Carers' Experience of Assistive Technology use in Dementia care

A thesis submitted in Trinity Term 2021 to the University of Oxford in partial fulfilment of the requirements for the degree of

Doctor of Philosophy



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Carers' Experience of Assistive Technology use in Dementia care

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Abstract:

Introduction:

Assistive technology such as motion detectors, tablet computers, and wearable sensors has the potential to support persons with dementia and their carers. This study investigated the experiences and impact of assistive technology on carers (family, friends and neighbours) who support persons with dementia living at home in the United Kingdom.

Methods:

Multiple methods were used in this study. Study 1: A systematic review of carers' experiences of assistive technology use in dementia care. Study 2: Exploratory interviews to identify the support carers need and how carers use assistive technology. Study 3: Cognitive interviews to develop the carers' assistive technology experience questionnaire and using this in a sequential explanatory mixed-method study, through a cross-sectional survey (quantitative phase), to identify types of assistive technology carers use and prefer and the benefits and disadvantages of using AT. Study 4: Explanatory interviews (qualitative phase) to describe the experiences and impact of assistive technology on carers.

Results:

Fifty-six studies were included in the systematic review and found a variety of assistive technologies. Twenty-three participants in the exploratory interviews and 201 participants in the cross-sectional survey confirmed assistive technology was predominantly used for safety and reassurance, followed by communication and reminders. Assistive technology is seen as an adjunct to providing care and carers perceived it as helping manage their stress and anxiety. Explanatory interviews with twenty-three participants showed that carers had predominantly positive experiences of using assistive technology and it often required adjustments to the role of carers and supported their wellbeing.

Conclusion:

Assistive technology development and its continued use should incorporate carers and match the needs of the person requiring it. This study demonstrated that assistive technology has a beneficial impact on carers and could be one way of supporting carers and ensuring people with dementia continue to live at home.

List of Abbreviations:

Abbreviation	Definition
ADL	Activities of Daily Living
AT	Assistive Technology
CATEQ	Carers' Assistive Technology Experience Questionnaire
CI	Confidence Interval
CJ	Professor Crispin Jenkinson
MCS	Mental Component Score from SF-12 version 1
MMAT	Mixed-Methods Appraisal Tool
MP	Associate Professor Michele Peters
NHS	National Health Service
NIHR	National Institute for Health Research
OxDARE	Oxford Dementia and Ageing Research
PCS	Physical Component Score from SF-12 version 1
PDSA cycles	Plan-Do-Study-Act cycles
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT	Randomised Controlled Trial
SD	Standard Deviation
SF-12	Short Form Survey Version 1
SPSS	Statistical Package for the Social Sciences
UK	United Kingdom
VS	Vimal Sriram
WHO	World Health Organisation

Publications and presentations:

The work presented in this thesis has been published and presented previously.

Peer-reviewed publications:

1. **Sriram V**, Jenkinson C, Peters M. Informal carers' experience and outcomes of assistive technology use in dementia care in the community: a systematic review protocol. Syst Rev. 2019;8:158. doi:10.1186/s13643-019-1081-x.

2. **Sriram V**, Jenkinson C, Peters M. Informal carers' experience of assistive technology use in dementia care at home: a systematic review. BMC Geriatr. 2019;19:160. doi:10.1186/s12877-019-1169-0.

3. **Sriram V**, Jenkinson C, Peters M. Carers' experience of using assistive technology for dementia care at home: a qualitative study. BMJ Open. 2020;10:e034460.

4. **Sriram V**, Jenkinson C, Peters M. Using rapid cycle tests of change to develop the Carers Assistive Technology Experience Questionnaire: a cognitive interview study in the UK. BMJ Open. 2021;11:e042361. doi:10.1136/bmjopen-2020-042361.

5. **Sriram V**, Jenkinson C, Peters M. Carers' experiences of assistive technology use in dementia care: a cross sectional survey. BMC Geriatr 2021 211. 2021;21:1–12. doi:10.1186/S12877-021-02417-1.

6. **Sriram V**, Jenkinson C, Peters M. Impact of COVID-19 restrictions on carers of persons with dementia in the UK: a qualitative study. Age Ageing. 2021;1. doi:10.1093/AGEING/AFAB156.

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2. **Sriram V**, Jenkinson C, Peters M. Better care through technology? Informal carers' experiences of assistive technology use in dementia: Poster. In: Alzheimer's Society International Annual Conference 2020. London: Alzheimer's Society, UK; 2020.

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2. **Sriram V**, Jenkinson C, Peters M. Better care through technology? Informal carers' experiences of assistive technology use in dementia - 5x5 presentation. In: Council for Allied Health Professions Research Conference. Oxford, UK; 2020.

3. **Sriram V**, Jenkinson C, Peters M. Impact of Covid-19 restrictions on carers of persons with dementia in the UK - A qualitative study. In: Nuffield Department of Population Health Symposium. Oxford, UK; 2021.

4. **Sriram V**, Jenkinson C, Peters M. Research Impacts and Contemporary Problems: Impact

of Covid-19 restrictions on carers of persons with dementia in the UK - A qualitative study.

In: Kellogg College Graduate Research Symposium. Oxford, UK; 2021.

Chapter 1 : Overview of the research

1.1 Introduction:

The world's older population is estimated to be nearly 900 million people [1]. Life expectancy from age 60 continues to increase globally [2]. Driven by this rapid population ageing there are an estimated 44 million people worldwide who are living with dementia, and this number is predicted to nearly double every 20 years [3]. Under the leadership of the UK, the G8 Dementia Summit held in London in December, 2013, committed to a global response to dementia and to identify a cure or a disease-modifying therapy by 2025 [4]. Dementia, perhaps more than any other disease, deeply affects the lives of not only those diagnosed with the condition, but also their families. Caring for a person with dementia has physical, emotional, social and economic costs for informal carers such as families, friends and neighbours [5]. Increased amount of time spent caring for a person with dementia may result in loss of spare time and consequent social isolation of family carers. Informal carers may restrict time spent with their own friends and family or change employment practices, which has led to suggestions that caring for a person with dementia is stressful [6].

Caring for a person with dementia is not a static process, as there is currently no cure for dementia and it is progressive. The trajectory of progress is uncertain, and family carers are faced with the complexity of not knowing how quickly the dementia will progress and it is vital to support these carers in their experiences of providing care. The quest for new drugs and a cure for dementia must not detract from improving the care and quality of life of persons with dementia and those who look after them. The World Health Organisation (WHO) found that there is a lack of awareness and understanding of dementia globally, which results in stigmatisation, barriers to diagnosis and care, and impacting families and society - physically, psychologically, and economically. The WHO decided that dementia can

no longer be neglected and in 2012 declared it a public health priority [7]. The total estimated global costs of dementia were US$ 604 billion in 2010 and set to increase to over a $1trillion by 2025 [8]. The WHO recognised that most care in dementia is offered by family and informal support systems and provides a valuable approach to tackling dementia worldwide by including support for informal carers, awareness raising and advocacy, innovative use of advances in technology, including assistive technology devices and making support context-specific and culturally relevant [7].

1.2 Patient and public engagement and involvement:

When developing research, it is important to understand patients' and family carers' needs - to ensure that it is in the best interests of the population group under study [9]. It is suggested that the quality, relevance and impact of research will be improved by involving the end recipients of a research study in shaping and contributing to the research process.

