To visit people with dementia and their informal carers at times that suited them, this often meant that I occasionally had weeks where I had three visits or weeks with no visits at all. The ebb and flow of travelling to the homes of people with dementia often made it difficult to account for everything that I observed during each visit. The resulting description often appeared 'thin' compared to my personal

expectations for what ethnographic fieldnotes should cover. The travelling also made it sometimes difficult to produce fieldnotes from the initial notes I took during a visit before my next visit to the home of another person with dementia. This made it difficult to produce memos and early analysis on the fieldnotes I produced so as to direct observations or conversations with other participants, whether people with dementia and/or their informal carers. To address this issue, I set up and shared with the study supervisors a weekly progress report, which described the 'completion plan' for carrying out all seven planned fieldwork visits with each case and highlighted whether I was behind with any particular case, with a traffic light system. This also illustrated information that was also analytically relevant data, since a carer cancelling at the last-minute or not responding to my calls may indicate that they were not visiting the person with dementia to provide physically co-located care either.

Multi-siting, therefore, seemed to work out as a methodologically-appropriate approach to 'follow the metaphor' (Marcus 1995) of how the policy of technology-enabled care services was actualised in the practices of people with dementia and their informal carers living in the community using assistive technologies. The practical requirements to co-locate myself with the participants in this study also required a multi-sited approach because people with dementia live in a variety of locations in the country. Problems that arose with managing travel commitments with analytical and descriptive depth were partially addressed through weekly fieldwork updates that served as a method for accounting on what fieldwork was carried out, what if any visits were delayed and why, and initial analytical interpretations of selected fieldnotes from the week. Such activities reflected techniques for providing data collection and analytical validity (Whittemore, Chase and Mandle 2001).

### 8.3.2 Focused and short-term versus extensive and emergent fieldwork

This subsection considers two additional and related methodological adaptations that I drew from scholars in communication studies and sociology: focused and short-term fieldwork. Both of these concepts were previously introduced in Section 3.5 as a methodological way to address the analytical and practical challenges that arose from the multi-sited approach to this study. Knoblauch coined the term 'focused ethnography' to describe an ethnographic approach that relied on a commitment to 'data intensity' (Knoblauch 2005). 'Data intensity' described an approach where an ethnographer intensively collected data on a specific phenomenon. Knoblauch contrasted this approach with early ethnographic accounts, especially from social anthropology, that examined systematically and holistically each cultural domain (e.g. religion, medicine, food subsistence strategy, economic system, political system, etc.) of a cultural group. Instead, Knoblauch suggested that contemporary

ethnography had more in common with sociologists from the Chicago School who examined a particular aspect of different professions and social groups living in Chicago in latter half of the twentieth century (Knoblauch 2005). In other words, this shifted the focus from comprehensively holistic accounts to specifying a particular aspect of social reality. The methodological requirement, here, therefore, was a focus on the single aspect of social reality: practices of people with dementia and their informal carers using assistive technology and telecare.

This study did not therefore examine or observe every facet of daily social reality for people with dementia or their informal carers. From the onset of this study, the research problem was specifically refined to examine the practices of people with dementia and their informal carers living in the community using assistive technologies and telecare. Attending specifically to the practices of people with dementia and informal carers involving assistive technologies and telecare focused the participant-observation fieldwork carried out as part of this ethnography. It was clear that this would require collecting data related to the practices of people with dementia and informal carers with these technologies in order to address my research problem.

There is a caveat to the data that could be collected through focused ethnography. Although the data collected during fieldwork may directly address the research problem, it may not account for other cultural domains that participants may actually have themselves found more directly meaningful. In other words, the data collected during this study may address the research problem, however, it may not consider other aspects or challenges in the everyday lives of people with dementia or their informal carers they view as more significant than how and why they use assistive technologies. This issue shifts the methodological dilemma from 'data intensity' to 'data relevance'. One of the goals of holistic ethnographic accounts was that researchers did not always know what they would find out during their fieldwork. The ethnographer may learn during fieldwork that the research problem they initially constructed was irrelevant. Ethnography allowed people to shift their observations to emergent phenomena that accounted for what was important to participants and why. A rigidly-focused ethnography would not allow this methodological agility.

This study therefore attempted to balance a focused ethnographic approach that allowed for emergent data and interests also to manifest. Conversations during each visit to the home of a person with dementia rarely involved directed conversation about the assistive technology or telecare. Occasionally, I intentionally steered the conversation toward discussing the assistive technologies and telecare they had. However, most of my time during visits was spent observing the everyday practices

of people with dementia and their informal carers. These observations led to the analysis not only of practices with assistive technologies, but how they affected understandings and other everyday relations of living with memory problems, providing and receiving care, and living at home and accessing the wider community. This meant that the findings were not only addressing the research problem, but attending to an analytic that allowed for critical interpretations of how the practices of people with dementia and their informal carers using assistive technologies reflected, refracted or reconfigured the preconceived ideas related to 'technology-enabled care services' as a component of dementia care in the lived context of the everyday.

Linked to the adaptation of the focused ethnography was the concept of 'short-term ethnography' identified by Pink and Morgan (2013) introduced in Section 3.5 as a methodological and practical adaptation for research contexts that may not allow for the same extensive fieldwork opportunities advocated in much anthropological research (Pink and Morgan 2013). Short-term ethnography relies on 'time intensive', detail and theoretically informed ethnographic accounts to compensate for the reduced time carrying out fieldwork (Pink and Morgan 2013). This study adopted a shorter-term ethnographic approach to examine the practices of people with dementia and their informal carers living in the community using assistive technologies and telecare.

The fieldwork in this study resulted in sixty visits across nine cases of people with dementia and their informal carers totalling 208 hours of observation. The average visit lasted for approximately three and one-half hours. After the initial recruitment visit, each case was visited once per month for six months as their schedule allowed. However, it was not always possible to visit people with dementia because they experienced an acute illness, were in hospital, or sudden death. One could argue that this study is a case of 'short-term' ethnographic fieldwork. However, the time I spent with each person with dementia and their carer was what was manageable for them. Ethnographers not only have a methodological and analytical commitment to understanding the lives of people they spend time with during their research, they, like all researchers, also have an ethical commitment to ensure that they 'fit' their activities into the routines of participants that still allow them to live their lives as they wish. Short-term ethnography was the only way that I could access data about the practices of people with dementia and their carers using assistive technologies. This meant that the data collected could not be a holistic account of dementia care. Instead, observation had to specifically attend to the practices of people with dementia and their informal carers. Such focused observations meant that collected data were appropriate for addressing the research problem yet may have missed out on potentially relevant contextual information that would add further analytical depth.

Some social anthropologists and sociologists may not fully agree on the definition of this study design as ethnographic if it did not entail continuous fieldwork for many months. However, there may be a case for questioning a rigid requirement for all ethnographers to spend extended periods in the field. Many research problems may not require an ethnographer to account for the everyday life or practices of a group of people during each season. Aspects of ethnographic activity could still be used to collect well-contextualised data appropriate to their research question using a focused and short-term ethnographic approach. It is worth considering how much time spent during fieldwork directly attends to observations addressing their research problem. A short-term and focused ethnographic approach may therefore demystify fieldwork by making the purposes of observation more explicit and to share these with research participants. For this study, it made it easier to account for time spent in the homes of people with dementia for this study and reflect on how it shaped the collection, analysis and presentation of findings. Demystifying ethnographic processes will have made our work easier to understand and share with a range of stakeholders potentially interested in our findings. It will also help us more easily teach ethnographic methods to future researchers and colleagues.

Short-term and focused ethnographies may not readily reflect the ethnographic conventions and traditional ideals for how people should carry out ethnographic studies. However, adopting such an approach allowed this study to examine the practices of people with dementia and their informal carers living in the community using assistive technologies and telecare whilst balancing the focus with reflections on other emergent phenomena significant to the participants in this study. As my first ethnographic study, I learned that I need to better balance 'data intensity' and 'time intensity' to create more detailed fieldnotes.

### 8.3.3 Collaborating versus participating

For this study, I did not fully realise a collaborative ethnography as Lassiter originally conceived it as I did intend to co-author publications nor this thesis with any participants from this study. It was inappropriate to invite one person with dementia or informal carer to help analyse and write the findings about other participants. I did not want to prioritise one participant describing the lives of other participants. It would also present new ethical challenges with people with dementia lacking mental capacity. People with dementia may forget that they had a diagnosis of dementia, collaborating during analysis and writing up of findings may remind them of this diagnosis that may result in reliving the trauma of receiving the diagnosis. Instead of co-authoring work with a person

with dementia or informal carer, the researcher collaborated with participants and the ATTILA team through embedding research activities in different ways with each respective group.

As noted in Chapter 2 and in Section 9.1, people with dementia were often excluded from participating in studies directly related to their care or experiences of it. Although such levels of exclusion appear to be diminishing in social care and social science research, many studies still rely on 'proxy' surveys filled out by family members or other informal carers. People including researchers commonly view people with dementia as lacking insight into their own everyday life and care. Formally-required ethical processes can also make it very time consuming to include people with dementia, as briefly described in Section 4.3. However, people with dementia should be directly included in research that may affect the care they receive (Wilkinson 2002). This study, because it needed to examine how people with dementia and their informal carers used assistive technologies and telecare therefore, directly involved people with dementia, even people with dementia who lacked mental capacity, as participants in this study. Many of the technologies encountered in this study were designed to allow informal carers to remotely monitor people with dementia in their own homes, instead of co-locating them. Rather than taking for granted the often-distant interactions these technologies appeared to support, this study problematised and examined how people with dementia interacted with these technologies.

Yet collaboration in this study, on reflection, appears too positive and progressive a concept to describe the logical requirement to include people with dementia as participants. Collaboration should evoke and represent more in research than allowing people with dementia to merely take part. However, the researcher still collaborated with another group of people, the ATTILA trial team, to realise this study. Such a collaboration would have made more elaborate attempts at collaborating with people with dementia inappropriate as it might affect access to this population recruited from the trial.

## 8.4 Consequences of embedding and disembedding ethnographic work with ATTILA on data collection and analysis

I previously introduced the concept of 'embedded ethnography' used by Lewis and Russell (2011) and Poland to describe collaborative processes where ethnographers often co-locate and share resources with another team of people to provide insights about the processes and practices of that team, organisation or their work. Lewis and Russell worked with a public health team implementing a smoking cessation programme in the Northeast of England. They described their presence in team's

office and fieldwork about the intervention as a process of 'being embedded' (Lewis and Russell 2013). I also drew on Prof Poland's previous work designed to integrate qualitative and ethnographic designs within other study design, notably clinical trials, rather than Lewis and Russell's informative stance (Horton et al 2010; Murdoch et al. 2010). This study critically drew on Lewis and Russell's concept of 'embedded ethnography' for articulating how it linked with the processes, practices and materials of the ATTILA team. This section, therefore, discusses how and to what extent I realised embedded and disembedded ethnographic activities of this study and their effect on recruitment, data collection and analysis.

#### 8.4.1 Recruitment

Embedding ACCOMMODATE recruitment with ATTILA's local research workers for each of the four geographic areas covered in this study, gave a reliable and efficient basis for approaching and inviting people with dementia to take part in this study. Only one person with dementia invited to take part in this study decided not to take part. However, I managed to recruit nine people with dementia participating in ATTILA to this study because of the recruitment system for ACCOMMODATE in place with each ATTILA research worker. I phoned each of the four local ATTILA research workers to discuss upcoming visits and how the person with dementia fit into this study's purposive sampling criteria. If a person with dementia differed from other people with dementia already in the study using the three sampling criteria, then the research worker asked the person with dementia and informal carer if I could attend the scheduled follow-up visit for the ATTILA trial. I attended the follow-up visit for each person the local ATTILA research worker approached to explain the study to both the person with dementia and his or her informal carer.

Although I worked alongside ATTILA research workers during the recruitment visit, I also started to differentiate ACCOMMODATE processes from those of ATTILA. This was perhaps best represented when I decided to recruit an additional person with dementia who did not take part in ATTILA. During the recruitment visit to the Stewarts' home, the informal carer, Sally, asked me whether only her father would take part in ACCOMMODATE, as in ATTILA, or if her mother would as well. I decided to include both of her parents to examine how a married couple, both of whom have a dementia, live with their adult daughter and made sense of their practices with assistive technologies and telecare. I did not needlessly follow the same ATTILA trial processes when carrying out recruitment for this study. Instead, I actively and intentionally made decisions that differentiated from ATTILA which reflected strengths of an ethnographic inquiry, namely allowing for observations to direct future research actions. Including Mary Stewart in this study represented disembedded departures from

how ATTILA's imagined diagnostic community and how the ethnographic community of this study realised people with dementia living in the community and the informal care they received. I may not have noticed such insights about the performative practice of memory problems discussed earlier if I had only recruited Michael Stewart like ATTILA.

#### 8.4.2 Fieldwork

My activities to embed recruitment affected how I conducted myself during fieldwork visits. Yet I did not always replicate the exact ways that I shared space or interacted with people with dementia and informal carers during each subsequent visit. Instead, the conduct of each fieldwork visit reflected differing ways the participants and I negotiated these spaces. Informal carers often invited me to other rooms of the house during later visits. They appeared to show their trust in me more through co-occupying the kitchen, office or other rooms in the house or flat instead of only the sitting room as we did during the recruitment visit. Participants not only invited me into these rooms but also into new conversations, and at times practices, associated with these new spaces. Spending time with participants provided access to new practices and conversations which may not have been possible if I always aligned visits and embedded the fieldwork within the visits and conduct of the local ATTILA research worker. Although these may suggest features one would expect in any qualitative study, I suggest that their presence in this particular study illustrates my ability to realise them despite the dis/embedded activities and relationships which shaped its design and methods.

The local ATTILA research workers only visited each person with dementia at the baseline with follow-up visits planned for 3, 6, 12, 26, 52, and 104 weeks from this initial visit. I planned the visits for ACCOMMODATE to take place every month to pick up not only on qualitatively different practices of people with dementia and their informal carers with the provided assistive technologies and telecare. I also discovered how participants' practices changed subtly over shorter durations between visits. Therefore, disembedding the timeframe for the observational visits of this study's fieldwork allowed me to observe how people with dementia and informal carers 'fit' these technologies into their lives over a less extensive and more intensive lengths of time. However, this more intensive and 'focused' approach meant that I could not consider how the practices of people with dementia and their informal carers may continue to change over more extensive lengths of time. In this way, the timeframe of visits for the ATTILA team matched the conventions of ethnographic inquiry perhaps better than this study. However, the intense time that I spent carrying out this study led to intensely collected data. The hours spent with each person with dementia and his or her informal carer allowed me to observe practices that the local ATTILA research workers could not see - nor could I have seen

them if they had accompanied me during each subsequent visit. Disembedding allowed me to create research relationships with participants based on attending to them, and only them, during each visit. Having a local ATTILA research worker present during each may have resulted in participants performing practices in different ways, because they knew that the local research worker was a health professional working with local Trust. In contrast, I was a 'young American researcher from Norwich' who spent several hours with them and had less formally dictated conversations with them than the local ATTILA research worker who had to follow the script of several validated questionnaires. On the other hand, my conversations with participants emerged more naturally during the visit rather than arise from the set task of completing questionnaires.