For this reason, in 2018, people who each support/care for a person with dementia were invited (Appendix 1) to act as advisors on this research study. For the purposes of the study, a carer was defined as a family member, friend or neighbour who helped with tasks like regular shopping, housework, washing and dressing, going out, managing finances, keeping appointments or providing emotional support for a person with dementia.

Following a recruitment exercise, with adverts placed through the National Institute of Health Research (NIHR) People in Research website - for family and friends of persons with dementia to join the research advisory group - three carers of a person with dementia and one person with dementia joined the research advisory group. All the research advisory group members lived in England (London, Hull or Birmingham). While one of the carer

members left the advisory group for personal reasons, three members stayed on and participated in the research process throughout.

The research advisory group:

- supported development of research materials and tools (the survey questionnaire, draft interview topic guide etc.,);
- assisted with research study recruitment by sharing adverts with their wider networks;
- supported the interpretation of study findings;
- assisted with the dissemination of research findings.

In exchange for their time and commitment, research advisory group members were informed that they could be expected to gain:

- more information about this study and its impact on others in a similar situation;
- learning about why research matters and an opportunity to influence research;
- an insight into how health care research is carried out;
- new skills;
- satisfaction of contributing and helping to improve research and future services for carers and persons with dementia.

The research advisory group had planned to meet twice a year in face-to-face meetings in Oxford. However, after an initial face-to-face meeting, due to travel arrangements, other time commitments for the group members and in 2020, the restrictions because of the COVID-19 pandemic - the group met virtually through web-based meetings and through the exchange of emails.

This research advisory group, as part of the study, supported interpretation of the findings from the systematic review, reviewed the interview topic guide for the first set of qualitative interviews, gave feedback on the first and final drafts of the Carers' Assistive Technology Experience Questionnaire used in a survey, and reviewed the interview topic guide for the explanatory interviews following the survey. The group also supported recruitment of participants for the survey by sharing the anonymous survey link to their wider dementia specific networks.

1.3 Carers of persons with dementia:

Carers are people who look after a relative, partner or friend who needs support because of age, physical or learning disability or illness. This 'looking after' can be through active physical support, supervision, social interaction or supporting activities such as shopping, banking, laundry, assisting with medication etc. Although the phrase 'informal carer' is often used, the looking after and caring provided by informal carers could be 'formal' in everything but the receipt of pay, and many carers feel that they have had little choice in taking on their role [10]. Indeed, it is possible for some informal carers in the UK to receive some form of financial remuneration (carer's allowance) through direct payments [11] for looking after a person who requires their support and help. In discussion with the research advisory group and using the Alzheimer's society positive language guide to talking about dementia [12], throughout this thesis, the term **carer** is used to refer to people who provide unpaid care, such as a partner, spouse, family member, friend or neighbour. For this study, family carers who received a carer's allowance were considered a carer. Professional and paid carers are referred to as healthcare professional, care worker or formal carers.

1.4 Ethical approval and consent:

This research study included interactions with carers of persons with dementia and therefore it was appropriate to seek ethics approval. As the carers were not identified by virtue of their involvement with the National Health Service (NHS), it was appropriate to apply for ethics approval from the Central University Research Ethics Committee at the University of Oxford. Ethics approval was sought for the entirety of the study to be completed in multiple phases – including exploratory interviews, a cross-sectional survey through a questionnaire for the quantitative phase of the mixed-methods study and explanatory interviews for the qualitative phase of the mixed-methods study. Ethics approval [R57703/RE001] was granted (Appendix 2) for a period of 34 months, commencing on 1st August 2018 based on submitted documents including participant information sheets, information on recruitment databases, participant recruitment adverts and consent forms. When the Carers' Assistive Technology Experience Questionnaire was finalised, an ethical amendment request was made and granted in February 2020 [R57703/RE002], to use the questionnaire in the cross-sectional survey.

One of the ethical considerations for this research study was the possibility that a participant could become distressed during an interview. Plans were made (Appendix 3) to support a participant if they become distressed. Participants were informed that the interviewer would stop the interview and not re-start the interview unless the participant consented. If the participant did not feel able or want to re-start the interview, the interviewer would ask if the participant was happy for the data collected so far to be used. The participant could agree to its use or ask the researcher to delete it entirely. In addition, the researcher had a list and contact details of local and national charities (Appendix 4) that

provide further information and support to carers, that could be given to the participants. The participants were also encouraged to contact their General Practitioner, should they need further assistance.

Informed consent was obtained from participants in the research study at the time of qualitative interviews using a consent form with reference to the participant information sheet. For the survey, a consent question was included at the start of the questionnaire and informed consent was required for online respondents to continue with the survey. Postal versions of the questionnaire included the consent question as part of the paper questionnaire and, in addition, participants were instructed to not send back the questionnaire if they did not consent to participating in the survey. For the explanatory interviews (conducted in 2020), due to the restrictions from the COVID-19 pandemic, consent forms were sent by pre-paid post to participants, arrangements for the telephone interviews were made only after receiving the signed consent forms.

1.5 Recruitment databases:

Participants for the exploratory qualitative interviews and the survey phase of the mixed-methods study were recruited mainly through two website-based databases.

1. *Join Dementia Research* [13] is a service delivered in partnership with the NIHR, Alzheimer's Scotland, Alzheimer's Research UK and Alzheimer's Society. This service enables people wishing to volunteer for dementia related research to register an interest to be matched with suitable research studies. Volunteers, including persons with dementia, their carers and members of the public willing to be participants in dementia related research can register on the service by answering a few basic questions in an online form. Volunteers are then matched to studies based on inclusion and exclusion criteria, submitted by research

investigators. Only studies approved by an ethics committee are included in the service and only the *Join Dementia Research* service approved researchers, NHS staff and the charity helplines registered to use *Join Dementia Research* will be able to see volunteer information. After signing up to *Join Dementia Researc*h, volunteers are given the opportunity to see which local studies match their health information and preferences. Then, on a case-by-case basis, volunteers can choose which studies to take part in. At the time of this research study, *Join Dementia Research* database had more than 48,000 registered volunteers from across the UK.

2. *Oxford Dementia and Ageing Research* (*OxDARE*) [14], is a database that engages the local community in Oxfordshire in educational events and research opportunities in dementia. The *OxDARE* database is hosted through the University of Oxford's Department of Psychiatry and the NIHR Oxford Health Biomedical Research Centre and works closely with Alzheimer's Research UK Thames Valley, the Oxford Brain Health Clinical Trials Unit and the Drug Discovery Alliance in relation to research and public engagement. A lay summary of the research project is circulated by the *OxDARE* team administrator to volunteer cohorts, who have agreed to be contacted and if they are interested, they indicate an acceptance to be contacted by the researcher on the database, following which the researcher can make contact providing further information about the research project and seeking consent for participation. At the time of this research study, the *OxDARE* database had more than 6,000 registered volunteers.

1.6 Risk management and data security:

The key concerns in this study were maintenance of confidentiality, anonymity, and lone working. Personal data (e.g., names, telephone numbers and addresses) were collected

from participants to arrange interviews and (where necessary) for the postal survey. Personal data was only collected as required for the purposes of the research.