Carrying out observational visits and ethical approval procedures separately from ATTILA also meant that I was not rigidly tied to observing what the ATTILA team thought I should investigate. If this study were 'fully' embedded as a component of the ATTILA trial, then my attention and conversations with participants would have only been concerned with participants use of assistive technologies and telecare. Instead, my observations could also engage with the built environment and how people occupied it, what people with dementia and their informal carers did during each visit with or without assistive technologies and telecare. My observations could consider more broadly the lived context and experience of everyday life for people with dementia and informal carers in this study and whether and how assistive technologies fit into these settings and ways of living. Therefore, the interpretations and conclusions made in this study were not based on disembodied and de-territorialised practices of people with dementia and informal carers with assistive technologies and telecare. My interpretations and conclusions represented my focus on the mundane and granular aspects of people with dementia living in the community *and* their practices with assistive technologies and telecare in this context. For this study, this meant that conversations with people with dementia and informal carers discussed a range of topics from reminiscing about eating cuisine from where the person with dementia lived as a child to writing Christmas cards. However, each of these would in turn reveal an aspect about living with dementia and providing care for a person with dementia.

Fieldwork was a mostly disembedded activity, specifically attending to and addressing the widely distributed practical and methodological needs of this study. Disembedding fieldwork allowed me to examine emergent, everyday practices so as to understand how practices with assistive technologies and telecare fit into the lived context of everyday life of people with dementia and their informal carers. Although the recruitment visits often structured the initial visits I carried out as a lone

fieldworker, the intensive time spent with participants allowed for each of us to continually renegotiate how we co-occupied spaces.

### 8.4.3 Analysis

As described in Sections 4.6 and 4.7 each week I sent a 'progress update' to the study supervisors. The progress update described who I carried out fieldwork with that week which also identified why some visits were cancelled or 'falling behind' from their scheduled date. The progress update also included a fieldnote excerpt that I selected for its analytical relevance for understanding the practices of people with dementia and their informal carers living in the community using assistive technologies and telecare. The dialogue considered the analytical relevance of the fieldnote excerpt for addressing the research problem of this study and whether the interpretations appeared framed in appropriate logic, coherent and contextually appropriate. Sharing early analytical comments with Profs Poland and Fox helped to ensure that the fieldnotes I produced were adequate for a doctoral research project but had reasonable fit with the qualitative needs of ATTILA. I produced the earliest analyses of this study with the views of two ATTILA research team members whilst I carried out fieldwork. A wider collective review of embedded analytical practices with the ATTILA team was enabled when I shared findings from the study with the ATTILA trial research workers and principal investigators during its annual management meeting in October 2016. This included a range of disciplines including psychologists, psychiatrists, statisticians, occupational therapists, sociologists, social gerontologists, and clinical trial unit administrators. This presented ACCOMMODATE findings in a way which could share with the mixed audience how and why I came to problematise my own understandings about the 'assistiveness' of assistive technologies and 'the home' might not only be taken for granted. Presenting these findings helped justify to the ATTILA researchers why 'embedding' ACCOMMODATE within the trial might complement and contextualise ATTILA findings by illustrating how ACCOMMODATE might capture complexity of everyday life processes of people with dementia and their informal carers in deciding decide to use or abandon assistive technologies and telecare over time.

The later stages of analysis highlighted that the terms relevant to the ATTILA trial research would often not reflect the language which people with dementia or their informal carers used to describe how and why they used assistive technologies or telecare or the other accounts they told me during fieldwork. For example, people with dementia and their informal carers never once discussed the 'severity' of the person's dementia. Severity was a concept that was useful for ATTILA research workers and investigators to frame the different needs of people with dementia for statistical comparison, but 'severity' was not how participants described and understood dementia. 'Severity'

was not the only purposive sampling criteria term that was later called into question by the data collection and analysis for the present study. Participants rarely talked about ‘assistive technology’ or ‘telecare’ in those precise terms. Instead, people discussed ‘your pendant’ or ‘the thing around your wrist’ to denote pendant alarms and falls detector in language that made sense to them.

Hence this raised a novel challenge for this study: the challenge of (re)presenting the everyday language and practices of people with dementia as they understood them. Yet I also needed to consider how this work contributed to academic discourses about technology-enabled care services in the context of community-based dementia care for embedded in a pragmatic, randomised controlled trial. As an ethnographer, I came to realise that my position and representational task was to bridge how people with dementia and informal carers made sense of and used assistive technologies and telecare while relating it to how the ATTILA trial envisioned their use. Instead, the interpretive analysis of these ethnographic findings allowed for these different ways of making sense of the world to be made visible. The ethnographic findings were presented as cases that allowed for the in-depth description and analysis of fieldnote excerpts grounded in the lived context of people with dementia and their informal carers yet in a structure and format that health researchers readily understand and use. Each case represented a conceptual feature that attended to the purposive criteria informing the original study design. Embedding my ethnographic decisions and activities with and within ATTILA meant these findings could underpin alternative interpretations of ‘memory problems’, ‘care’, and ‘home and community’.

## 8.5 Memory problems and co-producing ‘assistiveness’

The findings presented in Chapter 5 examined ‘memory problems’ as everyday experiences people with dementia performed. ‘Misremembering’ and ‘forgetting’ represented two practices of ‘memory problems’ participants with dementia frequently enacted when interacting with their informal carers. ‘Misremembering as a memory problem’ was a practice where a person with dementia recalled dated or partial information. ‘Forgetting as a memory problem’ illustrated different ways that people with dementia ‘forgot’ people, places, objects or abstract relations and ideas, such as ‘time’.

Section 2.3 presented one definition for assistive technology as ‘any item, piece of equipment, product or system, whether acquired commercially, off the shelf, modified or customised that is used to increase, maintain or improve the functional capabilities of individuals with cognitive, physical or communication disabilities’ (Marshall 2000). The more recent work of Marcia Scherer and her colleagues identified ‘memory functions’ as a mental function that dementia affected as the person’s

dementia progressed (Scherer et al. 2012). Therefore, 'forgetting as memory problem' and 'misremembering as memory problem' framed a functional capability that assistive technologies were designed to address.

People with dementia could not know that they misremembered information by themselves. People with dementia only learned that they misremembered when interacting with another person, such as informal carers in this study. Misremembering, therefore, highlighted the importance of other people in the lives of people with dementia who often told them the situationally accurate information. People with dementia, and the researcher, were only aware that what the person with dementia said was inaccurate when informal carers corrected them. Such interactions between a person with dementia and person familiar with them, such as an informal carer, problematised how assistive technologies can address 'misremembering as a memory problem' when identifying instances of 'misremembering' were specifically grounded in the individually situated and personal experiences of everyday life of the person with dementia. Current electronic assistive technologies, therefore, appeared unable to address misremembering as an everyday practice of people with dementia. Assistive technologies and telecare examined in this study could not attend to the granular detail of the information and how it was inaccurate. This suggested that 'misremembering as memory problem' was a 'functional capability' of the person with dementia that assistive technologies could not 'increase, maintain or improve', because they required human reflection, knowledge of the person with dementia and judgement so as to identify the inaccurate information and correct it with accurate information. In other words, assistive technologies would need the ability to reason with a catalogue about the life history of a person with dementia to address misremembering. Here informal carers 'assisted' more than any assistive technology.

Forgetting appeared as a more straightforward practice and more readily-recognised example of a memory problem. People with dementia did not attempt to present information at all; they just could not remember the information. However, forgetting also often emerged through social interactions. A person with dementia was usually asked a question which they could not answer because they forgot what the person asked or the information the person wanted to know. However, the person with dementia may have experienced 'forgetting' less frequently if another person, like an informal carer, had not questioned him or her. Of course, people with dementia also forgot to *do* specific activities such as eating meals or taking medication too. Many assistive technologies were considered 'memory aids' that helped remind a person with dementia to carry out these activities. However, as the findings from this study suggested the electronic assistive technologies which local authorities

provided people with dementia were not always the most 'useful' technology available. Everyday objects in the home of the person with dementia were often re-purposed to help the person with dementia 'remember' to carry out the activity or recall a specific type of information, such as using a simple calendar ornament to help people with dementia recall today's date.

Adapting simple household objects represented a case of what social anthropologists called 'bricolage' where people make use of readily available objects and assemble them to solve new problems (Lévi-Strauss 1962). Other scholars have also applied 'bricolage' to frame their own findings of older people and their carers adapting everyday technologies like computers and household objects to solve an individual need (Greenhalgh et al. 2013), what other researchers in the field characterised as 'DIY assistive technologies' (Gibson et al. 2015). The findings in this study also illustrated the importance of informal carers maintaining objects in order to help people with dementia use them. The practices of older people, people with dementia and carers adapting household objects and other mundane things to address their unmet needs suggests that the current selection of assistive technologies cannot do the same. If people with dementia and informal carers need to act as 'bricoleurs' to adapt existing objects into 'DIY assistive technologies, then we should reconsider what makes technologies 'assistive'. Findings from this study illustrated how people with dementia appeared to favour using relatively simple, everyday objects even when assistive technologies designed to address the same problem were also present. This suggests that people may make, or co-produce, technologies as 'assistive' through their interactive practices with them and other people rather than 'assistiveness' being an inherent trait of specific commercially available products.

Yet 'assistiveness' was not the only concept findings from this study problematised. Many assistive technologies were designated as 'memory aids', because they remind the person with dementia to *do* something, such as taking medication. However, technologies that reminded a person with dementia to carry out a specific activity could not address the 'memory problem' associated with remembering to initiate or sustain such activities. People with dementia supported with a memory aid will still forget or misremember. Instead, 'memory aids' reoriented a person with dementia to complete a specific set of prescribed activities as part of their routine. Although the term 'reorienter' may not possess the same simplicity as 'memory aid', it denotes the more specific function that practices with the technology allows. Memory functions will remain impaired, but the implications for the memory problems of a person with dementia, such as forgetting to complete a specific task or misremembering information, could be partially addressed through reorientation with assistive technologies. However,

the specificity and complexity of the information and tasks will likely still require human action so as to make the intervention appropriate and relevant for the needs of each person with dementia.

The findings of this study clarified the nature of 'memory aids' as devices which help re-orientate people with dementia rather than directly addressing memory issues. The findings also demonstrated that technologies were not inherently 'assistive', instead, participants co-produced 'assistiveness' through intentional interactions with the technologies.

## 8.6 Transforming care with assistive technologies and telecare

In Chapter 7, the key findings illustrated how informal carers in this study understood and practiced 'care' for a person living with dementia in specific ways mediated through assistive technologies and telecare. Two practices were identified as different domains of care: 'care as concern' and 'care as surveillance'. 'Care as concern' represented a practice where informal carers in this study frequently discussed their 'concern' for a person with dementia. 'Care as surveillance', on the other hand, represented informal carers' practices with telecare or adapted technologies to monitor the activities of a person with dementia.

'Care as concern' represented a practice of informal carers where they articulated their concerns about the person with dementia. Here informal carers were seen to identify particular actions of the person with dementia they viewed as 'risky'. 'Concern' allowed carers to share their views about these 'risky actions' with other people, namely formal care providers, which often appeared to lead employees of the local authority to carry out a home assessment. In the cases presented in this study, each home assessment resulted in every person with dementia receiving some type of assistive technology and/or telecare system. In other words, 'concern' represented an instance of how informal carers 'cared about' people with dementia. Yet 'care as concern' also represented the first step in a process for caregiving. Now that the informal carer's concern identified and shared the perceived risky actions of a person with dementia, it could allow them to intervene in some capacity. Although 'care as concern' was an affectively driven practice, it led to informal carers 'caring for' a person with dementia.

The concept of 'care as concern' as a practice for 'caring about' a person with dementia aligns with how previous research conceptualised 'care'. The widely cited work of Berenice Fisher and Joan Tronto (1990) drew on the work of feminist scholars to propose four phases of care: 'caring about', 'caring for', 'caregiving', and 'care receiving'. For Fisher and Tronto, 'caring about' was the first phase

of care that denoted a person identifying another person's unmet need (Fisher and Tronto 1990; Tronto 1993). The findings from this thesis also presented 'concern' as the first instance of 'care', specifically 'caring about' the wellbeing of a person living with dementia. However, Fisher and Turner's definition for 'caring about' highlights how identifying the unmet need relies on the interpretation of another person rather than the person with the need. Such a one-sided process of identifying needs may help health and social care professionals identify the needs of their patients or clients. Yet it may not be an appropriate approach for informal care. How informal carers identified risks in this study may not always align with how people with dementia imagined the same risks associated with a particular action. If a person with dementia lost their authority to make their own decisions, i.e. their mental capacity in British law, then it is possible an informal carer may make relatively uninformed decisions on the behalf of the person with dementia based on their own views about appropriate risks.

'Care as concern' also signified a shift in the practices of informal carers taking part in this study. Informal carers' concerns were not only an affective response to what they perceived as the needs of people with dementia emerging from the risky actions they performed. Informal carers also shared their concerns with other people. This could be seen as the informal carer 'caring for' the person with dementia. Here I presented 'caring for' as informal carers seeking additional support from formal care services. The conceptual work of Fisher and Tronto (1990) suggested that 'caring for' would be the act of an organisation or person taking responsibility after a person's unmet needs were identified. Informal carers seeking the support of formal care services could be seen as 'taking responsibility' for the person with dementia through this action.

The practices of 'care as concern' could be seen to allow for informal carers to respond to what they perceived as risky actions of people with dementia. Informal carers sharing their concerns was another step in the process of care where they took shared responsibility with care professionals to address the needs of a person with dementia. Participants in this study received assistive technologies and telecare as interventions to address the unmet needs or risky actions of people with dementia. Telecare allowed informal carers to monitor the activities of a person with dementia in their home, such as how often they left a room or whether they got out of bed for the day. Informal carers often described having 'peace of mind' as a result of monitoring the person with dementia under their care. However, the findings from this study suggested telecare could not prevent or address the actual risks to the person with dementia. People with dementia could still leave their home despite the remote monitoring from informal carers with the telecare systems. Practices with telecare, therefore,

appeared to only help informal carers believe that they were addressing the risks to a person with dementia when they were not co-located.

Fisher and Tronto's (1990), next step for providing care was 'caregiving', the phase where people actually gave care to another person (Tronto 2017). Here the findings from this study presented material for considering whether and how practices with assistive technologies and telecare were also practices of care. Fisher and Tronto defined 'care' as human activity that included 'everything we do to maintain, continue, and repair our 'world' so we can live in it for as long as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex life-sustaining web' (Fisher and Tronto 1990: 40; Tronto 1993; Tronto 2017). This broad definition could consider almost any human action as an act of care. Deploying such a broad definition, therefore, can allow us to consider how practices with assistive technologies and telecare could represent care practices.

The key findings presented for the second care domain, 'care as surveillance' provided additional material for discussing the appropriateness of care as a concept applied to informal carers monitoring practices of people with.

Observing practices of 'care as surveillance' suggested that monitoring a person with dementia was practice seen as acceptable by informal carers and care professionals in helping ensure the person with dementia remained safe. However, different stakeholders defined suitable technologies in different ways: carers preferred technologies they knew how to use and sometimes purchased themselves, such as CCTV systems, whereas health and social care professionals provided their own approved set of assistive technologies and telecare systems. Practices with both adapted technologies and formally provided telecare systems were based on informal carers or a call centre operator monitoring the person with dementia in their own home. Yet informal carers and telecare call centre operators did not constantly monitor each person with dementia. Instead, both types of monitoring technologies were used only to assess a situation to determine whether an intervention was required to help a person with dementia.

These findings illustrated that monitoring technologies only facilitated informal carers and care professionals to identify whether a person with dementia was harmed or at potential risk of harm from their actions, such as leaving the house in clothing inappropriate for the weather. Practices of both carer groups with adapted surveillance technologies and service provided telecare did not appear

to 'maintain, continue, and repair' the bodies or environments of people with dementia in this study. Practices with monitoring technologies could not prevent or reduce the incidence of harm. However, practices with monitoring technologies could only prompt informal carers and care professionals to respond appropriately to each situation as it occurred. Therefore, monitoring technologies, whether telecare or adapted everyday technologies, still required a physical, co-located human response if a person with dementia experienced an emergency. However, over-relying on monitoring technologies may reduce the amount of time informal carers and people dementia spend co-located. Such a reduction in time spent together could reduce other care practices such as helping people with dementia prepare and eat food, bathe, get dressed or toilet. It also may further reduce the amount of social contact people with dementia experience. This suggests that telecare systems do not provide 'care at a distance, but practices with telecare and other monitoring technologies may identify the need for an appropriate care response to a crisis or other unmet need for a person with dementia involving co-located human action to address.

It can also be questioned whether practices with telecare and assistive technologies constitute care, and if so, how have ideas about care shifted from previous understandings. Practices with telecare did not appear to 'maintain, continue, and repair' the bodies, sense of self or environment of the person with dementia taking part in this study. To clarify this point, consider Fisher and Tronto's (1990) final phase of care, 'care receiving', where a person responds to the care they receive so the person giving care can judge its effectiveness. People with dementia taking part in this study rarely acknowledged the presence of monitoring technologies in their lives. The only 'response' that informal carers' practices with monitoring technologies could detect was whether people with dementia activated motion sensors for telecare or were in the field of view of cameras. However, these passive 'responses' by people with dementia, still allowed informal carers and telecare call centre operators to argue for a judgement about whether additional care was needed. Yet informal carers also sometimes misattributed what telecare systems recorded through their motion sensors. Misattributing the actor who was recorded meant that informal carers thought a person with dementia was more active than they were. Here is a potential pitfall for what could happen when caring is no longer co-located; informal carers must rely on technologies to monitor the wellbeing of the person with dementia under their care yet may not understand the capabilities of the technology for enabling care practices.

The findings from this study suggest that practices with telecare aligned with the procedural approach to care identified by Fisher and Tronto if these practices constituted care. The findings from this study

address this final consideration, by examining recent work from medical anthropology about 'care as sensibilities'.

Although practices with telecare appeared to align with a procedural approach for understanding care as a set of processes relating to taking responsibility for another person's wellbeing, 'care' could be seen as more than just activities for attending to a moral duty. 'Care as sensibilities' offers an alternative approach for considering activities as 'care' through considering how they reflect specific affective responses between people. Arthur Kleinman, a recently published a series of 'Perspectives' essays in *The Lancet* where he reflected on his fifty years of work as an anthropologist, psychiatrist, and caregiver to his wife, Joan Kleinman, before her death from Alzheimer's disease. In these essays, Kleinman particularly drew on his experiences and observations across cultures and lived contexts from the professional clinical encounter to the deeply personal family relationships to consider 'care'. Kleinman suggested that 'caring acts' were based on physically interacting with another person through 'touching, embracing, steadying, lifting, [and] toileting' but also how people look at each other, 'connect' and 'the quality of our voice' (Kleinman 2015: 240). Kleinman identified 'caring' as related to 'sensibilities of empathy, compassion, respect and love' involving 'cognitive, emotional, and moral processes' (Kleinman 2015: 240). Here, then, could be seen as 'relational and reciprocal' (Kleinman 2012; Kleinman 2015). However, a core feature of Kleinman's concept of care was 'presence' whether with family (Kleinman 2015) or 'co-presence' as a clinician (Kleinman 2017). Co-presence allowed for people to share the same space and exchange physical contact, converse, and otherwise share each other's experiences. Co-presence could, therefore, be regarded as facilitating reciprocity between the person giving and the person receiving care during each exchange. The co-presence of such 'caring acts' enacted the sensibilities of empathy, compassion, respect and love, which Kleinman previously identified.

Kleinman's concept of 'caring' and its associated 'sensibilities' allows us to reconsider the extent to which the ethnographic material presented about practices with assistive technologies and telecare reflected this sense of 'care'. The prominence of 'co-presence' could be interpreted as excluding practices with telecare as constituting care. However, monitoring could be seen as being co-present in an alternative way when distance separates informal carer or care professional from the community where the person with dementia lives. If we consider 'co-presence' as relational and contingent rather than a simple question of co-location, then practices with telecare may still constitute care according to Kleinman. Likewise, practices with telecare may be based on those 'sensibilities of care' which Kleinman identified depending on why informal carers decided to start using telecare and assistive

technologies to help support the person living with dementia in their lives. The results from this study illustrated the initial stage of 'care as concern' as one stage for recognising the potential need of care for a person with dementia. Such concern was usually experienced by family members, friends, or long-term acquaintances who may share these sensibilities when they interact with the person with dementia. Yet informal carers' practices with telecare in this study did not appear to support reciprocity nor the physicality of care between the informal carer and person with dementia. Practices with telecare mitigated the length of time informal carers spent with people with dementia who could not then observe the informal carer nor did they often realise that their informal carer was now monitoring them. Monitoring practices with assistive technology and telecare instead appeared to constrain interactions to informal carers having the power to observe whilst not being observable. This suggests that practices with telecare may not adhere to these theoretical conventions and concepts of care. If informal carers consider their practices with telecare as constituting care (Section 7.3), then this understanding of care is physically absent, asocial, one-sided monitoring of people with dementia rather than co-present, interactive and reciprocal conventions of response care giving and receiving. The policy and formal service provision implications for transforming our ideas about care to accommodate telecare practices, could affect how future 'community-based care' will be provided in informal and professional interactions.

## 8.7 Reconfiguring how people with dementia occupy the home and community through technologies

As described in Chapter 1, policy makers and care service providers have increasingly emphasised the aspiration to support people with dementia to 'live in the community'. 'Care in the community' or 'community-based care' was meant to provide people with dementia with support to help them continue living in the community for as long as they wished. Therefore, this study considered how practices with assistive technologies and telecare affected to reconfigure the ways people with dementia occupied their home and accessed their wider community.

The key findings from Chapter 8 drew on three cases which identified the importance of location for situating practices with assistive technologies and telecare. Observations from the different homes of participants in this study identified how living with dementia and changing care needs affected how people with dementia and informal carers occupied and used rooms in the 'home' and accessed people, services and areas located in their community: 'reconfiguring rooms in the home', 'abandoning rooms in the home', and 'accessing communities outside the home'.

Findings presented for 'reconfiguring rooms in the home' illustrated how informal carers adding and removing objects into specific rooms affected the practices of people with dementia performed in the specific room. Reconfiguring the room with new objects or removing other objects from a room also changed how people with dementia and informal carers occupied that room and the rest of the home. These reconfigurations allowed us to reconsider how we envisioned people with dementia living in the community and, therefore, the potential types of 'care' that care in the community would entail.

Previous research made similar connections with how assistive technologies and telecare affected where care was located and how it affected domestic spaces like rooms in the home. Milligan, Roberts and Mort (2011) drew on the concept of 'extitution' to explain how older people using telecare represented institutional arrangements focused on 'regulation, monitoring, and surveillance' manifested in new times and spaces despite the 'de-territorialised' location. However, describing the findings of this study as 'de-territorialising' institutional arrangements would ignore that these practices were located in the home of the person with dementia. Practices with telecare, therefore, could be seen as 're-territorialising' the institution in people's homes as it appeared to do in this study.

Whereas 'reconfiguring rooms in the home' showed how people with dementia and informal carers occupied rooms and changed their practices as the carer added and removed objects, 'abandoning rooms in the home' presented the corresponding absence of people with dementia and informal carers from rooms in the home. 'Abandoning rooms in the home' illustrated how informal carers and care professionals removed objects from rooms in the home that resulted in people with dementia abandoning them all together or some associated practices with the location. In other words, changing how a location in the home looked and functioned affected what practices people with dementia and informal carers could do in these spaces. When people with dementia and informal carers could no longer enact practices relevant to how they wanted to live their lives, then they were seen to abandon the rooms where these locations took place. Practices with assistive technologies and telecare could have prevented some of the incidents people with dementia encountered, such as the kitchen fire described in Section 8.3. However, practices with assistive technologies and telecare could only prevent these incidents if the person with dementia and other people co-located with him or her at the time understood how to use the technologies. When technologies were not used in the designed way or in a suitably adapted way, then people with dementia faced potential harm to themselves or their property.

Reconfiguring and abandoning rooms in the home was seen to reflect how people with dementia came to occupy an ever-diminishing amount of space in their home, rather than empowering them to reclaim this space. As everyday practices were displaced or abandoned so were the places where people with dementia enacted them. These findings presented material for us to reconsider what 'home' means when discussing 'home care'. The findings from this study illustrated that 'home' was not a static location people with dementia all occupied in the same. First, people with dementia in this study occupied different styles and layouts of their home from small flats in Metropolitan to bungalows in market towns to large, multi-storey homes outside of villages. No participant's home was designed the same way. Second, people with dementia and informal carers were seen to intentionally place different objects in their homes, which had special significance or utility to them. Yet as the care needs of the person with dementia changed, so did the spaces in their home so as to accommodate new care practices to address these needs. Reconfiguring and abandoning rooms in their homes could be seen as an effect of accommodating these care needs. However, participants' relations with rooms also changed as did the home. Sitting rooms were seen to become places where people with dementia slept and toileted as informal carers introduced beds and commodes into a single room.

Research in human geography has described home as 'the materialisation of identity', because it works as extension of the body where spaces 'serve as memory deposits' which provide ways to access and remember habits whilst the material objects located in the home reflects how we exhibit our status and connect us to places, people and memories from our past and present (Young 1997; Varley 2008). This may suggest that as people with dementia occupied fewer rooms they will also have lost their connections to people and places that objects located in these spaces represented. With so much of public discourse about dementia centred on loss, it is worth considering how people with dementia could still access and engage with their whole home and the objects within it to reminisce and portray aspects of their identity.

The key findings from 'accessing communities outside the home' examined how people with dementia accessed spaces and engaged with people outside of their home and how practices with assistive technologies and telecare could affect them in ways not suggested by policy discussions of telecare. The findings illustrated that informal carers and people with dementia prioritised distinctly different community connections from each other. Informal carers emphasised the importance of attending to physical health and attending doctor's appointments as often the only time a person with dementia left their home. People with dementia, on the other hand, preferred pursuing leisure or recreational

activities outside of their home. Assistive technologies and telecare mediated the contested views of how people with dementia engaged with their community. However, informal carers could use these technologies to control and influence when, where and what types of services and community groups a person with dementia accessed.

These findings indicated how informal carers' practices with assistive technologies and telecare could confine people with dementia to their homes rather than allow them to engage with their communities. Many telecare products only had a limited range to monitor the person with dementia if it was a wearable device. However, most telecare and assistive technologies were either household objects or technologies installed into the structure of the home. If informal carers needed to monitor people with dementia, then people with dementia needed to remain in the spaces where the telecare was installed. This could be seen as telecare reducing the ability for people with dementia to leave their house even though they may still have the physical and mental capabilities to do so.

These cases illustrated how everyday and technological practices of people with dementia and their informal carers led them to reconfigure or even abandon rooms in their home. This in turn was seen to constrain how people with dementia could experience their everyday lives. It suggests that what policy makers called 'care in the community' and care professionals called 'community-based care' might be conflating the term 'community' with practices actually located only in the home of the person with dementia. This suggests that 'home care' and 'living at home' may sometimes be more useful and precise ways of describing the reality of where people live and receive care than a less precise term like 'community'. However, even the concept of 'home' required more nuanced reference when considering how people with dementia and their informal carers may reconfigure rooms so as to locate a new set of practices whilst also abandoning other rooms in the now-shrinking 'home'.

Current practices with assistive technologies and telecare appeared to constrain the location and activities of people with dementia in their homes whilst providing little support to help them maintain their current relations with the spaces and objects in their home, let alone the wider community. For people with dementia, being supported to maintaining familiar relations, practices and spaces within and outside the home may be particularly important if they are to be successfully supported to continue their relative independence, participation and wellbeing. The ACCOMMODATE study helped identify practical, social and cultural reasons why this may be important and may also help inform

concepts and policies for attending more closely to the important interactions with people and homes which may be most relevant to the success of future developments in this area.

## 8.8 Value and limitations of the work of this thesis

This final section of this chapter considers the methodological, empirical and conceptual contributions of this thesis to an interdisciplinary community of scholars working in medical anthropology, sociology, social gerontology, and policy.

### 8.8.1 Methodology

Four characteristics were described in Section 3.3.1 as common features for ethnographic inquiry. Reflecting on these characteristics evaluates the extent to which the study presented in this thesis was ethnographic and how being dis/embedded constrained or facilitated fulfilling these methodological commitments.

- i. Offers a longitudinal approach

This study involved a monthly visit to the home of each person with dementia over a six month period. This clearly fulfilled the longitudinal requirement for an ethnographic study.

- ii. Places primacy on participating and observing people with dementia and their informal carers' experiences and performances of everyday activities

The researcher was intermittently able to participate and observe people with dementia and their informal carers taking part in everyday activities. However, the requirement to spend time with a geographically dispersed population required a relatively small amount of time to be spent at each visit. Some participants also appeared to prefer talking with the researcher during each visit rather than continue to carry out other activities.

- iii. Where an overt (not covert) researcher immerses themselves in the socially- and physically-bounded research field of the local community of each study participant with dementia

This characteristic was also only partially successful as the short-term and multi-sited methodological requirements of working with participants could not result in a total immersion in the field. Immersion in the local community of each person with dementia was always limited to the particular brief encounter during each monthly visit rather than a sustained, daily commitment of immersion.

- iv. To reflect and to interpret participants' social realities represented through 'thick descriptive' accounts.

This final characteristic was reasonably successful as the data collected during each visit and the concurrent and subsequent analysis of participants' practices provided further understanding about how technology-enabled dementia care was realised.

The thesis contributed a new methodological approach to ethnographic study which could be closely connected with a randomised controlled trial. Drawing on the concept of 'embedded ethnography' to develop the design of this study, helped demonstrate ways in which working with trialists in a national, randomised controlled trial could help bring together findings from larger projects with ethnographic principles and anthropological sensibilities to help examine and make more contextualised sense of the experiences of people with dementia taking part in trial. Setting the fieldwork within the activities of the trial helped shape a conceptual framework to observe, interpret and compare practices of people with dementia and their informal carers using assistive technologies and telecare with each other and with formally-expressed measures and policies. The challenges of explicitly pursuing fieldwork within a trial also provided further learning in terms of how to negotiate and collaborate with new sets of gate keepers. Additionally, to realise this work as ethnographic while working with a mobile and geographically dispersed population also required novel methodological adaptations. Although the study differed from more conventional ethnographic approaches, it demonstrated that a focused, multi-sited and embedded ethnography of contemporary communities can provide contextually relevant data to examine complex interventions in health research.

#### 8.8.2 Empirical contribution

The thesis also described the empirical contribution of a qualitative study which involved people with dementia and their informal carers as participants. The empirical study involved spending 208 hours of participant-observation with nine cases involving at least one person with dementia and his or her informal carer who also participated in ATTILA. The precise account of fieldwork time and interactions helped to demystify ethnographic fieldwork to a range of stakeholders interested in understanding findings relevant to understanding current technology-enabled care practices and for fellow qualitative health researchers requiring such an approach in their own work. The study is one of very few which applied an ethnographic approach to examining the practices of people with dementia and their informal carers using assistive technologies and telecare in the context of their everyday lives.