Signed consent forms were transported in a locked case from participants' homes and stored securely in a locked cabinet in the researcher's office at the Nuffield Department of Population Health, University of Oxford. These forms were held separately from any interview data or personal participant data in accordance with the University of Oxford's data management policy.

Interviews were recorded using a digital voice recorder device with an in-built 256-bit encryption algorithm. Upon completion of the exploratory interviews, the recordings were transferred onto a secure research study folder on a university computer as an encrypted file and the original interview recordings were deleted from the recorder. The online survey was carried out using the Qualtrics survey tool [15], which is licenced for use for the Health Services Research Unit, Nuffield Department of Population Health, University of Oxford. The postal survey forms were stored in the researcher's office in a locked cabinet in the Nuffield Department of Population Health. At the time when the explanatory interviews were carried out in 2020, due to the restrictions on access and use of the University's computer systems and offices because of the COVID-19 pandemic, the consent forms addressed to the Nuffield Department of Population Health, were collected periodically from the department's reception, and stored in the researcher's office. The audio recordings of the telephone interviews were recorded on a digital voice recorder in an encrypted format and were uploaded to the secure University of Oxford's 'one drive cloud' folder of the researcher. The transcription services used for the interviews exchanged audio files and transcripts using a password secured access website.

For the interviews, participants were given the option to withdraw after the interview (in the days or weeks afterwards, before the interview data was anonymised and transcribed), with the assurance that the researcher would delete any data including personal information and interview recordings and that it would not be used in the analysis. All data analyses for this research project were carried out using licenced data analysis software: Covidence [16], SPSS version 26 [17] and NVivo version 12 [18].

As the researcher visited some of the participants in their own homes, the Lone Worker Policy and the Safety in Fieldwork Policy of the University of Oxford were followed.

1.7 Research aim:

Dementia is a health and care priority globally. Caring for persons with dementia is a challenge and often leads to negative psychological, physiological and financial consequences for carers. Advances in technology have the potential to assist persons with dementia and their carers, through assistive technology devices such as electronic medication dispensers, robotic devices, smart phones and motion detectors. However, little is known about carers' experience and the impact of these technologies on them. The research study described in this thesis addresses this gap.

The overarching aim of this research study is to:

Explore carers' experiences and the impact of assistive technology used in dementia.

The objectives are to:

- Review what types of assistive technology carers use and prefer
- Understand how carers use assistive technology
- Understand what support carers need to use assistive technology

- Explore the benefits and disadvantages of assistive technology use
- Explore the facilitators and barriers to using assistive technology
- Investigate the impact of assistive technology use on carer wellbeing

Further information on how the study was structured and specific methods used to achieve the objectives are described in the subsequent chapters.

1.8 Thesis structure:

This thesis consists of nine chapters.

Chapter 1: Overview of the research

This introductory chapter provides an overview of the research study including involvement of a patient and carers in the research advisory group, the databases used for recruitment, ethical considerations, data handling and the broad research aims and objectives of this research project. A synopsis of the thesis chapters is included.

Chapter 2: Background

This chapter discusses the context of this research study including an overview of dementia and providing care for a person with dementia living at home. The chapter provides a definition for assistive technology and examples of some commonly used assistive technology devices and what is known about assistive technology use in dementia care and the gaps in knowledge at the commencement of this study.

Chapter 3: Systematic Review

This chapter describes the search strategy, quality appraisal and analysis of findings from the systematic review carried out to investigate the types and uses of assistive technology in

dementia care, how do carers use it, what assistive technology do they prefer and what is known about the impact of assistive technology on carers of persons with dementia. The systematic review analysis included 56 publications and highlighted the need for further research into the experiences of carers and the impact of assistive technology on carers who look after a person with dementia at home. The themes from this systematic review informed the interview topic guide for the exploratory interviews.

Chapter 4: Exploration of carers' use of Assistive Technology in dementia care

This chapter describes an exploratory qualitative study of experiences of carers who are current users of assistive technology in the care of a person with dementia, and who are resident in the UK. Twenty-three carers were interviewed, and the themes and sub-themes provided information on how carers consider assistive technology as an adjunct to provide care for a person with dementia. The themes from the interviews informed the development of the Carers' Assistive Technology Experience Questionnaire (CATEQ).

Chapter 5: Carers' Assistive Technology Experience Questionnaire (CATEQ)

This chapter describes the process of developing the Carers' Assistive Technology Experience Questionnaire (CATEQ). Cognitive interviews were carried out with nine participants of carers of persons with dementia using seven rapid cycle tests of change as a framework, to reduce participant burden and resources expended in the pre-testing phase of survey questionnaire development.

Chapter 6: Cross-sectional survey of carers' experiences of assistive technology use in dementia care

This chapter sets out the method, results, and analysis of the cross-sectional survey (quantitative phase of the mixed-methods study) in which 201 participants completed the

CATEQ. A detailed description of the statistical procedures used and interpretation of the survey results on types and uses of assistive technology, the costs of assistive technology being used as well as the impact of assistive technology on carers of persons with dementia is described.

Chapter 7: Impact of assistive technology use on carers of persons with dementia

This chapter details the qualitative phase of the sequential explanatory mixed-methods study and provides additional context to the findings from the survey. The analysis from 23 survey participants enriches and deepens the understanding of a range of carers' experiences and the impact of assistive technology on physical, mental and social well-being of carers of persons with dementia.

Chapter 8: Discussion

This chapter discusses the themes emerging from the research study on carers' experiences of assistive technology use in dementia, alongside an appraisal of the research, lessons learnt and discussion on the strengths and limitations of various stages of this study.

Chapter 9: Conclusions

The final chapter includes concluding remarks on the overall findings of this research and discusses areas for future research as well as recommendations for carers, healthcare professionals, policy makers and assistive technology developers.

1.9 Summary:

This introductory chapter has highlighted how dementia is a public health priority. Important considerations of how carers are defined, ethics, patient and public involvement in this research study, sources for participant recruitment and data management issues

have been introduced. An overarching view of the thesis structure sets the scene for the next chapter which focuses on dementia, how carers support persons living with dementia at home and what is known about assistive technology and its use in dementia care.

Chapter 2 : Background

2.1 Introduction:

This chapter provides an overview of dementia and management of persons with dementia in the community. The chapter also details how carers provide support and care for persons with dementia and what is known about assistive technology use in dementia care. It then outlines the research phases in this study and links it with the research aims and objectives.

2.2 Dementia:

Dementia is defined under the International Classification of Diseases, 11th Revision [19] as

> '*An acquired brain syndrome characterised by a decline from a previous level of cognitive functioning with impairment in two or more cognitive domains (such as memory, executive functions, attention, language, social cognition and judgement, psychomotor speed, visuo-perceptual or visuospatial abilities)*'.

The cognitive impairment is not entirely attributable to normal ageing and significantly interferes with independence in the person's performance of activities of daily living. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation [20].