### 8.8.3 Conceptual development

Finally, the thesis provided findings of three different domains of practices: memory problems, care, and community. The findings presented alternative interpretations of these domains and re-considered the limits and shifts in how technology-enabled dementia care represents, reflects, or reconfigures these concepts as they are realised in the everyday lives of people with dementia and their informal carers. The thesis draws on the concept of 'imagined community' to illustrate and compare how policy makers, practitioners, researchers and the product of this ethnography variously attended to different imaginings of technology-enabled dementia care in seeking to develop appropriate care practices.

The thesis, has therefore contributed a possible novel approach for ethnographers to work within complex and developing health and social care contexts whilst still attending to conceptual disciplinary interests *and* wider social and health problems which people with dementia and their informal carers encounter in their everyday lives.

# Chapter 9: Conclusions

## 9.1 Introduction

The study set out to examine the practices of people with dementia and their informal carers with assistive technologies and telecare to consider how practices with these technologies may affect their experiences of living with dementia, their meanings and practices of care, and their relations with their own homes and communities. To address this research problem, four questions were posed:

1. How do people with dementia experience everyday life in the community?
2. How do carers provide community-based care and through what activities?
3. How and why do people with dementia and their informal carers use, or choose not to use, assistive technologies and/or telecare in the community?
4. How do assistive technologies and telecare fit into the communities of people with dementia?

Although this thesis did not provide conclusive answers to these questions, it addressed each one in part through examining ethnographic cases based on a novel ethnographic study initially ‘embedded’ within the ATTILA trial. As the researcher further disassociated his practices from the ATTILA trial, he reconsidered the assumptions about technology-enabled dementia care previously encountered through reviewing the literature and working with the ATTILA team. The ‘dis/embedded’ activities of the lone ethnographer also revealed how practices of informal carers and people with dementia using assistive technologies appeared to challenge the role of assistive technologies for addressing memory problems, the constitution of care, and the ways people with dementia occupied spaces and places within and outside their homes.

Here I return to each of the key findings and concepts in this thesis to offer how attending to more precisely realised practices of people with dementia and their informal carers using assistive technologies and telecare may provide policy which better attends to actual technology-enabled dementia care than aspirational rhetoric.

## 9.2 Imagined and realised communities

Anderson’s concepts of ‘imagined communities’ was used to help examine how policy makers, health researchers, people with dementia and their carers, and ACCOMMODATE differently ‘imagined’ contested ideas about current technology-enabled dementia care in the community. Three different

imagined communities could then be identified and examined in this thesis: imagined care communities, imagined diagnostic communities, and imagined ethnographic communities.

Policy makers' imagined care communities could be seen to have focus on how aspirational policies aimed to enable innovative care practices with technologies for people with dementia living in the community. However, such a policy-focus could be seen not to directly engage with *current and actual* technology-enabled care practices in community-based dementia care.

Health researchers' imagined diagnostic communities, as articulated by the ATTILA trial-based study, were focused specifically on how their research controlled the specific characteristics of included and excluded participants in their studies focused on having a particular diagnosis. In the case of ATTILA, this was a diagnosis of dementia. Yet such controlled parameters could be seen not to engage with the actuality of many people seen as not having a formal dementia diagnosis. Other parameters such as 'not having an unstable medical condition' despite the increased prevalence of comorbidities of people with dementia, as older people. The need to control for specific diagnostics may mean that otherwise statistically significant findings may require further work to implement in *actual* clinical or domestic care settings and practices.

An imagined ethnographic community represented the starting point for the ACCOMMODATE study and its planned ethnographic activity. This imagined ethnographic community was focused on relating the practices of people with dementia and their informal carers living in their homes in 'the community' identified as using assistive technologies and telecare and therefore to be connected through the fieldwork visits of the ethnographer. Observing people with dementia and their informal carers carrying out everyday routines revealed when (or whether) and how they may also have used the technological interventions provided by statutory services within those routines. The study, therefore, differed from the work of health researchers and policy makers in engaging over time with the everyday practices and experiences of people with dementia and their informal carers using assistive technologies and telecare. This meant the imagined ethnographic community could be informed and modified by encounters with research participants and settings. Nonetheless, the imagined ethnographic community was also limited as its findings could not represent these practices in terms of a whole population of people with dementia but the particular cases of people with dementia and their informal carers taking part not only in this study, but also in a randomised controlled trial. In realising an ethnographic approach, the framing and activities of this study will have created its own 'ethnographic community' based on the very diagnostic criteria critiqued in the

imagined diagnostic community promoted in health research in dementia, and reproduced through the visits, connections and relationships built through the ethnographic fieldwork. Referring to, modifying and then distinguishing between the different cases depicted here meant that the imagined ethnographic community was seen not to apply to *all* people with dementia and informal carers and to represent them as using assistive technologies or telecare. Instead, it could come to highlight more realistically granular details about how *some* people with dementia and *some* informal carers did use these technologies to inform further imaginings to realise as new care practices.

Each of these imagined communities framed living with dementia in the community in a particular way which will have reflected the distinct and differing interests of the people who envisioned them. However, the imagined ethnographic community, which articulated the work of this thesis, did provide a modifiable approach to help reconsider and refine its emergent concepts and processes with potential also to inform those used in policy and health research.

### 9.3 People living with memory problems: attending to memory rather than dementia?

Previous policy and research reviewed in this study were seen often to focus on promoting 'living well' with dementia or developing and evaluating technological interventions to support the independence and functional capabilities of people with dementia. Yet in practice, the research focus reduced specifically to countering challenges which arose from memory problems expressed as symptoms of the person's dementia, often to the exclusion of other symptoms which may also have affected their life. Many of the technologies examined in this study were explicitly designed as 'memory aids' to help people with dementia recall the time or locate lost objects. Therefore, 'memory' was one of the central foci of assistive technologies designed to support people with dementia. Other technologies in this study such as fall detectors were no different from the same technologies provided to other older adults or other people at increased risk of a fall. Therefore, what appeared to separate technologies for people with dementia from generic technologies designed for older people was the focus on supporting memory functions. Therefore, the centrality of memory problems as 1) a particular functional problem to support or address through technological interventions, 2) the specific focus on research which evaluates these technologies, and 3) the preferred descriptor for sensitively talking with people with dementia requires us to re-examine what claims we make about dementia care. If the work of researchers attends more specifically to memory problems than the range of symptoms comprising the dementia syndrome, then describing the research as 'on dementia'

may misattribute the generalisability and implications we claim from such research. 'People living with memory problems' acts as a more suitable heuristic for research which cannot examine the range of symptoms and their expressions for people living with dementia.

This study's focus on practices around memory problems also helped identify specific limitations of current technology-enabled dementia care when considered in relation to addressing memory problems. Findings from this study demonstrated how 'memory aids' appeared to re-orientate the person with dementia rather than to directly support memory.

Future policy, research and technological interventions should therefore more holistic approaches which seek to address the multitude of care needs people with dementia require rather than only memory problems.

#### 9.4 Care and technologies: care realised, reconsidered, and reconfigured

People with dementia and their informal carers received assistive technology and telecare which could be seen to dramatically change the ways in which they interacted with each other and therefore how care could be delivered. Informal carers could now monitor the activities of people with dementia remotely. Yet informal carers still appeared to view monitoring practices with technologies as facilitating or providing care to a person with dementia. However, such practices reframed care as primarily surveillance.

ACCOMMODATE findings therefore helped problematise what constitutes appropriate care and what assumptions this entails. Whilst in the wider society monitoring individual people with CCTV may be called into question as intrusive and coercive, service providers and carers appeared to readily consider monitoring people with dementia to be appropriate. This was not necessarily so readily accepted by the people living with dementia. This highlights the differences between different groups in attending to the context and specific features of monitoring which affected their judgement of telecare-supported monitoring as appropriate care.

People may often prefer technologies which they have control over. However, there was only limited potential for service providers, carers and people with dementia to have equal control over the telecare technologies observed in use here. Such findings from this study underlined that practices

with technologies attended to sensibilities of care which were markedly different from those supported by other physical and co-located care activities.

Where informal carers used telecare to mediate their care practices with people with dementia, it seems that these practices may be replacing rather than supplementing other care practices, with consequences which if caring is actually diminished or undermined may need to be reviewed. If a person with dementia needs assistance with preparing and eating food, dressing, or toileting, then remote monitoring or 'care as surveillance' cannot address these needs and may undermine their being continued through traditional caring. Other care arrangements will then need to be put in place. Therefore, reconfiguring concepts of care around perhaps more visible innovative technological interventions provided by 'technology-enabled care services', may devalue or obscure the care work performed by humans co-located with people with dementia.

Future research and policy needs therefore to incorporate understandings of how people identify their own and others' practices, both those which may use assistive technologies or telecare and also those which do not, as contingent on locally-situated considerations. Doing so may challenge current service provider assumptions about what practices will constitute and be agreed to constitute care in any given case.

## 9.5 Community care and home care: the importance and implications of more precise concepts

Policy and research literature have frequently framed care and living arrangements as located 'in the community' or 'community-based'. However, 'community' was seen to be an ambiguous concept which was rarely defined. If living in the community implies that a person with dementia engages in social relationships with people outside their immediate family or accessing a variety of person-centred services, then technologies designed to support independence in the community should promote such interactions. The findings from this study did not readily support such a definition of 'community-based' for the living circumstances of the people with dementia for whom assistive technologies and telecare were supplied.

Findings from this study demonstrated that practices with assistive technologies and telecare may actually further confine people with dementia to their homes or limit their access to places and people outside the home. Many of the technologies examined in this study were only functional if the person with dementia stayed in his or her home. In consequence, informal carers appeared to make efforts

to limit how and when people with dementia left the home. Rather than promoting community engagement, practices with assistive technologies and telecare could be seen as constraining them. In other words, practices with assistive technologies appeared to work against the 'community' aspect of community care. Following their installation, care practices became more located within the home of people with dementia. Therefore, 'home care' rather than 'community care' may be a more precise way for describing the location of current practices constituting technology-enabled dementia care.

Yet neither can policy makers nor researchers take even the concepts of 'home' and 'home care' for granted. ACCOMMODATE findings illustrated that the home was not a static place over the relatively few months of study observations. Informal carers, building managers, and other people with care responsibilities were continuously reconfiguring rooms and their possible uses by adding or removing objects and equipment. Such practices of reconfiguring rooms affected how people with dementia occupied these spaces, some of which were even abandoned completely.

Policy makers may need to consider 'home care' as a concept for more precisely describing the location of current technology-enabled dementia care but also to understand the home not as a static location. More precisely attending to the actual locations and relocations of current practices of technology-enabled dementia care will ensure guidance they provide can be responsive to real practices in peoples' life-worlds rather than only expressing ungrounded aspirational rhetoric.

## 9.6 Futures and omissions of ethnography in realising technology-supported care

Lewis and Russell (2011) suggested that their methodological approach of 'embedded ethnography' represented a future direction for ethnography. In the current financial constraints for proliferating a diversity of funded research, this may have some value. This approach may enable ethnographers to generate new opportunities to pursue original, empirical work alongside large-scale studies such as national trials, public health interventions or development work. However, embedding ethnographies in such studies may constrain or confine how ethnographers can view the field, their fieldwork, and their professional relationships with participants. This study has identified alternative ways to open opportunities to work in dis/embedded relations with trials and other large programmes so as to introduce social scientific methods and approaches to academics, practitioners and professionals from other backgrounds. Lessons from the ACCOMMODATE study show ways in which embedded ethnographies can also provide contextualised analytical insights which can sensitise, health and social

care services evaluators, trialists and public health bodies to re-interpret recommendations from their own datasets.

ACCOMMODATE demonstrated ways in which the dis/embedded ethnographic approach which related to its origins in the ATTILA trial provided access and resources to help recruit people with dementia and their informal carers who were more readily identified as receiving assistive technologies or telecare. However, the ACCOMMODATE cases also showed how realising such a dis/embedded approach called for the ethnographer to carefully consider when and how it would be possible to approach and sustain contact with participants and what might be the implications of choices made. Dis/embedded ethnography could be seen to provide an adapted ethnographic methodology for social researchers requiring a focused and shorter-term alternative route to understanding situated practices. However, neither could this be seen as a comprehensive replacement for conventional ethnographic approaches where these are needed to address broad questions about holistic community or collective living.

The ACCOMMODATE study clearly could realise only limited insights into the constitution of technology-enabled dementia care in diverse localities and individuals living in their homes. A larger multi-sited study which also observed the practices of telecare centre operators, allied health professionals carrying out home assessments, and the interactions of people with dementia and informal carers with people and places outside the home may provide more holistic or alternative interpretations of the lived reality of current technology-enabled dementia care. Such a whole-system approach would still have much to gain from ethnographic principles identifying the complex related imaginaries of living with dementia, providing care, and the community which have been furthered through the distinct empirical, conceptual and methodological work of ACCOMMODATE.

## 9.7 Directions for future research

This scope of this study precluded a holistic study to comprehend every facet of technology-enabled dementia care. However, it provided practice-based findings which challenged many assumptions apparent informing the provision of such technologies to study participants. Such study findings can inform future research and development.

The study focused on the practices of people with dementia and their informal carers living in England. People with dementia in this study expressed particular difficulties related to progressive memory loss

resulting from their condition. However, it also illustrated how awareness of memory problems appeared through social interactions with other people in the everyday routines of people with dementia. People with dementia only became aware of saying something 'incorrect' when an informal carer corrected them. However, the experiences of memory loss described in this study, may not reflect people from other backgrounds elsewhere in the world. Cross-cultural studies which consider how people perceive memory loss may suggest how different groups of people characterise forgetting as: 1) an infrequent, mundane occurrence (e.g. forgetting where one left his or her keys), 2) a 'natural' sign of ageing or senility, or 3) a symptom of pathology.

Another area of research would be to further examine how informal carers and people with dementia conceive and realise care practices and responsibilities in dementia care. A cross-cultural study which explores the practices of carers from different sociocultural background(s) may reveal different practices or sensibilities about what constitutes care and who fulfils the responsibilities for providing it. Further research could also investigate how people identify and differentiate 'care practices' from 'everyday practices'.

ACCOMMODATE findings suggest a dis/embedded ethnographic approach could also investigate ways in which practices of people with dementia and their informal carers are affected by introducing different types of technologies into their lives. The rise of the Internet of Things (Hannaford 2017), social robots (Baraniuk 2014), and apps may further change how technologies continue to mediate ways of providing care and will also create new social, ethical and regulatory implications. The implications of practices with these new technologies will need to be identified and considered if care is to be provided which can appropriately and holistically support people with dementia to live well in their own homes and in the community.

To close, a quote from Mark Clyde on my first visit expressed concern with the automatic falls detector and the help it might provide for his father if he fell:

*'Dad doesn't pick up the phone because he can't hear it and the phone is even louder than the alarm. Next, they call me to see if I am with my dad because his sensor has activated on his falls detector. They [the service provider] don't check though. I could be a burglar and my dad could be under the stairs. They never ask to speak with him. They always just take my word that he is fine.'*

Such words clearly highlight the need to more carefully consider the specific needs and capabilities of people with dementia when selecting assistive technologies and telecare. Such technologies cannot support peoples' independence if they cannot respond to the alarm or call from the service provider. They question who benefits from these technologies if they continue to exclude people with dementia from making decisions about or actively taking part in their care. A future technology-enabled dementia care *with* people with dementia would include them as active citizens rather than objects of care. Research-informed technological care practices and policies need to help restore social connections between people, not further diminish them.