The WHO estimates that dementia is one of the major causes of disability and dependency among older people worldwide [7]. However, dementia does not exclusively affect older people, with young onset dementia (onset of symptoms before 65 years) accounting for up to 9% of dementia [7]. Alzheimer disease is the most common form of dementia and may contribute to 70–80% of cases [20, 21]. Other major forms include vascular dementia, dementia with Lewy bodies, a group of diseases that contribute to frontotemporal dementia, dementia due to Parkinson's disease, dementia due to Huntington disease, dementia due to certain specified infectious diseases such as Human Immunodeficiency

Virus or neurosyphilis and dementia due to mixed pathologies [19–21]. Dementia is experienced in different ways depending on the specific type of dementia diagnosed and an individual's past experiences and wider support systems available. Table 2-1 gives an overview of the common types of dementia and their characteristics [21].

Table 2-1 Common types of dementia and associated characteristics:

Type of dementia	Characteristics
Alzheimer's disease	Alzheimer's disease is the most common cause of dementia, accounting for an estimated 70% to 80% of cases. Difficulty remembering recent conversations, names or events, apathy and depression are often early symptoms. Later symptoms include impaired communication, disorientation, confusion, poor judgment, behavioural changes and, ultimately, difficulty speaking, swallowing and walking.
Vascular dementia	About 5% to 10% of individuals with dementia show evidence of vascular dementia. Cerebrovascular disease refers to the process by which blood vessels in the brain are damaged and/or brain tissue is injured from not receiving enough blood, oxygen or nutrients. People with dementia whose brains show evidence of cerebrovascular disease are said to have vascular dementia. Impaired judgment or impaired ability to make decisions, plan or organise may be the initial symptom, but memory may also be affected. In addition to changes in cognitive function, people with vascular dementia commonly have difficulty with motor function, especially slow gait and poor balance. The location, number and size of the brain injuries determine whether dementia will result and how the individual's thinking and physical functioning will be affected.

Type of dementia	Characteristics
Lewy body dementia	About 5% of individuals with dementia show evidence of Lewy body dementia alone, but most people also have Alzheimer's disease pathology. Dementia with Lewy bodies can result, when abnormal aggregations (or clumps) of the protein alpha-synuclein in neurons develop in a part of the brain called the cortex. The condition is named after Dr Friederich Lewy, a German neurologist who first documented the condition in 1912. Some of the symptoms are like Alzheimer's disease, but people are more likely to have initial or early symptoms of sleep disturbances, well-formed visual hallucinations, and visuospatial impairment. These symptoms may occur in the absence of significant memory impairment, but memory loss often occurs.
Fronto-Temporal dementia	In Fronto-Temporal dementia, nerve cells in the front (frontal lobe) and side regions (temporal lobes) of the brain are especially affected, and these regions become markedly shrunken. This dementia type also includes dementias such as behavioural-variant, primary progressive aphasia, Pick's disease, cortico-basal degeneration and progressive supranuclear palsy. Typical early symptoms include marked changes in personality and behaviour and/or difficulty with producing or comprehending language. Unlike Alzheimer's, memory is typically spared in the early stages of disease. Most people develop symptoms at a younger age, usually between the ages of 40 and 65.
Parkinson's disease dementia	Problems with movement (slowness, rigidity, tremor and changes in gait) are common symptoms. Cognitive symptoms develop either just before movement symptoms or later in the disease.

Type of dementia	Characteristics
Mixed dementia	When an individual shows the brain changes of more than one cause of dementia the person is said to have mixed dementia. The likelihood of having mixed dementia increases with age and is highest in people age 85 or older.
Wernicke-Korsakoff Syndrome	Werknicke-Korsakoff syndrome is a chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1). The most common cause is alcohol misuse. Wernicke's syndrome is characterised by confusion, inability to coordinate voluntary movement (ataxia), and eye abnormalities. Korsakoff's syndrome is characterised by disproportionate memory loss in relation to other mental aspects. When these two disorders occur together, the term Wernicke-Korsakoff syndrome is used. Symptoms include severe memory problems while other thinking and social skills seem relatively unaffected.

In 2015, dementia affected around 47 million people globally and this is predicted to increase to 75 million people living with dementia by 2030 and 132 million by 2050 [20]. Dementia is estimated to cost around US$ 818 billion currently and by 2030, it is estimated that the cost of caring for people with dementia worldwide will have risen to US$ 2 trillion [22]. This increased cost could undermine social and economic development across the world and is likely to overwhelm health and social services, especially long term care systems [1].

There is currently no treatment to cure dementia or to alter its progressive course and present goals for dementia care is focused on:

- early diagnosis to promote early and optimal management;

- optimising physical health, cognition, activity, and wellbeing;
- identifying and treating associated physical illness;
- detecting and treating challenging behavioural and psychological symptoms;
- providing information and long-term support to carers.

All these goals should be anchored in person-centred care to ensure people with dementia can take part in the things they enjoy and family as well as the person with dementia should always be involved in developing and delivering this care.

2.3 Living with dementia in the community:

Dementia has an impact on activities of daily living (ADL), which may involve difficulties in shopping, maintaining a home and personal care. In more advanced cases, dementia may lead to difficulties in mobility, toileting and language skills. Decreased mobility and reduced attention to personal care and diet, coupled with a lack of compliance with medical treatments could leave people with dementia more susceptible to other illnesses and cause challenges for continued living at home.

People live for many years after the onset of symptoms of dementia [20, 23]. With appropriate support, many can and should be enabled to continue to engage and contribute within society and have a good quality of life. People with dementia can benefit from their local community network and from being included in social activities [24]. Continued social participation can promote a sense of belonging, safety and contribution for people with dementia [25], this happens better when people with dementia live in their own homes as opposed to living in a residential or nursing care setting. Living at home brings with it a sense of security and freedom and persons with dementia will strive to live at home for as long as possible [26]. A change of routine and environment can be very daunting for

someone with dementia, and it may be better for them to stay in the place they know and love instead of in care homes. There is an increasing drive to support persons with dementia to live at home due, in part, to an ever increasing threshold for access to assistance from professional carers [27].

For persons with dementia to continue to live at home, they require additional support from their carers, formal support from healthcare professionals and social support from the wider community, including friends and neighbours. Many carers do not identify themselves as such until they have been caring for a number of years, and especially when caring for a person with dementia, the caring role develops gradually with additional support being provided as the condition of the person with dementia deteriorates.

2.4 Carers of persons with dementia:

It is estimated that globally carers provide 82 billion hours to people with dementia living at home, equating to more than 6 hours per day [28]. In the UK, there are around 700,000 carers providing care for the estimated 850,000 persons with dementia [29] and the value of time given by informal carers to persons with dementia has been estimated at approximately £12.4 billion a year [29, 30].

A significant number of people with caring responsibilities do not readily identify themselves as carers [31]. They see themselves mainly as a spouse, partner, child, relative, friend or neighbour. Many carers are relatives or extended family members, but close friends and neighbours can also take on responsibilities for caring. In the UK, 60 -70% of carers for people with dementia are women [32] and in 2018/2019, 30% of carers for people with dementia had been doing so for between 5 and 10 years and 22% for over 10 years [33]. In

addition, about 15% of carers of a person with dementia say they are not in work because of their caring responsibilities and around 39% of carers spend more than 100 hours per week caring for a person with dementia [34].

Providing care for a person with dementia can be emotionally rewarding because it can affirm family ties, respect past support the carer received from the person now needing care, and save family resources [35]. However, caring for a person with dementia can also be distressing for carers [36]. The nature of dementia leaves carers to cope with the strain induced by watching their loved one deteriorate. There is an increased risk of experiencing anxiety and stress among carers and this leads to a higher rate of mortality [23]. In addition, a large proportion (55%) of the cost of looking after a person with dementia is borne by carers [37].

Spousal carers could face challenges because they are more likely to be living with the person with dementia [38]. They also have little choice in taking on the caring role, are likely to be less aware of the effect that their caring tasks have on them and are further vulnerable because of their older age and associated morbidities. Children as carers might have to provide care and assistance to the person with dementia balancing this with looking after their own children and spouse. In addition, they could be faced with added stress and anxiety, especially if they live away from a person with dementia and are concerned about their safety and welfare. Carers are often untrained and seldom prepared for taking on caring tasks, especially when it involves tasks such as moving and handling, complex medication management issues, changing catheter bags, diapers, and wound care. Carers, in addition also act as the primary interface with the health and social care system, liaising on behalf of the person with dementia for professional care and support, facilitating hospital

appointments, approving, sourcing, and maintaining equipment and when needed organising and supporting formal carers.

The individual needs of persons with dementia and their carers can differ considerably because of a number of personal and contextual factors, including but not limited to issues such as the cognitive and behavioural changes seen in a person with dementia, living arrangements and geographical distance of carers from the person with dementia, characteristics of carers and the coping strategies they use, the relationship between the carer and the person with dementia, carers' own medical and psychological needs, the support systems available to the carer, including from professionals and support from other family members and the quality of support that is offered.

As explained earlier, national and international policy is now geared towards enabling people with dementia to live in their own homes for as long as possible and care homes are increasingly seen as a last resort option [39]. When persons with dementia have difficulty or are unable to perform tasks at home, they need intensive support to maintain independence and continue living at home. Since professional care is limited and expensive, this support invariably is provided by carers. This in turn results in increased responsibility on them and frequently leads to social isolation, increased physical burden and decreased mental wellbeing. Overburdening of the informal carer is the leading cause for institutionalisation of the person with dementia [40].

To support carers, help to reduce their burden and improve their confidence in caring, assistive technology is suggested as a potential solution [41–43]. The assistive technology could support persons with dementia to improve their independence and improving their

quality of life [44–46] and allow them to stay in their own homes safely for a longer period [47] and by extension could potentially help carers.

2.5 Assistive Technology:

Assistive technology (AT) can play a vital role in supporting persons with dementia. AT has been suggested as a means to support someone who has dementia and their carers to stay independent and remain in the community [48, 49]. AT also influences how health and social care services are currently delivered [50–52]. AT can be used to support a wide range of user needs for independence, such as devices that are supportive, responsive and preventative. There are various definitions for AT. For this research study, the definition of AT is based on the work done by the Royal Commission on Long Term Care [53] and is defined as:

> "*Any electronic item, piece of equipment, product or system that is used to increase, maintain or improve the functional capabilities and independence of people with cognitive, physical or communication difficulties*".

Examples of AT include devices such as pendant alarms, home monitors, bed/seat occupancy sensors, falls alarms, electric hoists, electric beds, GPS tracking devices, smart phones, tablet computers, computers/laptops, web cameras, motion sensors, wearable sensors, medication dispensers, alarms, stove timers, dementia clocks, web-based communication systems, virtual assistants and devices connected through them, such as Alexa/Siri/Google assistant.

Internet of Things (electronic devices connected together and communicating through the internet) enabled technologies, such as 'smart' sensors, artificial intelligence and the adoption of wireless networks like 5G present huge opportunities for innovative care

designs and integration with digital solutions such as ‘smart homes’ in the care of persons with dementia [54]. It is suggested that the use of AT for a person with dementia can give the following benefits [55]:

- promote independence and autonomy, both for the person with dementia and those around them;
- help manage potential risks in and outside the home;
- reduce admission into care homes and hospitals;
- facilitate memory, recall, and provide leisure and improve communication;
- reduce the stress on carers, improving their quality of life, and that of the person with dementia.

AT can help support some of the impacts of providing support and help by enabling carers to take a break, knowing they will be contacted immediately if they are needed. Web cam and video conferencing technology can help the person with dementia communicate with their loved ones and contribute to their social networks and communities. AT can thus facilitate independence for persons with dementia and reduce dependency on carers [35].

Carers can use AT to prompt and assist a person with dementia, even if they are not physically present at home and more importantly provide psychological reassurance that their loved one is safe at home. Independence and reassurance of safety can be one of the critical factors in carers deciding whether a person with dementia should move into long term care [56].

The relative success of using AT in care depends on a series of changes and adaptations such as changes to a person’s social and environmental spaces, changes made to everyday

routines and the AT itself. If AT devices are to work for individuals with dementia in everyday use, this is dependent upon both bricolage [57] –

> "*characterised by individuals adapting ATs in dynamic ways according to their lived experience and the needs emerging from them as the person and their carer experience the dementia journey*"

as well as the carer's ability to place AT within the 'arrangements' such as daily routines that constitute caring [26].

2.6 Gap in knowledge:

Carer burden – a term used to describe the cumulative physical, emotional, social and financial impact of providing care [58, 59], can predict institutionalisation of the person with dementia [56, 60]. Persons with dementia and their carers typically prefer for them to live at home for as long as possible, and consequently methods and processes to support carers in their role need to be established to delay institutionalisation and the associated costs, loss of independence and quality of life. Carer burden can affect their quality of life through decreased mental wellbeing caused by stress and worry, physical wellbeing and also the cost of reduced time for leisure activities and self-care [37]. Caring for a person with dementia is not a static process [61], yet there is no code or formal acknowledgement of carer wellbeing and burden in the International Classification of Diseases, 11th Revision [19]. The James Lind Alliance identified investigating "What are the most effective ways of supporting carers of people with dementia living at home?" as a Top 10 priority for research in dementia [62] and in particular - the factors that enable people with dementia to stay at home as long as possible and delay institutionalisation, maintain quality of life for people with dementia and carers, maintain physical and mental health for carers.

In the UK, a national strategy for carers [31, 63] acknowledges supporting carers and the Care Act [64] sets out requirements for assessment and support centred around carers' wellbeing. One suggested way of supporting persons with dementia at home is through the use of AT [56, 65–67]. AT potentially assists carers to address the increased level of responsibility whilst caring for a person with dementia [68, 69] and future generations will be more familiar with technology with people having lived their entire lives influenced by it [70].

Carers of persons with dementia are in the unique position of using their views regarding AT to suggest or even decide on the access and use of AT [71, 72], yet very little is known about the experiences of carers in using AT and what, if any, impact AT has on carers' wellbeing. This research study aims to fill this gap in knowledge and looks at how AT use influences caring for a person with dementia living at home from the perspective of carers.

2.7 Research structure:

The research aims and objectives for this study was investigated in phases using multiple research methods. This included a systematic literature review, exploratory qualitative interviews and creating a survey questionnaire using cognitive interviews. A mixed-methods approach was then used to complete a cross-sectional survey with carers, and interviews with some of the carers to explain the findings from the survey.

The various phases were structured as different studies within this research study and answered questions in line with the aims and objectives.

<u>Study 1:</u> What types of AT do carers use and prefer? How do carers use AT?

These questions were answered by conducting a systematic review with predefined criteria for inclusion of relevant studies, quality appraisal of these studies, combining results from the included studies and analysing and drawing conclusions from the themes of these studies.