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# Appendices

# Appendix I : Participant Information Sheet

## *Participant Information Sheet (Person with Memory Problems)*

*The experiences of assistive technology use by people with memory problems and their carers*

Who is running this project?

- Matthew Lariviere, a postgraduate research student at the University of East Anglia as part of his research degree.
- He is supervised by Prof Fiona Poland and Dr Chris Fox from the University of East Anglia and Prof Stan Newman of City University London.

What is the project for?

- This study wants to understand your experiences about assistive technology (AT) as a person with memory problems.
- This is an extra study for the ATTILA trial in which you already take part.

Why have I been chosen?

- Your experiences with assistive technology may improve how the equipment is designed and used in future practice.
- In order to take part you must:
  - Be a person with memory problems who is a participant in the ATTILA Trial,
  - Have been given assistive technology at least six months ago, and
  - Be living in London, Cambridgeshire, Norfolk or Suffolk areas of England.

What do you get from taking part?

- By taking part in the project you may help change the ways that AT is designed and used by people with memory problems in the future
- There is no financial compensation for taking part in this study

What are the potential risks of taking part?

- There is not expected to be any increased risk than you would normally face each day.

- If you feel uneasy or wish to go outside the home at any time, then the researcher will leave.
- You are free to withdraw from the study at any time without any reason without jeopardising the continued use of assistive technology or taking part in ATTILA.
- If the researcher believes that either you or your carer are at risk, then they will notify a local authority.

### What will taking part involve?

If you agree to take part:

- The researcher will visit you at your home
- The researcher will find out how you and your carer live with and use the AT equipment by talking and spending time with you
- The researcher will visit once every month for six months.
- Each visit will take between one and five hours to complete.
- The researcher will ask your permission to audio-record some of the conversations with them and to jot notes during his visit
- You are not expected to provide food or drink for the researcher

### How will your information be protected?

- Your name will be replaced with a fake name which makes it impossible for you to be identified in any reports
- All information from the visits will be kept in a securely locked place.
  - Physical data will be kept in a locked filing cabinet within the Postgraduate Research Student Office at the University of East Anglia
  - Typed data will be kept on a password protected computer to which the researcher has sole access.
- Data may be shared only with his three supervisors who may listen to recordings or read about them to check his work.

### How will the results of this study be shared?

- The results of this study will be written up into the researcher's thesis to complete his research degree.

- The results are also expected to be published in journals, presented at conferences, and shared with government and businesses.
- A report of the results will also be sent to the ATTILA team at King's College London

If you have any concerns about the research, then please contact my supervisor.

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Thank you!

## Participant Information Sheet (Carers)

*The experiences of assistive technology use by people with memory problems and their carers*

Who is running this project?

- Matthew Lariviere, a postgraduate research student at the University of East Anglia as part of his research degree.
- He is supervised by Prof Fiona Poland and Dr Chris Fox from the University of East Anglia and Prof Stan Newman of City University London.

What is the project for?

- This study wants to understand your experiences of how assistive technology (AT) can help a person with memory problems.
- This is an extra study for the ATTILA trial in which you and the person you care for already take part.

Why have I been chosen?

- You have been chosen because your experiences with assistive technology may improve how the equipment is designed and used in future practice.
- In order to participate you must:
  - Be a carer of a person with memory problems who is taking part in the ATTILA Trial,
  - Have been given assistive technology at least six months ago
  - Be living in London, Cambridgeshire, Norfolk or Suffolk areas of England.

What do you get from taking part?

- By taking part in the project you may help change the ways that AT is designed and used by people with memory problems in the future
- There is no financial compensation for taking part in this study

What are the potential risks of taking part?

- There is not expected to be any increased risk than you would normally face each day.

- If you or the person you care for feel uneasy or wish to go outside the home at any time, then the researcher will leave.
- You are free to withdraw from the study at any time without any reason without jeopardising the continued use of assistive technology or taking part in ATTILA.
- If the researcher believes that either you or the person to whom you provide care are at risk, then he will notify a local authority.

### What will taking part involve?

If you agree to take part:

- The researcher will visit you at the home of the person that you care for
- The researcher will find out how you and the person you care for live with and use the AT equipment by talking and spending time with you
- The researcher will visit once every month for six months.
- Each visit will take between one and five hours.
- The researcher will ask your permission to audio-record some of the conversations with them and to take notes during his stay
- You are not expected to provide food or drink for the researcher

### How will your personal details be protected?

- Your name will be replaced with a fake name which makes it impossible for you to be identified in any reports
- All information from the visits will be kept in a securely locked place.
  - Physical data will be kept in a locked filing cabinet within the Postgraduate Research Student Office at the University of East Anglia
  - Typed data will be kept on a password protected computer to which the researcher has sole access.
- Data may be shared only with my two supervisors who may listen to recordings or read about them to check his work.

How will the results of this study be shared?

- The results of this study will be written up in the researcher's thesis to complete his research degree.
- The results are also expected to be published in journals, presented at conferences, and shared with government and businesses.
- A report of the results will also be sent to the ATTILA team at King's College London

If you have any concerns about the research, then please contact my supervisor.

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Thank you!

## Consultee's Information Sheet

### *The experiences of assistive technology use by people with memory problems and their carers*

Your friend or relative is being invited to take part in a study which explores his or her experiences using assistive technology at home. Matthew Lariviere, the researcher for this study, will spend time and talk with your friend or relative in his or her home. The researcher will visit one day every month for six months. Each visit will last for approximately one to five hours based on the desires the participants and the consultee. You or your friend or relative may ask the researcher to leave the home at any time.

We feel your relative or friend is unable to decide for himself/herself whether to take part in this research. We are asking you to act as a consultee to determine whether taking part in this study would be in your friend or relative's interests. This role is in addition to your own potential role as a participant in this study.

To help decide if he or she should join the study, we would like to ask your opinion whether or not they would want to be involved. We would ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide your relative or friend would have no objection to taking part, we will ask you to read and sign the consultee declaration on the last page of this information leaflet. We will then give you a copy to keep. We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should be withdrawn. You may withdraw yourself or your friend or relative from this study without giving a reason at any time.

If you decide that your friend/relative would not wish to take part, it will not affect the standard of care they receive in any way.

If you are unsure about taking the role of consultee you may seek independent advice.

We will understand if you do not want to take on this responsibility.

The following information is the same as would have been provided to your relative or friend but edited to reflect your role as a consultee.

### Who is running this project?

- Matthew Lariviere, a postgraduate research student at the University of East Anglia as part of his research degree.
- He is supervised by Prof Fiona Poland and Dr Chris Fox from the University of East Anglia and Prof Stan Newman of City University London.

### What is the project for?

- This study wants to understand the experiences about assistive technology (AT) for people with memory problems and their carers.
- This is an extra study for the ATTILA trial in which you already take part.

### Why have I been chosen as a consultee?

- The experiences of people with memory problems is important
- Their experiences with assistive technology may improve how the equipment is designed and used in future practice.
- As the memory problems of the person you care for increase, they may be unable to make informed choices
- You are being asked to give your opinion on whether the person to whom you provide care for would like to take part in this study

### What does the person with memory problems receive from taking part?

- By taking part your relative or friend may help change the ways that AT is designed and used by people with memory problems in the future
- There is no financial compensation for any participants in this study

### What are the potential risks of taking part?

- There is not expected to be any increased risk more than a person would normally face each day.
- If your relative or friend feel uneasy at any time, then the researcher will leave and arrange another visit to suit his or hers schedule.
- If the researcher believes that either the person with memory problems or the carer is at risk, then they will notify his or her local authority

### What will taking part involve?

If you believe that your friend or relative would agree to take part, then:

- The researcher will visit him or her at their home
- The researcher will find out how your friend or relative and his or her carer live with and use the AT equipment by talking and spending time with them
- The researcher will visit once every month for six months.
- Each visit will take between one and five hours.
- The researcher will ask whether you believe that your friend or relative would agree to audio-recording some of the conversations between them and the researcher and to jotting notes during the researcher's visit
- You are free to withdraw your relative or friend from the study at any time without any reason without jeopardising the continued use of assistive technology, taking part in ATTILA, or other social or health care provisions
- Your friend or relative are not expected to provide food or drink for the researcher

### How will your information be protected?

- The name of the person with memory problems will be replaced with a fake name which makes it impossible for them to be identified in any reports
- All information from the visits will be kept in a securely locked place.
  - Physical data will be kept in a locked filing cabinet within the Postgraduate Research Student Office at the University of East Anglia
  - Typed data will be kept on a password protected computer to which the researcher has sole access.
- Data may be shared only with his three supervisors who may listen to recordings or read about them to check his work

### How will the results of this study be shared?

- The results of this study will be written up into the researcher's thesis to complete his research degree.

- The results are also expected to be published in journals, presented at conferences, and shared with government and businesses.
- A report of the results will also be sent to the ATTILA team at King's College London

If you have any concerns about the research, then please contact my supervisor.

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Thank you!

# Appendix II: Informed Consent and Consultee Declaration Forms

## Informed Consent Form (Person with Memory Problems)

*The experiences of assistive technology use by people with memory problems and their carers*

- I have read and understood the participant information sheet ((Version: 1.2, dated 28 January 2015) and this consent form.
- I have had a chance to ask questions about taking part in this study.
- I will be given a copy of both forms for my own records.
- I do not have to take part in this study and have the right to withdraw from this study at any stage without giving any reason without this affecting my continued use of AT or taking part in ATTILA.

Please initial in the boxes and sign below.

I agree to take part in this study.

I agree to have of my conversations with the researcher recorded using an audio-recorder.

Name of participant: \_\_\_\_\_

Signature of participant: \_\_\_\_\_

Signature of researcher: \_\_\_\_\_

Date: \_\_\_\_\_

Contact details for the researcher are located on the back side.



Name of researcher                      Matthew Lariviere  
Address:                                      1.23 Queen's Building  
    Chancellor's Drive  
    University of East Anglia  
    Norwich NR4 7TJ  
Email/Telephone:                      [m.lariviere@uea.ac.uk](mailto:m.lariviere@uea.ac.uk) / 07860 87 655

## Informed Consent Form (Carer)

*The experiences of assistive technology use by people with memory problems and their carers*

- I have read and understood the participant information sheet (Version: 1.2, dated 28 January 2015) and this consent form.
- I have had a chance to ask questions about taking part in this study.
- I will be given a copy of both forms for my own records.
- I do not have to take part in this study and have the right to withdraw from this study at any stage without giving any reason without this affecting my continued use of AT or taking part in ATTILA.

Please initial in the boxes and sign below.

I agree to take part in this study.

I agree to have some of my conversations with the researcher audio-recorded.

Name of participant: \_\_\_\_\_

Signature of participant: \_\_\_\_\_

Signature of researcher: \_\_\_\_\_

Date: \_\_\_\_\_

Contact details for the researcher are located on the back side.



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Email/Telephone:                      [m.lariviere@uea.ac.uk](mailto:m.lariviere@uea.ac.uk) / 07860 87 65

## Consultee Declaration Form

*The experiences of assistive technology use and non-use by people with memory problems and their carers*

- I have been consulted about my friend or relative, [person with memory problem's name], taking part in this study.
- I understand that I can request that or she be withdrawn at any time from this study without giving any reason and without this affecting his or her continued use of AT or taking part in ATTILA.
- I will be given a copy of this form for my own records.

Please initial in the boxes and sign below.

I believe that my relative or friend would agree to take part in this study.

I believe that my relative or friend would agree to having some conversations audio-recorded.

Name of consultee: \_\_\_\_\_

Signature of consultee: \_\_\_\_\_

Signature of researcher: \_\_\_\_\_

Date: \_\_\_\_\_

Contact details for the researcher are located on the back side.



Name of researcher                      Matthew Lariviere  
Address:                                      1.23 Queen's Building  
    Chancellor's Drive  
    University of East Anglia  
    Norwich NR4 7TJ  
Email/Telephone:                      [m.lariviere@uea.ac.uk](mailto:m.lariviere@uea.ac.uk) / 07860 87 6552

# Appendix III: Indicative list of ethnographic interview principles and topics

## Indicative list of ethnographic interview principles and topics

It is important to understand that the interviews carried out in this research will be ethnographic interviews, so therefore fitting into ongoing activities and conversations in the setting rather than separate formal interviews. The researcher (ML) will initiate discussions during his observations in to seek specific information about the activities being observed so as to understand more about what they mean to people with dementia and their carers and what is usual for them. Therefore, formally-specified questions are not appropriate to this naturalistic approach although some topic areas relevant to the research are likely to be the focus of potential questions that may arise during the course of the researcher's (ML) ethnographic data collection. The questions will be generated according to the ongoing activities and conversations of the setting and reflect the specific context of the activities and environment of each participant. The following list of indicative questions may be used to help the researcher (ML) determine to what extent what is observed reflect what the participants would consider to be normal for them. Questions may also be used to probe in order to find out more about the specific activity that is taking place or about their assistive technology and telecare (ATT) in their home. Questions are open-ended to generate rich data and due to close ended questions being difficult for people with dementia to sometimes understand.

### Potential questions for person with dementia:

Is this the kind of thing you usually do when you e.g. prepare your lunch? [Probe: Why is that? How easy is it for you?]

What do you use this ATT device] for?

[Probe: Why is that? What do you use it for?]

### Potential questions for carer:

How often do you visit [the person with dementia]?

Is this the kind of thing you usually do during your visits?

What do you use this ATT device] for?

[Probe: Why is that? What do you use it for?]

# Appendix IV: Opinion Letters from Research Ethics Committees



## Health Research Authority

NRES Committee London - Bromley  
Level 3, Block B  
Whitefriars  
Lewins Mead  
Bristol  
BS1 2NT

16 December 2014

Mr Matthew Lariviere  
1.23 Queen's Building  
Chancellor's Drive  
University of East Anglia  
NR4 7TJ

Rectangular Snip

Dear Mr Lariviere

**Study title:** Examining the experiences of how and why people with dementia and their carers use assistive technology and telecare at home: An ethnographic study linked to the ATTILA(Assistive Technology and Telecare to maintain Independent Living At Home for People with Dementia) Trial

**REC reference:** 14/LO/2244

**Protocol number:** 1.0

**IRAS project ID:** 143521

The Research Ethics Committee reviewed the above application at the meeting held on 11 December 2014. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager Miss Lauren Allen, [nrescommittee.london-bromley@nhs.net](mailto:nrescommittee.london-bromley@nhs.net).

### Ethical opinion

The members of the Committee present decided to issue an unfavourable opinion for the following reasons:

- 1) The Committee considered that it was not ethical to allow a researcher who lacks experience of face-to-face contact with dementia patients, who has limited experience of handling challenging behaviours, and who is unprepared for situations that may arise such as emotional unloading, to enter into patients' homes. The Committee considered that it would be unsafe for the researcher and participants to allow this.
- 2) The Committee was concerned that the applicant has only limited experience in assessing mental capacity which puts the applicant and the patient and their family at risk.
- 3) The Committee was concerned that the researcher's inexperience may mean that he is

A Research Ethics Committee established by the Health Research Authority

unable to pre-empt or recognise a potential crisis and he will need help and support in dealing with these situations.