Study 2: How do carers use AT? And what support do carers need to use AT?

These questions were answered by exploratory qualitative interviews with carers who use AT in the care and support of persons with dementia living at home.

Study 3 and 4: What type of AT do carers use and prefer? What are the benefits and disadvantages of AT? How does the use of AT impact on carer burden and wellbeing?

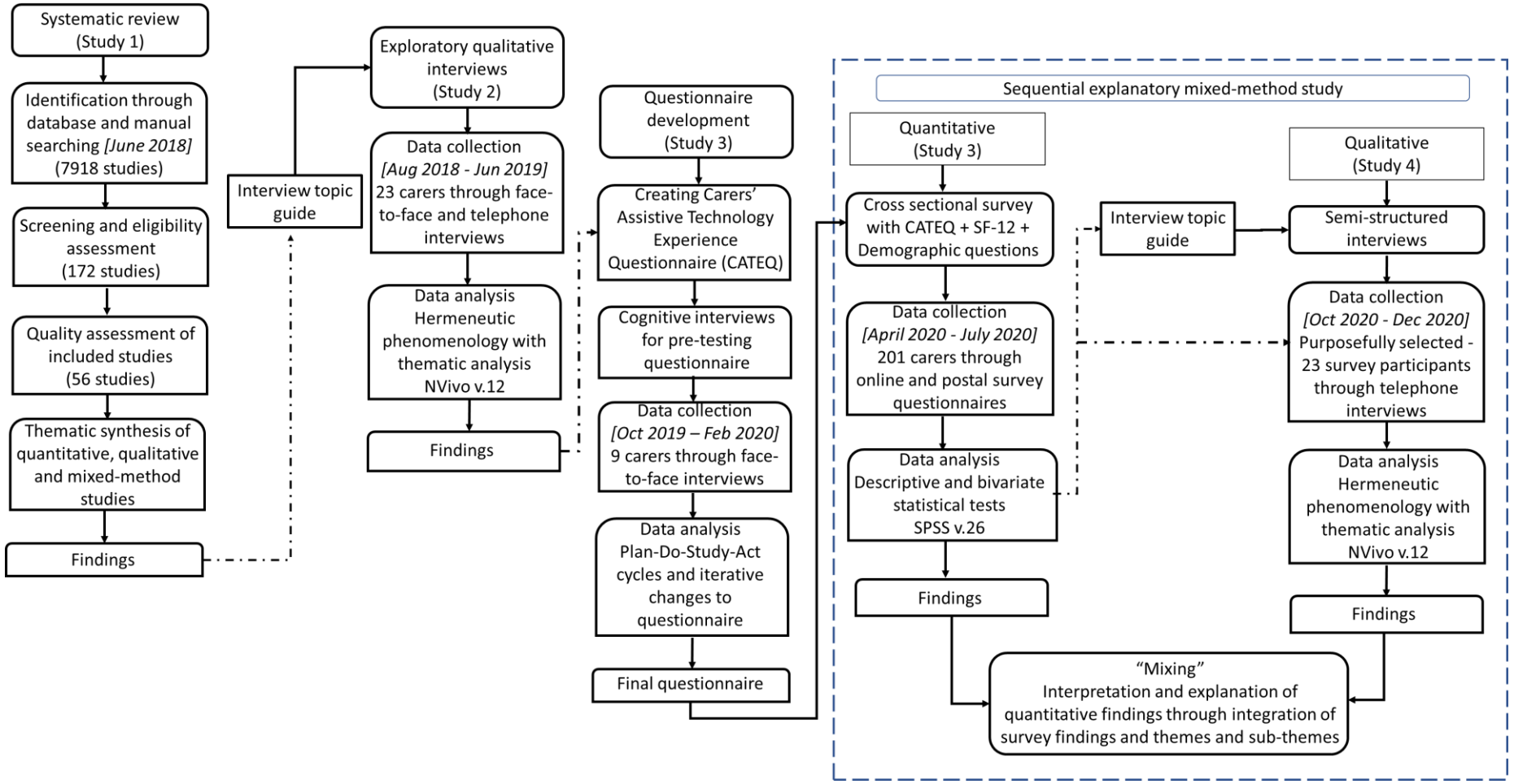
These questions were answered by creating a survey questionnaire, using themes from Study 1 and 2 and using cognitive interviews to finalise the questionnaire. A cross-sectional survey using the questionnaire - which was the quantitative phase of the sequential explanatory mixed-methods study - was then carried out amongst adult carers in the UK, who provided a minimum of 10 hours of care for a person with dementia and who had used at least one AT.

Study 4: What are the facilitators and/or barriers in using AT? What impact does AT have on carers whilst caring for a person with dementia?

These questions were answered using the qualitative phase of the sequential explanatory mixed-methods study. Results from the survey were used to inform additional questions and explanatory interviews were carried out with a sample of the survey participants to explain the impact of AT on carers.

Figure 2-1 gives a visual overview of the research structure for this study.

Figure 2-1 Research structure of carers' experience of AT use in dementia care study:



2.8 Summary:

This chapter provides background and context of dementia and carers of persons with dementia. The chapter also highlights the current gaps in knowledge of how AT is used in the care of persons with dementia from the perspective of carers. The chapter concludes with a structure of how the research study was carried out. The next chapter describes study 1, which is a systematic review of what is known about the types of AT being used and how they are used by carers in the care of individuals with dementia, who live at home.

Chapter 3 : Systematic Review

3.1 Introduction:

Home is a special and safe space when ageing. Persons with dementia want to continue to live at home for as long as possible [24] and AT can be one way of supporting this to happen. Carers support the person with dementia by assisting with activities of daily living, housekeeping, supporting financial matters, providing transport, supporting medication adherence and engaging in leisure activities [5]. Carers also support persons with dementia by making decisions on AT, including buying, maintaining and replacing AT at home. Despite this, most research studies have focused on the use of AT from the perspective of persons with dementia [72–74] or the use of AT to support them in institutional settings [75, 76].

Carers could be using the AT together with the person with dementia (e.g., safety alarms, tablet computers), independent of the person with dementia (e.g., video monitoring systems, GPS trackers) and/or carers could be looking after someone with dementia, who uses AT independently of the carer (e.g., electronic medication dispensers, smart phones). Little is known about the experiences of carers using these AT solutions, what impact AT has on carers, and if it supports their wellbeing. This information could benefit carers, as well as persons with dementia, considering AT solutions for use at home. The information could be used by health and social care professionals who prescribe and set up AT solutions at home, to better support carers and persons with dementia, with the knowledge of what works and why. Industry and AT developers could use the information to tailor the AT not just to the needs of a person with dementia but also consider the needs of carers who provide substantial amounts of support for persons with dementia to continue to live at home.

A systematic review can deliver a summary of all available primary research and avoid bias [77] by identifying (through a comprehensive search), appraising (through pre-defined

quality criteria), and synthesising all relevant studies on this topic. Taking account of these considerations, a systematic review was carried out to identify the variety of AT available for use in dementia care and the experiences of carers of persons with dementia who use AT.