- 4) There are no processes in place for dealing with disclosure of information that could put dementia patients and/or their carers at risk or of criminal activity. This should be clearly set out in the information sheets.
- 5) There is no mention in the application of the relationship between the patient and carer being analysed.
- 6) The Committee thought that the lone worker policy appeared inadequate considering that the researcher will be visiting participants in their homes which may be during unsociable hours.
- 7) There needs to have been a robust risk assessment before the researcher visits participants' homes. The researcher will not have access to patients' care records himself, therefore someone needs to have assessed who he will be visiting to ensure his safety when entering their homes.
- 8) The Committee did not think it was acceptable for the researcher to be in participants' homes for 5 hours. It was a concern that he would not be able to sense when he should leave and he may be asked for assistance with tasks that it would not be appropriate for him to help the patient with.
- 9) The Consultee Declaration Form needs to be reworded as in parts it refers to the consultee giving consent. The Consultee Information Sheet also reads in places as though it is addressed to the person with dementia. Please see the templates available on the HRA website:- <http://www.hra-decisiontools.org.uk/consent/examples.html>
- 10) The Consent Forms should follow the template on the HRA website:- <http://www.hra-decisiontools.org.uk/consent/examples.html>

I regret to inform you therefore that the application is not approved.

**If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact Miss Lauren Allen, [nrescommittee.london-bromley@nhs.net](mailto:nrescommittee.london-bromley@nhs.net)**

### **Mental Capacity Act 2005**

The Committee did not approve this research project for the purposes of the Mental Capacity Act 2005. The research may not be carried out on, or in relation to, a person who lacks capacity to consent to taking part in the project.

### **Options for further ethical review**

You may submit a new application for ethical review, taking into account the Committee's concerns. You should enter details of this application on the application form and include a copy of this letter, together with a covering letter explaining what changes have been made from the previous application.

We strongly recommend that you submit the new application to this REC. In order to arrange

for the new application to be reviewed by this REC, please contact **Miss Lauren Allen** at [nrescommittee.london-bromley@nhs.net](mailto:nrescommittee.london-bromley@nhs.net) when you have prepared the new application in order to book a slot at the meeting. If you prefer, you may submit the application to a different REC by contacting the Central Booking Service. Please note, you must be able to submit the application on the same day as making the booking.

Alternatively, you may appeal against the decision of the Committee by seeking a second opinion on this application from another Research Ethics Committee. The appeal would be based on the application form and supporting documentation reviewed by this Committee, without amendment. If you wish to appeal, you should notify the relevant Research Ethics Service manager (see below) in writing within 90 days of the date of this letter. If the appeal is allowed, another REC will be appointed to give a second opinion within 60 days and the second REC will be provided with a copy of the application, together with this letter and other relevant correspondence on the application. You will be notified of the arrangements for the meeting of the second REC and will be able to attend and/or make written representations if you wish to do so.

The contact point for appeals is:

Catherine Blewett  
HRA Improvement & Liaison Manager  
National Research Ethics Service

Email: [catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)

### Summary of discussion at the meeting

#### Social or scientific value; scientific design and conduct of the study

*The Committee commented that having someone in participants' homes observing their use of the assistive technology may impact on how they behave. Participants may not use the technology at all when the researcher is there or they may use it more frequently than they would if they were not being observed. It was asked whether you had considered this.*

You replied that you were aware of the Hawthorne Effect and would take this into consideration and reflect this accurately in the data. You expect to build a rapport with participants during the visits and hope they will become used to your presence and act more naturally around you over time.

*The Committee considered that the technology will have different levels of use depending on the stage of the person with dementia. Patients at an early stage may find the technology useful as it could help maintain their independence, whereas at a later stage the technology will probably be more helpful for the carer than the patient. It was questioned whether the research will cover all assistive technology or if it will be limited to a specific area.*

You answered that you hope to catch as wide a range as possible. This will be a small study however you intend to include those with a range of severity, technologies, and relationships between patient and carer. The technology used depends on what participants have been offered as part of the ATILLA study, although you explained that you will look at cases which are different, for example one participant may have a fall detector whereas another may use a medication dispenser, in order to highlight potential issues and challenges with that specific device.

*Relevance of the research to the impairing condition*

The Committee agreed the research is connected with an impairing condition affecting persons lacking capacity or with the treatment of the condition.

*Justification for including adults lacking capacity to meet the research objectives*

The Committee considered that the research could be carried out equally effectively if it was confined to participants able to give consent for the following reasons:

*The Committee queried whether the research could be carried out effectively by talking to people who work with dementia patients and their carers rather than visiting patients in their homes.*

You answered that potentially the research could be carried out in this way but it would not be more appropriate to do this. The technology is for use in patients' homes and the best way of monitoring this is to observe patients using the technology. You explained that some data can only be obtained by being in the home, for example you may be able to find out why the technology is not being used.

**Recruitment arrangements and access to health information, and fair participant selection**

*The Committee noted that the research will exclude patients who have an urgent need for a care package due to immediate or severe risks to themselves or others. It was asked how these patients will be identified and why they will be excluded.*

You explained that this was an exclusion criteria for the ATILLA trial and participants for this research will be recruited from the same pool of patients that took part in the trial.

*Arrangements for appointing consultees*

The Committee considered the arrangements set out in the application for appointing consultees under Section 32 of the Mental Capacity Act to advise on whether participants lacking capacity should take part and on what their wishes and feelings would be likely to be if they had capacity.

After discussion the Committee agreed that reasonable arrangements were in place for identifying personal consultees and for nominated consultees independent of the project where no person can be identified to act as a personal consultee.

**Favourable risk benefit ratio: anticipated benefit/risks for research participants (present and future)**

*Balance between benefit and risk, burden and intrusion*

After discussion, the Committee agreed that the research has the potential to benefit participants lacking capacity without imposing a disproportionate burden on them.

The Committee decided that the research did not require Site-Specific Assessment at non-NHS sites as it involves no clinical interventions and all study procedures at sites would be undertaken by the Chief Investigator's team and the Committee was satisfied that the risk to participants is likely to be negligible, and the study procedures will not significantly interfere with participants' freedom of action or privacy or be unduly invasive or restrictive.

### Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

#### *Additional safeguards*

The Committee was satisfied that reasonable arrangements would be in place to comply with the additional safeguards set out in Section 33 of the Mental Capacity Act.

*The Committee was however concerned that if you became aware of or had a concern relating to abuse then you would phone the emergency services or the abuse hotline. The Committee asked about more subtle signs of abuse and what you would do in these situations.*

You replied that you had been told that if it was not an emergency then it would be best to contact the abuse hotline, however you will also speak to your academic supervisors who may suggest other, more appropriate routes.

*The Committee agreed that you will need to investigate other services that are available for different levels of abuse.*

*The Committee was concerned that the sessions could last up to 5 hours and was unclear how this would work. It was considered that some participants may live on their own and their carer may not necessarily be there all day with them. The Committee also raised a concern about whether you will be able to get a sense of how long participants want your company.*

You explained that the sessions will last from between 1 to 5 hours. The length of the sessions will be negotiated with participants each time. You made clear that it will be the participants' decision how long the sessions last. Based on a previous study it was thought that 5 hours would be appropriate however you realised that this may not be possible.

You hope that both the patient and carer will be able to communicate when they want you to leave and you will also be able to pick up on any signs such as distress or discomfort. You understood that you will be a guest in participants' homes and will be careful not to outstay your welcome.

*The Committee was also concerned that carers may view the applicants visit as an opportunity to offload their feelings, even though you will be there to look at their use of the technology only. The Committee was worried that this could put both you and the carer in a vulnerable position and carers may expect you to follow-up on what they have told you, for*

*example if they were to disclose that they are not receiving enough support from social services. It was asked what you will do if this were to happen.*

You answered that you could discuss this with the ATILLA research team and discuss how best to proceed. The team will have processes in place and will be able to contact a range of local services.

• Rectangular Snip

*The Committee asked how prepared you were to deal with emotional distress from patients and carers. It may be upsetting and difficult to hear if for example someone revealed that they were feeling depressed and suicidal.*

You responded that you will suggest services who participants could contact if they are distressed. If you found anything upsetting then you would discuss this with your academic supervisors and there are also services available to you through the University. You informed the Committee that although you do not have a background in Health and Social Care you have been exposed to difficult stories in the past through your work as a qualitative researcher.

### **Informed consent process and the adequacy and completeness of participant information**

#### ***Information for consultees***

The Committee reviewed the information to be provided to consultees about the proposed research and their role and responsibilities as a consultee.

The Committee considered that the information was not adequate for the following reasons: parts of the consultee declaration form read as though the consultee is giving consent to take part in the research rather than referring to their relative or friend. Parts of the consultee information sheet also read as though it is addressed to the person with dementia. The Committee advised that you look at the consent form and consultee declaration form and information sheet templates available on the HRA website.

### **Suitability of the applicant and supporting staff**

*The Committee noted that you are not clinically registered and it was asked whether you have undergone the required CRB checks and if you have an honorary contract which will allow you access to these patients.*

You answered that you are a PhD student at the University of East Anglia. Participants will be recruited through the ATILLA study and you will visit patients in their homes therefore no honorary NHS contract is required. You confirmed that you have had the necessary CRB checks.

*The Committee asked whether you have any experience or training in interacting with persons with dementia. It was a concern that patients may become irritable or aggressive and the Committee was unsure if you will be capable of dealing with these situations.*

You responded that prior to your PhD you had no experience; therefore you have carried out a literature review of research involving patients with dementia and of research involving

assistive technology. Since then you have volunteered at Age UK which has given you some experience and you have also worked with and observed your academic supervisor Dr Chris Fox.

*The Committee noted that while the application mentions 'challenging behaviours' this has not been expanded on. You were asked what challenging behaviours you expect to encounter during the research.*

You answered that behaviours could vary according to different situations. You understood that participants may become aggressive or lash out in order to get attention or communicate a need. You informed the Committee that you have completed an online training module on safe-guarding which will help you to prepare for these situations and to know who to contact.

*The Committee questioned whether you have any training in assessing capacity.*

You confirmed that you have completed e-learning modules and are aware that there needs to be a clear indication that the person is able to retain information and communicate a decision. It will be an informal assessment of capacity and will be recorded in your field-notes. You added that you have practical training from visitation trips with your academic supervisors where you were asked to assess whether the patient had capacity or not afterwards.

### **Suitability of supporting information**

*The Committee commented that the list of questions to ask participants was inadequate and consisted of only three questions.*

Mr Lariviere explained that the questions are just examples of situations that might occur. He intends for the discussion to be more naturalistic rather than a structured interview. Only as activities occur will he ask questions relating to that activity.

### **Documents reviewed**

The documents reviewed at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance and Indemnity Letter- University of East Anglia]		03 December 2014
Interview schedules or topic guides for participants [Potential topics for ethnographic conversations]	v1.0	03 December 2014
Other [non_NHS SSA exemption letter]		05 December 2014
Participant consent form [Person with memory problems consent form]	v1.0	03 December 2014
Participant consent form [Carer consent form]	v1.0	03 December 2014
Participant consent form [Consultee declaration form]	v1.0	03 December 2014
Participant information sheet (PIS) [Consultee PIS]	v1.0	03 December 2014
Participant information sheet (PIS) [Person with memory problems PIS]	v1.0	03 December 2014
Participant information sheet (PIS) [Carers PIS]	v1.0	03 December 2014

REC Application Form [REC_Form_03122014]		03 December 2014
Referee's report or other scientific critique report [PPI Feedback]		
Research protocol or project proposal [Research protocol]	v1.0	28 November 2014
Summary CV for Chief Investigator (CI) [CI CV]	v1.0	27 November 2014
Summary CV for supervisor (student research) [Supervisor CV]	v1.0	27 November 2014
Summary CV for supervisor (student research) [Supervisor CV]	v1.0	03 December 2014

### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

There were no declarations of interest.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

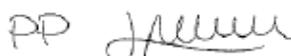
<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

### HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

14/LO/2244	Please quote this number on all correspondence
------------	--

Yours sincerely



**Ms Carol Jones**  
Chair

Email: [nrescommittee.london-bromley@nhs.net](mailto:nrescommittee.london-bromley@nhs.net)

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.*



**Health Research Authority**

Copy to: *Mrs Yvonne Kirkham*

A Research Ethics Committee established by the Health Research Authority

## NRES Committee London - Bromley

Attendance at Committee meeting on 11 December 2014

### Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mr Munir Ahmed	Consultant Urologist	No	
Mrs Susan Beer	Retired Project Manager	Yes	
Dr Jo Brooke	Senior Lecturer and Nurse Consultant in Dementia	Yes	
Mrs Angela Clayton-Turner	Retired NHS Therapy Manager	Yes	
Mr Abdulzahra Hussain	Speciality Dr in general surgery/senior lecturer	Yes	
Ms Carol Jones (Chair)	Management Consultant	Yes	
Mrs Kathryn Kinnear	Solicitor	Yes	
Mrs Fran McMillan	Retired	Yes	
Canon Tim Mercer	Hospital Chaplain	Yes	
Dr Angela Orunta	Consultant Anaesthetist	No	
Mrs Heather Salzer	Ultrasound Clinical Specialist	Yes	
Ms Jayne Steadman	Consultant Physiotherapist	Yes	

### Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Lauren Allen	REC Manager



## Health Research Authority

NRES Committee East of England - Norfolk

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 883 9525

03 February 2015

Mr Matthew Lariviere  
1.23 Queen's Building  
Chancellor's Drive  
University of East Anglia  
NR4 7TJ

Dear Mr Lariviere

<b>Study title:</b>	Examining the experiences of how and why people with dementia and their carers use assistive technology and telecare at home: An ethnographic study linked to the ATTLA(Assistive Technology and Telecare to maintain Independent Living At Home for People with Dementia) Trial
<b>REC reference:</b>	15/EE/0015
<b>Protocol number:</b>	1.1
<b>IRAS project ID:</b>	171559

Thank you for your letter of 02 February 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Lead Reviewer.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Tracy Leavesley, NRESCommittee.EastofEngland-Norfolk@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person

who lacks capacity to consent to taking part in the project.

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### Ethical review of research sites

##### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management

permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Cover letter with justifications for resubmission]		
Covering letter on headed paper [Cover letter with justifications for approval]		02 February 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UEA Insurance and Indemnity]		09 December 2014
Interview schedules or topic guides for participants [List of potential observation discussion topics]	v1.0	03 December 2014
IRAS Checklist XML [Checklist_02022015]		02 February 2015
Other [NRES Bromley - Unfavourable opinion letter]		16 December 2014
Other [Poland CV]		
Other [Non-NHS SSA]		22 December 2014
Other [SCIE Learning Record - Safeguarding]		
Other [SCIE Learning Record - Open Dementia Programme]		
Other [SCIE Learning Record - MCA]		
Other [ATTILA REC Approval]		18 December 2012
Other [ATTILA REC Amendment Approval]		04 September 2013
Other [ATTILA REC Provisional]		30 November 2012
Participant consent form [Carer Consent Form]	v1.1	17 December 2014
Participant consent form [Person with memory problems consent form]	v1.1	17 December 2014
Participant consent form [Consultee Declaration Form]	v1.1	17 December 2014
Participant information sheet (PIS) [Person with memory problems PIS]	v1.2	28 January 2015
Participant information sheet (PIS) [Carers PIS]	v1.2	28 January 2015
Participant information sheet (PIS) [Consultee IS]	v1.2	28 January 2015
REC Application Form [REC_Form_23122014]		23 December 2014
Referee's report or other scientific critique report [Inspire PPI commentary]		
Research protocol or project proposal [Research protocol]	v1.1	22 December 2014
Summary CV for Chief Investigator (CI) [CI CV]		
Summary CV for supervisor (student research) [Fox CV]		

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

### HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

15/EE/0015

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Michael Sheldon  
Chair

Email: NRESCCommittee.EastofEngland-Norfolk@nhs.net

Enclosures: "After ethical review – guidance for researchers"

# Appendix V: Consultation letter from Patient and Public Involvement Group

## inspire: Feedback for Researchers

All inspire members are handed this form with any piece of research they are asked to review. Members are encouraged to use the form as a guide and to add any additional comments not covered on the form at the end. This form is based on the feedback form issued to lay reviewers by the NIHR (National Institute for Health Research) for the Research for Patient Benefit (RfPB) funding stream.

*Comments below are as written by the inspire panel members.*

Research Title: An ethnographic exploration of the experiences of assistive technology use and non-use by community-dwelling people and their carers.

Lead Researcher Name: Matthew Lariviere

Inspire Panel: Older Age

Total Number of Completed Reviews: 3

1) HOW RELEVANT IS THE PROPOSED RESEARCH TO THE NEEDS OF THE NHS? WILL THIS RESEARCH BENEFIT THE NHS – IS THIS STATED CLEARLY?

*REVIEWER 1: N/A I think...*

*REVIEWER 2: A study looking at this research topic should benefit the NHS by achieving a greater understanding of the reasons why the various forms of assistive technology are accepted as useful or are rejected by the users. However I have concerns that the project in its present form will not be able to gather enough information to further this topic very far.*

*REVIEWER 3: No*

2) DOES THE RESEARCH AIM TO PRODUCE SOMETHING THAT IS OF BENEFIT TO PATIENTS? IS THIS STATED CLEARLY?

*REVIEWER 1: In the long run – implicit*

*REVIEWER 2: Knowing why the various forms of assistive technology are accepted or rejected by the target group should help future patients by helping to ensure that they are offered appropriate devices to use. However, I have not seen this laid out clearly in this proposal.*

*REVIEWER 3: The technology being suggested is already out there for people to use if they so wish.*

3) IS THE PROPOSAL OF HIGH QUALITY? DOES IT IDENTIFY CLEARLY HOW IT INTENDS TO MEET THE RESEARCH QUESTION?

*REVIEWER 1: Bit wordy but means business. Would have welcomed more detail about what was being observed and how as well the theoretical detail.*

*REVIEWER 2: I find that the proposal is of mixed quality.*

*The method of data gathering is laid out clearly, but its full details are scattered through this long and somewhat repetitious proposal. It would have been easier to assess the proposal if the theoretical justification for the project were clearly separated from the practical details of data gathering.*

*The methods of data processing are described. I am unable to comment on these.*

*REVIEWER 3: Yes it does identify how it intends to meet its research*

4) IS THE PROPOSED DESIGN OF THE RESEARCH AND STRUCTURE OF THE RESEARCH SUITABLE AND APPROPRIATE FOR THE PARTICIPANT/PATIENT GROUP?

*REVIEWER 1: Probably*

*REVIEWER 2: The main method of data gathering is for the researcher to immerse himself for up to 5 hours per session within the patient's (and patient's carer's) own normal setting. The researcher is to employ a mixture of observation and informal questioning.*

*I suggest that up to 5 hours per visit is likely to be too long to be tolerated well by either the patient or the patient's carer. It may be that these long visits might work if the researcher became a 'part of the background', but if this is a successful 'tried and tested' method of research I would like to know of other projects where it has worked. I would have thought a period of 2 and ½ hours should be the maximum time for each visit.*

*REVIEWER 3: No*

5) DO YOU HAVE ANY CONCERNS ABOUT PARTICIPATION IN THIS STUDY (THIS COULD BE ABOUT TIME, COMMITMENT, TRAVEL, REIMBURSEMENT OR ANY OTHER ISSUES THAT MAY AFFECT PARTICIPANTS IN THE STUDY)?

*REVIEWER 1: Emphasis on carer role rather than person with memory problems*

*REVIEWER 2: The patient and carer are asked to give up to 5 hours of their time in any one session. This might be feasible if the patient has a full-time carer, but the use of assistive technology in itself tends to indicate that the patient is to be left alone for some periods. Is the researcher to be left alone with the subject when the carer is absent? Will this cause anxiety in either the patient or their carer or the researcher? (If I were a carer who was housebound with a person with dementia I might well want to make use of the presence of a*

*researcher as a responsible person to be present with the patient whilst I did the shopping etc. – is the researcher prepared for this?!*

*The repeat visits of every 2 months for a year seem fine to me.*

*REVIEWER 3: The timescale suggested is far too long. Spending 5 – 6 hours at a time with a dementia patient carrying out observation studies will place patient and carer under undue stress.*

6) ARE TIMESCALES APPROPRIATE FOR THE RESEARCH AND ALSO FOR THE PROJECT AS A WHOLE?

*REVIEWER 1: Probably*

*REVIEWER 2: I think so.*

*REVIEWER 3: If the visits were carried out – leaving 6 months between each visit is too long. Patient will forget who researcher is over this period and will become agitated and stressed by having who they think is a stranger in their home.*

7) DO YOU THINK THE INCLUSION AND EXCLUSION CRITERIA FOR THE STUDY IS APPROPRIATE? IS THERE ANYTHING MISSING?

*REVIEWER 1: No Comment*

*REVIEWER 2: There is some confusion in the proposal as to whether the person and their carer should or should not have used some form of assistive technology before the project. On page 2 it is stated that the participants must have been offered the assistive technology for at least 6 months. However on page 16 it states that people will be ineligible if they are receiving assistive technology already. This apparent contradiction should be clarified.*

*REVIEWER 3: No*

8) IS THE CONSENT PROCESS TO TAKE PART IN THE RESEARCH CLEAR AND FAIR? DO YOU HAVE ANY CONCERNS ABOUT THIS?

*REVIEWER 1:*

- *Withdrawal of one or other of the dyad?*
- *Permission from PWD to continue if is there loss of capacity.*
- *Definition of lack of capacity (repeating details)*

3

- *On PIS and consent forms carers are called carers and consultees consultees, but PWD are named first as 'Memory Problems'(!) and then 'Memory Issues'!! This is casually insulting and disrespectful – please amend.*

*REVIEWER 2: I like the proposed consent process, particularly the proposal that consent is sought afresh on each researcher visit, not just on the first visit.*

*REVIEWER 3: An early diagnosed patient who gives consent will not necessarily agree to consent further down the study. You will need to check regularly that they are still consenting as you progress.*

9) ARE THE APPROPRIATE PROJECT MANAGEMENT ARRANGEMENTS IN PLACE? (FOR EXAMPLE A CLEAR CHAIN OF COMMAND, WHERE TO GO IF SOMETHING GOES WRONG? )

*REVIEWER 1: Yes*

*REVIEWER 2: N/A*

*REVIEWER 3: Not specified*

10) IS THE RESEARCH TEAM APPROPRIATE? IS THERE THE NECESSARY BREADTH OF EXPERTISE PRESENT TO BE ABLE TO CARRY OUT THIS RESEARCH WELL?

*REVIEWER 1: I can't tell – more info?*

*REVIEWER 2: N/A*

*REVIEWER 3: Yes*

11) HAVE THE RESEARCHERS EXPLAINED ABOUT PUBLIC PATIENT INVOLVEMENT IN THE RESEARCH? DO YOU HAVE ANY ADDITIONAL COMMENTS ABOUT THIS?

*REVIEWER 1: No*

*REVIEWER 2: As a member of the Inspire Older Age panel we were asked to for specific comments. I am using this box to answer point 1) Review of participant information sheets and consent forms.*

*Appendix 1: Participant Information Sheet (carers).*

*a) The sheet assumes that the carer knows what assistive technology is. I would not have known. Could it be explained and examples given?*

b) *It is not made clear that Matthew Lariviere is also the researcher who will be visiting, and again ML is spoken of as 'the researcher' and as 'my/I' without clarification that this is the same person.*

c) *There is no mention that the researcher/me/I may be writing notes as well as recording the interchanges.*

d) *I think that the term 'large book' as explanation for a PhD thesis is too childish. Could it either be referred to just as a PhD thesis?*

*Appendix II The same comments apply to the sheet for the participant with memory problems. I might prefer just to be called the Patient in the heading for this sheet.*

*Appendix III. Sorry, as a consultee, I don't fit your selection criteria!*

*Appendix IV, V, VI: Informed Consent Form. Again this form does not mention possible note taking.*

*I think that points 2) and 3) are covered elsewhere in this feedback form.*

*REVIEWER 3: Yes they have explained. I feel that most of the technology they wish to use will have to be operated by the carer as the patient in later dementia will not understand how to work the equipment or will not remember to activate them. Those patients who do not have a resident carer, will be in a dilemma living on their own– if they have a contracted visiting carer who are only on the premises for 20 mins at a time the technology will not be activated or answered.*

12) DO YOU FEEL THIS RESEARCH IS VALUE FOR MONEY? (IF COST INFORMATION IS INCLUDED ONLY).

*REVIEWER 1: Dunno - probably*

*REVIEWER 2: N/A*

*REVIEWER 3: NO*

13) DO YOU HAVE ANY ADDITIONAL COMMENTS OR QUESTIONS ABOUT THE RESEARCH OR ABOUT HOW IT MIGHT BE IMPROVED?

*REVIEWER 1: Ethnographic exploration. Matthew Lariviere*

*Have tackled the supporting bits and forms first – body of the text later!!!*

*Review request form:*

5

*Summary – bit wordy? Much of this is said more succinctly in the first part of the If you do not need section...*

- *Para 1: 'dearth of support' = do you mean dearth of evidence supporting??*
- *People with dementia and their carers – no apostrophe!*
- *Para 2: 'Observations may be particularly necessary where the ability...' ?*
- *If you do not need: see above: why is this first para here?*

*ATTILA Qualitative Exec Summary An ethnographic...*

*Background*

- *Para 1 line 7: 'to evidence the use...by local authorities...' –does this mean to prove whether local authorities are commissioning or not, or to produce evidence of whether clients are using the AT?*
- *Para 1, line 11: 'As the experiences...' Makes no sense grammatically: should it connect with the next sentence?*

*Aims*

- *Perhaps clearer? 'To undertake an e e of the experiences of community-dwelling PWD and their carers in using and not using assistive technology.'*

*Objectives*

- *Para 2: don't understand 'shared and/or contested' - shared with whom?, and use of the word 'contested' here and elsewhere.*

*Methods*

- *Line 8: 'consent from the carer and PWD...'*
- *What happens if either member of the dyad withdraws from the study??*

*Appendix 1 PIS (Carers)*

*Who is running:*

- *'to earn !! – too personal and potentially loaded. Perhaps 'as part of his PhD degree'?*
- *Supervised by? The addresses come at the end, but a link to higher command is reassuring at this point too*

*Why have I been chosen?*

- *Second points sound like requirements, not reasons – perhaps begin each with ‘because you are..., because you have... because you live...’*

*What do you get?*

- *Perhaps the positive point first?!*
- *Then: ‘there is no financial compensation...’ Sounds a bit worrying otherwise!*

*Potential risks*

- *Perhaps: ‘the researcher will leave and arrange another visit to suit you.’?*

*Involves ...*

- *2. Tautology – Perhaps: ‘The researcher will find out....by talking and spending time with you’?*
- *4. Omit ‘to complete’.*
- *Free to withdraw – add some reassurance that their continued use of AT or participation in ATTILA would not be jeopardised?*

*Data protection*

- *Typed data ... ‘to which the researcher has sole access’*
- *Data may be shared only with the researcher’s supervisor .....to check his work.*

*Results shared*

- *Infantilising! ‘Will be written as a thesis to complete...’*

*Appendix11 mainly as above*

*PIS Person with memory problems - please!!*

*Project for?*

*‘experiences with AT’*

*Why chosen?*

- *Your experiences with...*
- *Next three points: because*

*What do you get and risks? and Involve As in Appendix 1*

- *Do you need permission for continued participation in the case of me losing capacity during the course of the research?*

7

### *Appendix III (Consultees)*

#### *Who and what for? As App II*

#### *Why me?*

- *4. You are being asked to act on behalf ...for whom you provide care and who cannot...*
- *Pagination then fails goes from p40 (incomplete consultee) to two pages, both p43 and headed Informed Consent (carer)*
- *Comments as for Appendix I*

#### *Appendix IV ICF (Carer)*

- *Under withdrawal – no prejudice to continued use of AT or participation in ATTILA*

#### *Appendix V*

*Person/participant with memory issues - they are people too! Last time they were just 'memory problems' – perhaps choose one (respectful) term and stick to it?*

- *Withdrawal without prejudice...*
- *Permission in case of loss of capacity?*

#### *Appendix VI (Consultee)*

*As above, withdrawal without prejudice*

*Tick box 1 I agree that the person who I provide care for(for whom I provide care??) may take part in this study.*

#### *VERSION 0.3 Main text – general comments*

*Sounds a jolly useful idea. At times I found the language heavy-going (especially the explanation of methodology) and it needs a fair bit of proof-reading but that's not my job...*

*Gaining informed consent (p18) – not sure whether inability to repeat the details is valid? (They have memory problems, dammit) and in general I am uneasy at the ease with which the person with memory problems is left out of the equation.*

*5 hours stints – but on p20 it says sessions will take 'between 2 -6 hours each' – clarify?*

*Will these be planned to cover the hours of day (and night?) fully?*

*Please outline the dementia training and experience of the researcher. Would advice from NSFT dementia trainers be valuable here?*

*Hope this helps – good luck!*

*REVIEWER 2: My main concerns about this research include:*

*a) The bracketing together of all the various forms of assistive technology. It is not spelt out in the proposal which technologies are to be tested. I think it would be preferable to concentrate on one, or at most two, forms of the technology only. I suspect that this would produce more specific and useful information. There are two strands to this investigation (1) the practicality of the proffered technology and (2) the mental barriers to its uptake. I suspect that attempting to cover several forms of assistive technology whilst using just 7 pairs of patients and carer is not going to produce any useful data.*

*b) The small numbers of pairs of patient and carer is a problem. I understand that the numbers will be limited by subject availability, but, by the time the 'drop outs' are factored in, the sample could become very small indeed. Has the likely dropout rate been assessed?*

*General points*

*Reading this proposal has been confusing for me because the person carrying out the research is sometimes referred to as 'the researcher' and sometimes referred to as 'me' or 'my' or 'I'. It was not until I reached the end of the proposal that I realised these terms referred to the same person. This added to my confusion in commenting on this proposal.*

*There is a lot of repetition of the theoretical justification for the project. If this were brought together into one section it would greatly add to the clarity of the proposal, and I suspect reduce repetition.*

*There is too much detail given about the practical details to be undertaken by me/I/the researcher. Is it needed to describe car hire etc.? It left me wondering whether the long 5 hour sessions proposed for each visit were designed around the details of car hire rather than around the needs of the project? (On page 20 the length of session is stated as between 22 and 6 hours. This is inconsistent with a statement elsewhere that the maximum session will be 5 hours.)*

*Page 26 states that "It is unlikely that there will be any additional stress or trauma caused by participation in this study." I think that for many people with dementia the presence of a stranger and the disruption of routine in itself may cause stress.*

*I hope that these comments are of some help.*

*REVIEWER 3: No. Don't feel that this research is cost effective. No guarantee that the equipment installed with patient will ever be used.*

*The timing of the interviews is spread too far apart and also the length of the interviews suggested far too long and stressful for patient.*



# Appendix VI: Processes for ensuring trustworthiness

## Trustworthiness

The quality of qualitative research is determined by different criteria than the more quantitative requirements of validity, reliability and objectivity, because qualitative research cannot use statistical significance as signs of rigorous engagement with a research question. Trustworthiness is a more common approach to determining quality by reflecting and critiquing four concepts – credibility, transferability, dependability, and confirmability (Guba 1981; Guba and Lincoln 1994).