3.2 Aims and objectives of the systematic review:

This review aimed to:

1) Identify the types and uses of AT in dementia care
2) Describe the effectiveness of AT for outcomes (including burden, wellbeing and quality of life) of carers of people with dementia living at home
3) Describe carers' experiences of using AT in dementia care
4) Describe what aspects of AT that are valued and work well for carers by integrating (2) and (3) as above

3.3 Methods:

To ensure quality and decrease personal bias while completing a systematic review, this review was done in collaboration with others. The screening for eligible studies was performed by two independent reviewers (VS – researcher and author of this thesis and MP – Supervisor of the researcher for this DPhil). The quality appraisal and data extraction were done by VS. A third reviewer (CJ – Supervisor of the researcher for this DPhil) was consulted as needed and any disagreements were resolved, and consensus was reached, by mutual discussion.

3.3.1 Protocol and publication:

The review described in this chapter was carried out in 2018. The review protocol was registered with the international prospective register of systematic reviews PROSPERO (CRD42017082268).

The protocol for this review [78] and the results of the systematic review [79] were published in peer-reviewed journals. Most sections of this chapter will reflect the published version of the review[1]. This review was updated in April 2021. An addendum at the end of this chapter describes this.

3.3.2 Eligibility criteria:

3.3.2.1 Types of studies:

Quantitative, qualitative and mixed-method study designs were included for the review. Letters to the editor, abstracts from conference proceedings, book reviews, study protocols and theses/dissertations were excluded. To ensure all primary studies were identified and included, other reviews on AT use in dementia were checked and references within those reviews were included. Due to funding constraints, only studies in the English language or those translated to English language were included.

<u>Evaluation of effectiveness:</u>

All randomised and controlled trials that compared AT use by and for carers of persons with dementia, to those not provided with the AT, and/or those who received usual care were included. Observational and cohort studies were also included.

[1] **Sriram V**, Jenkinson C, Peters M. Informal carers' experience of assistive technology use in dementia care at home: a systematic review. BMC Geriatr. 2019;19:160. doi:10.1186/s12877-019-1169-0.

Evaluation of experience:

Studies that used qualitative methods of data collection and analysis, either as a stand-alone qualitative study or when reported as part of a mixed-method study were included.

3.3.2.2 Types of participants:

Studies involving carers who provide unpaid care for a person with dementia at home were included. Providing care was defined for the purposes of this review as:

'*supporting a person with dementia physically, emotionally, financially or socially*'.

Care could be provided by a spouse, partner, relative, a friend or a neighbour. There were no restrictions based on gender, living arrangements or ethnic background. Studies that reported on carers who provide support to a person with dementia receiving care in a hospital and/or long-term institutions and carers younger than 18 years and formal/paid carers were excluded.

3.3.2.3 Types of Assistive Technology:

For this review, studies that evaluated AT use in dementia involving carers were included. AT was defined as [53]

> '*any advanced electronic equipment, which can be used to enhance support and care, act as a prompt for intervention by carers, monitor welfare and assist in communication and leisure activities for a person with dementia*'.

The AT could be stand-alone (e.g., tablet computers, eBook readers) or be part of an integrated system (e.g., GPS trackers, movement activated web cameras) and can be stationary (e.g., electric beds, hoists) or mobile (e.g., electronic medicine dispenser, smart phones). The focus of most research studies invariably is likely to be on the person with dementia, so any study that reported on effects or experiences of AT use on carers from

these studies was included. Studies that reported exclusively on AT use for people with dementia without including carers were excluded, as were studies that focused only on electronic therapeutic interventions that are not AT (e.g., computer-based education or support for carers).

3.3.2.4 Types of study outcome measures:

As this review explored experiences and effectiveness of AT, the search was not limited to specific types of outcome measures and included carer self-reported outcome measures of burden; quality of life; and wellbeing; and self-reported or researcher observed experiences of usefulness; benefits and disadvantages of AT and impact on the relationship of a carer to a person with dementia.

3.3.3 Search Strategy:

The search strategy for the review was developed in collaboration with a Bodleian medical library librarian at the University of Oxford. The searches were carried out on electronic databases and through manual searches.

3.3.3.1 Databases:

The search was carried out in electronic databases including MEDLINE (Ovid) from 1946 to June 2018; EMBASE from 1974 to June 2018; PsycINFO from 1806 to June 2018; AMED 1985 to June 2018; CINAHL from 1981 to June 2018; Database of Abstracts of Reviews of Effects (DARE), OT seeker and The Cochrane Library of Systematic Reviews. The search included studies within the Cochrane Dementia and Cognitive Improvement Group's online ALOIS register [80] (from inception to June 2018).

3.3.3.2 Unpublished Literature:

The International Standard Randomised Controlled Trials Number (ISRCTN) registry [81] and the National Institutes of Health Clinical Trials Database [82] were searched for information on unpublished ongoing trials. Searches within these databases were used to identify additional studies and authors to contact for full text reports.

3.3.3.3 Manual searches:

Manual searches of reference lists were also done to identify relevant research studies.

3.3.3.4 Search Terms

Details of the full search on MEDLINE (Ovid) and the number of records identified is described below. Details of the search from the other database are included in Appendix 5.

Database: Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to 2018>

Search Strategy:

# ▲	*Searches*
1	*exp Dementia/ or dement*.mp. (197638)*
2	*(lewy bodies or alzheimer*).mp. (150642)*
3	*exp Wernicke Encephalopathy/ or wernicke encephalopath*.mp. (1915)*
4	*exp Korsakoff Syndrome/ or korsakoff.mp. (1214)*
5	*1 or 2 or 3 or 4 (243505)*
6	*Technology/ or technolo*.mp. (468577)*
7	*(informat* adj2 communicat*).mp. (7204)*
8	*ict.mp. (45500)*
9	*Information Systems/ or Telemedicine/ or Monitoring, Ambulatory/ (45266)*

10 (telemedicine or tele medicine or telehealth or tele health or telemonitor or tele monitor* or ehealth or e-health or mhealth or m-health).mp. (28210)*

11 Telephone/ or remote consultation/ (16139)

12 "Activities of Daily Living"/ or Self-Help Devices/ or assistive.mp. (70880)

13 device.mp. (417837)*

14 self care.mp. or Self Care/ (41709)

15 self help.mp. (18226)

16 (gero adj2 tech*).mp. (35)*

17 robo.mp. or Robotics/ (41477)*

18 (assist adj2 (aid? or device?)).mp. (20630)*

19 "Equipment and Supplies"/ or Equipment Design/ or equipm.mp. (314337)*

20 Signal Processing, Computer-Assisted/ or Clothing/ or wearable.mp. (61224)*

21 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 (1312200)

22 Caregivers/ or caregiv.mp. (68731)*

23 (relatives or family or families).mp. or exp Family/ (1264961)

24 friend.mp. or Friends/ (74209)*

25 (neighbour? or neighbor?).mp. (27191)

26 Spouses/ or spous.mp. (30883)*

27 (wife or wives).mp. (10105)

28 husband?.mp. (11790)

29 (couple? or partner?).mp. (463702)

30 son?.mp. (46342)

31 daughter?.mp. (25773)

32 Home Nursing/ or carer.mp. (21540)*

33 Home Care Services/ or home.mp. (227871)

34 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 (2014136)

35 5 and 21 and 34 (3857)

3.3.3.5 Screening:

Results from the electronic search were downloaded as *.ris* files into Covidence software [16] which is an online digital platform that streamlines the production of systematic reviews and allows screening and data extraction between collaborating reviewers. Reviewers VS and MP independently screened all titles and abstracts for eligibility against the inclusion/exclusion criteria. For studies that had inadequate information from the title and abstract, full text articles were retrieved to determine inclusion. Studies that were marked for possible inclusion underwent a full-text review. At full-text review, when both reviewers agreed that a study did not meet the full eligibility criteria, the study was excluded. Discrepancies were resolved by mutual discussion and in consultation with the third reviewer, CJ.