### Credibility (internal validity)

Credibility is used to provide assurance that the data and analyses reflect the social reality of the specific research context. In this study, credibility was addressed by prolonged engagement with participants during fieldwork, and critical discussions with supervisors (FP, CF) to challenge the researcher's (ML) interpretations and themes during analysis.

### Transferability (external validity)

Transferability is a reflection point where the data and analyses provided by qualitative research must be assessed for its ability to apply to other social contexts and/or the same context within a different time. Transferability will be addressed in this study by the use of a research diary and field journal to record decisions made by the researcher (ML) and by the use of rich descriptions of the social context in which the research takes place in order to challenge its applicability to other milieux.

### Dependability (reliability)

Dependability is a tenet which requires qualitative researchers to adopt an approach which allows researchers to audit and challenge the findings of the study. In order to address dependability, the researcher (ML) will keep the transcribed conversations and fieldnotes for ten years for retrospective audit. Transparency with the data collection, data analysis, and dissemination of results will also allow other researchers to challenge the researcher's (ML) interpretations.

### Confirmability (objectivity)

Confirmability is concerned with making transparent the researcher's (ML) education level, gender, ethnicity, class, nationality, disabled status and professional positions in order to address potential biases and standpoints that the researcher (ML) may have. Confirmability was addressed by the use of a reflective journal to record and question my own preconceptions about my experiences throughout the whole of the research process (planning, fieldwork, analysis, dissemination). Direct

quotes from participants will be used whenever possible to illustrate and ground my own interpretations during the dissemination of my findings.

# Appendix VII: Examples of coded fieldnotes

Fieldnote extract from September 2015 visit to Arthur Clyde's house

Actors: Mark Clyde (carer), Catherine Clyde (carer), Mr [Arthur] Clyde (person with dementia) and Matthew Lariviere (researcher)

Setting: Sitting room

Approx. 2:20 pm

Coding legend:

Domain: Care; Instance: Care as concern

Domain: Home and the community; Instance: Reconfiguring rooms in the home

'I have something for you.' Mark left the room and returned with a paper in his hand. He handed it to me. It was a phone bill with four pages that detailed all of the charges that the line had incurred for the month. It totalled to just over £72. I looked at who kept on calling - it was listed as a service provider. 'This is how often this sensor goes off. Every time there is a 30p connection fee and it costs £5 per minute. His phone bill has doubled since he got this sensor.' Mark explained that despite its apparent sensitivity that 'he had a fall before the last [24 week] visit [for ATTILA] where he 'fell down four or five stairs' in the home. The device had not 'gone off'. 'Yet when I stubbed my big toe on the wall one time, the alarm went off!' Mark told me that that he had 'different expectations' for the device. When the alarm is activated it calls his father's home, but his father does not always respond due to not being able to hear the incoming call from the service provider. 'He doesn't pick up the phone because he can't hear it and the phone is even louder than the alarm. Next, they call me to see if I am with my dad because his sensor has activated on his falls detector. They [the service provider] don't check though.' 'They must send somebody over,' I suggested. 'No, they go through all four contacts first to see if one of them can go over. What am I paying for?' 'You should have started a business that phones emergency contacts!' Catherine exclaimed wryly. 'I would be rich!' Catherine, Mark, and I laughed. Mr Clyde did not respond. 'It costs £60 to install it {falls sensors] and all it does is contact a centre down the road which then calls me to check on my dad - even in the middle of the night. Why do I need them? Just link it to my iPhone!' Mark exclaimed throwing his arms up in incredulity. He let out a short laugh and shook his head. There was a pause in conversation. Mark broke the silence, 'I had a key safe installed after too for them to check in on dad but they always call me instead.'

He 'blamed' the health professional but 'not you' [me] for the products. He trusted the health professional because 'she is there to help look after him [pointed at Arthur].' However, he could not believe how 'useless' the device was when the one time that his father fell it failed to go off. He

mentioned a previous product called 'HEARS' that his dad used to have. He explained that it was 'cheaper' and that they would come over and check on his dad rather than just calling him.

Catherine and Mark explained that they couldn't believe they didn't ask for their name and relationship to Mr Clyde when the alarm goes off. 'I could be a burglar and my dad could be under the stairs. They never ask to speak with him. They always just take my word that he is fine.' They chose the new device because the health professional recommended it.

As I got up to leave, Arthur's dog immediately took my seat. Catherine explained that the place where I had sat was 'Spot's seat'. 'I usually sleep on the sofa and she will lay down right at my feet,' Mr Clyde demonstrated by shifting onto his side approximating his sleeping position with legs still hanging off of the sofa.

Fieldnote extract from December 2015 visit to Rose's house

Actors: Rose (person with dementia), Betty (carer) and Matthew Lariviere (researcher)

Setting: Sitting room in the rear of Rose's bungalow

Approx. 11:00 – 11:30 am

Coding legend:

Domain: Memory problems; Instance: Misremembering

Domain: Care; Instance: Concern

Domain: Home and the community; Instance: N/A

Betty: 'I will fill it out. You just need to sign it, 'Love, Rose'.' Betty explained to Rose as she passed her a Christmas card with a robin covered with glitter on it. 'I'll write out the addresses.'

Betty grabbed the envelope from the pile and placed it on the white, plastic cutting board on her lap. She picked up a pen from the settee cushion to her left. Next she looked at Rose's address book and copied the address from inside of it.

Betty: 'This is for Sarah and Andrew. Do you remember them?' Betty looked up from the envelope toward Rose.

Rose slowly turned her head toward Betty.

Rose: 'No.'

Betty: 'Sarah and Andrew from Market Town? You don't remember them?' Betty asked once again, her voice becoming gentler. Silence.

I looked up from my jottings to find Rose staring at me. I returned her eye contact. Next she tilted her head and pulled a face at me. We both smiled.

Betty: 'No, then?' Betty persisted.

Betty stood up and walked to the opposite side of the room. She stood in front of a large bookshelf that took up the whole wall. She pointed at a photograph on the top-centre shelf.

Betty: 'This is Andrew and Sarah. Sarah is Carol, your niece's daughter, that would make her your...'  
Betty paused and looked at me.

Rose: 'Great-niece?'

Matthew Lariviere: 'Yes, great-niece.' I agreed.

Rose: 'Oh yes, Sarah,' Rose nodded her head.

Betty: 'Andrew is Sarah's husband. I think that he is pastor in the church or something,' Betty suggested.

Rose: 'I don't know. (10) I thought Sarah lived in East Village.'

Betty: 'No. She hasn't lived there for years. Since 2010?'

Rose did not respond. Betty walked back over to the settee and sat down.

Betty: 'Have you written, 'Love, Rose' yet?' Betty asked as she closer to Rose in her chair.

Rose: 'No.'

Betty: 'Well, go ahead.'

Rose picked up a ballpoint pen on the wood and metal desk in front of her and wrote something inside the card. She handed the card to Betty who, then, placed it in the addressed envelope and folded the flap into it.

Fieldnote extract from February 2016 visit to Mrs Archer's sheltered housing flat

Actors: Mrs Archer (person with dementia), Anthony (carer) and Matthew Lariviere (researcher)

Setting: Sitting room in the rear of Rose's bungalow

Approx. 2:30 – 2:50 pm

Coding legend:

Domain: Memory problems; Instance: Forgetting

Domain: Care; Instance: Concern

Domain: Home and the community; Instance: Abandoning rooms in the home

Anthony: 'Do you want to see it?' he asked me.

ML: 'The fire?'

A: 'Where it happened.'

He used his walking stick to stand up from the table in the sitting room. He motioned me to follow him into the kitchen. It only took a couple of steps, then we were inside Mrs Archer's small kitchen. I looked at the oven first at the entryway. There was no damage nor signs of fire. Anthony walked over to the left side of the kitchen. My gaze traced his movements.

A: 'Here.'

Anthony moved to in front of the sink for me to get a better view. Next to the cooker was a worktop that ran down the length of the left half of the kitchen. **On the far left side of the worktop and next to the sink, there was a round crater in the worktop. The outer edges were amber that darkened to brown to black as I gazed toward the middle. The walls and cupboards above the worktop were charred and smoke-damaged. The air still smelt acrid.**

ML: 'Wow. What happened? Why was the fire on the worktop?'

Anthony did not answer immediately me. He motioned for me to follow him back to the sitting room where Mrs Archer still sat on the couch. We took our seats at the table once again.

Anthony explained that Mrs Archer was cooking something last night when her 'fourteen year old granddaughter' visited. They both 'fell asleep' watching 'telly' though. The granddaughter woke up to 'smoke' coming from the kitchen. She went to the kitchen and moved the 'pan' from the cooker to the worktop, then she went back to sleep. They both slept until the smoke alarm went off because the walls and cupboards were on fire. The fire brigade came over and put on the fire.

Mrs Archer: 'That's not what I said. I was sleeping the whole time.' She moved forward from her slumped back position on the couch until her arms were on the table. '[The granddaughter] fried chicken by herself. She fell asleep again. When she woke again, she took the pan off of the cooker.'

A: 'So you were sleeping until the alarm?' he asked Mrs Archer. **\*\*Potential confusion in narrative from forgetting?\*\*\***

Mrs Archer nodded. **Anthony asked why the granddaughter was cooking by herself.** Mrs Archer did not respond.

Fieldnote extract from April 2016 visit to the Campbells' house

Actors: Lillian Campbell (person with dementia), Kenneth Campbell (carer) and Matthew Lariviere (researcher)

Setting: Sitting room on the ground floor of the rear of Campbells' home

Approx. 2:20 – 2:40 pm

Coding legend:

Domain: Memory problems; Instance: Forgetting

Domain: Care; Instance: Surveillance

Domain: Home and the community; Instance: Reconfiguring rooms in the home

Light came in from a single window in the far side of the room. Kenneth never turned on the light. The space was cluttered with litter – empty bottles of fizzy drink, food wrappers, old newspapers and other things that I could not identify in the faint lighting.

He brought me over to a flat screen television situated against the wall adjacent to where we came. He sat down at an office chair perpendicular to the television where one might expect a desk was a grey, metallic book shelf. Monitors were displayed on a screen at his eye level. He explained to me this was the CCTV system that he installed about a year ago. There was one old CRT monitor that was divided into quarters like a Cartesian plane. Each of the four parts was streaming footage. He told me that he had one above the front door, so he could make sure no one stole his car. He picked up a small, plastic box with a joystick fixed atop it.

Kenneth Campbell: 'I can see what else is going on on the street too.'

He explained that he had one camera downstairs in the corridor just above the step down to the downstairs sitting room facing the front door.

Kenneth Campbell: 'This gives me a clear view of my mum's bedroom door, the door to the bathroom and the laundry room so I can see if she tries to get up.'

The third screen displayed the downstairs sitting room and kitchen. The fourth screen was black. Kenneth explained that he did not have any reason for a fourth camera yet. He was not sure where

he would place it. He told me that these three cameras were always on and could record if he wanted them to do so. On a lower shelf, there was another screen that was black.

Matthew Lariviere: 'What's that?' I asked.

Kenneth Campbell: 'This is for a camera in my mum's bedroom. It can't record anything and I usually keep it off. However, if I hear a bang downstairs then I can switch it on and see if she fell or what not. If I see she is fine, then I don't have to bother her. I'll show you.'

He flipped on a switch just below the black screen. The video was black in white compared to the colour images of the other cameras. Lillian was sitting up in bed. Her arms stretched out before her with palms facing down. She began to move her arms back and forth over her patterned duvet. 'What's she up to?' he wondered aloud before turning off the screen.

# Appendix VIII: Presentation conventions for fieldnotes and conversations

## Conversations

Conversations quoted fully, *verbatim*, are represented as standard interview conversations. They also begin with an expository commentary indicating who is participating in the conversation, where the conversation is taking place, and the analytical relevance of the selected conversation. Analytical commentary is provided after the selected conversation in non-italicised text aligned with the main body of text of this thesis.

## Maps

Maps of the homes of people with dementia illustrate where movement and interactions described in fieldnotes or conversations took place. An accompanying legend identifies each object and person on the map. Maps are always located on a separate page from the main text of the chapter. Text from the preceding or succeeding page will link to the content of the map. Maps are labelled with the month of the visit and the name of the person who lives there.

## Transcription notation

The following three chapters (Chapters 5-7) include excerpts from selected fieldnotes and conversations. When conversations occurred whilst I participated in another activity, then I rarely had the opportunity to write down more than what I identified as a few keywords that helped clarify the ongoing practice. In this instance, you may see some words in the selected fieldnotes in inverted commas, e.g. “. Inverted commas indicate that these are words spoken *verbatim* by a participant or myself during a particular event. Although my use of inverted commas may appear inconsequential, it offers analytical or methodological insight into the chosen practice from my fieldnotes. If I was busy *doing* an activity with a participant such as following them around the house as they prepared meals and ate, then I argue this demonstrates a specific level of trust developed with a participant. They are inviting me to follow or help out rather than just observe. They are inviting me to participate in their everyday lives. However, most of the participants never invited me to take part in everyday activities. No matter how many times I explained the role of my research as an opportunity to spend time with them to observe their everyday activities and how they used assistive technologies and/or telecare, I spent most of my time sitting with both the informal carer and the person with dementia talking about a wide-range of different topics. Informal carers always spoke more often than the person they cared for in these interactions. These interactions were more like informal interviews where participants discussed topics that were meaningful to them. Therefore, I am adopting some standard interview notation techniques for representing these conversations:

- Brackets without letters or other punctuation indicates a pause. Significant pauses indicate the time elapsed in seconds. E.g. ( ); (23).
  - Square brackets with an ellipsis enclosed indicates that words were omitted from the text either because they were unintelligible so I could not transcribe them or that I purposefully removed them for brevity. E.g. [...]
  - Square brackets with letters or words enclosed indicates that I added words in order to anonymise details or add non-verbal behaviours. E.g. I went to [my local shop]; [He laughed].
  - Lines always start with the speaker's name. For longer excerpts, the name is reduced to initials during future turns in the conversation. All names are pseudonyms which I have selected. E.g. John Stewart; JS.
- ML indicates I am speaking as the fieldworker in the conversation.

Appendix IX: Pictures of indicative  
assistive technologies from  
ethnographic cases

Figure 9. Electronic calendar-clock, a similar model to the one located in the home of the Stewarts and Violet Draper.



*Figure 10. Door alarm, a similar model as those located in the homes of the Campbells and Christopher Smith.*



*Figure 11. JustChecking, an activity monitoring system, the same model as located in Christopher Smith's home.*



*Figure 12. Bed occupancy sensor, a similar model as the one located in the Campbells' home.*



Figure 13. Automatic cooker shut-off device, a similar model as one located in Mrs Archer's home.



Figure 14. Buddi, a GPS tracking system, the same model as the one William Anansi wore.