3.3.4 Data extraction:

<u>Effectiveness:</u>

Data extraction items for quantitative studies were based on the recommended items from the Cochrane handbook for systematic reviews of interventions [83]. Information on citation including authors, date of publication, study design, duration of the study, number of participants, participant gender, age, ethnicity, country where the study took place, relationship status to the person living with dementia, types and use of the AT, outcome measures used, time points of data collection, missing participants and key conclusions from the study authors were extracted.

Experience:

Data extraction for qualitative studies were based on guides to synthesise qualitative research [84, 85]. Information from qualitative studies on citation, author details, study design, duration of the study, number of participants, participant gender, age, ethnicity, country where the study took place, relationship status to the person living with dementia, types and use of the AT, data based on study authors' commentaries and conclusions were extracted.

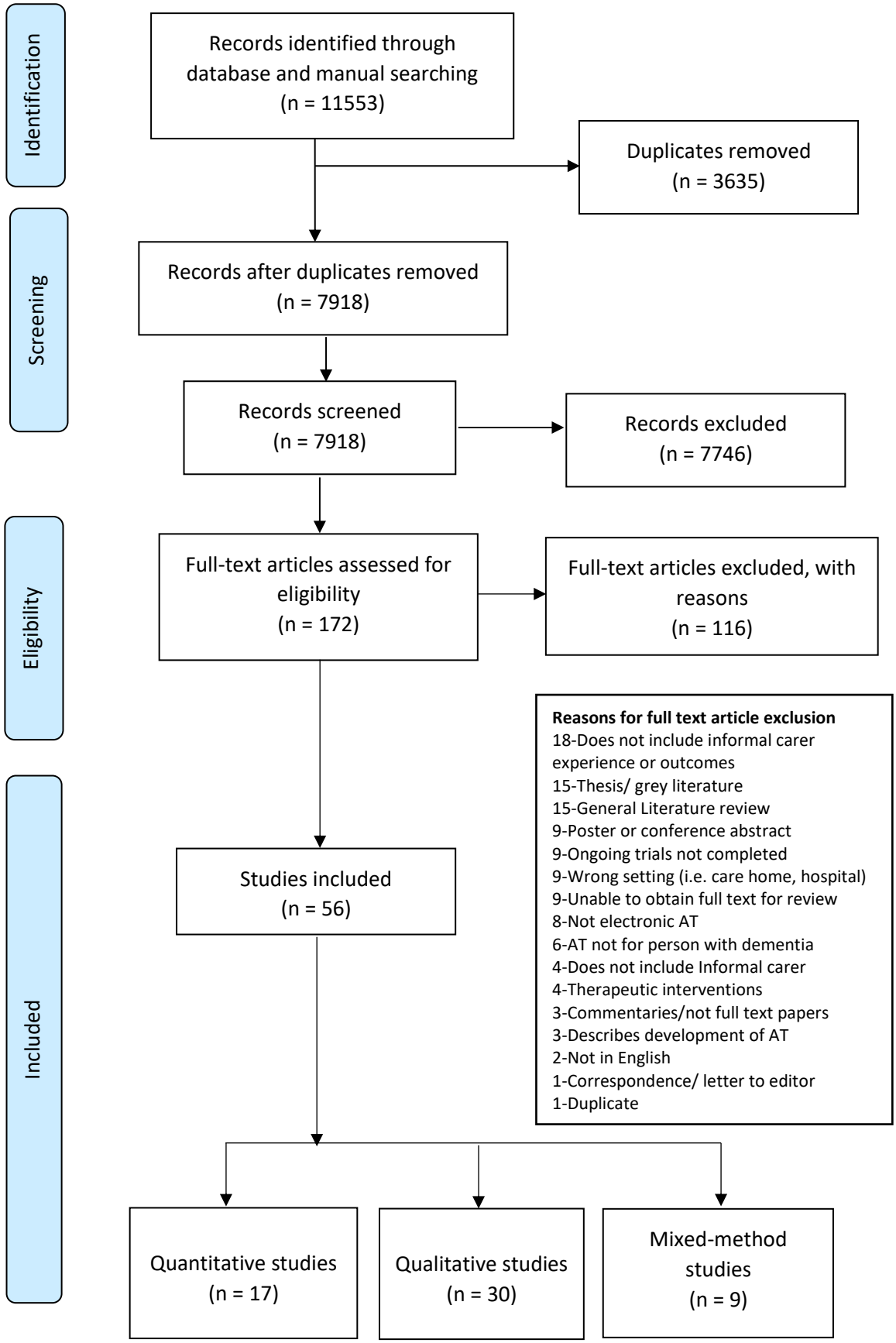
A bespoke data extraction table was developed for this review and was initially piloted on a sample of studies to refine the form. Reviewer VS extracted the data and reviewers MP and CJ checked the extracted data for accuracy and completeness. Disagreements and clarifications were resolved by discussion. The final data extraction table was created in Microsoft Excel 2016 and is shown in Appendix 6. There were no deviations from the published protocol [78].

3.4 Results:

The search was carried out in June 2018. Searching multiple databases, resulted in the retrieval of numerous duplicate citations. The search results were screened for duplicate records [86] using Mendeley software [87] and Covidence [16]. Of the 11,553 records retrieved from the database search 3635 were removed as duplicates. The titles and abstracts of the 7918 retrieved records were independently screened by VS and MP. A total of 7746 records were excluded (including further duplicate records). VS and MP then independently assessed the remaining 172 articles based on full texts for inclusion. Fifty-six publications met the inclusion criteria and were included in this review for data extraction. A summary of the search results and reasons for exclusion of the full-text papers were

documented and are presented as a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) [88] flow chart in Figure 3-1.

Figure 3-1 PRISMA flow diagram of study selection and inclusion:



3.4.1 Included studies:

In the 56 included publications, 30 were qualitative, 17 quantitative and 9 mixed-methods, reporting on a total of 50 studies from 19 countries. The publications spanned from years 2000 to 2018. The studies included 2,016 carers (660 men and 1,165 women, where gender was reported) and 84 types of AT. The carers' ages ranged from 19-91 years. Thirteen publications did not report an age range for participants.

Two of the studies were Randomised Controlled Trials (RCTs) and one was a Controlled Clinical Trial. Multiple methods were used for data collection including interviews (32), surveys (14), observations (8), focus groups (7), questionnaires (6), diary/log entries (4) and video recording and email and blog reviews (one each), with 19 studies using more than one method for data collection.

Seven studies [89–96] reported on ethnic backgrounds of participants which were predominantly from white backgrounds alongside Hispanic, African American, Asian and 'other' backgrounds. Most studies reported the severity and type of dementia, without specifying a classification system and involved people with dementia who had mild or moderate dementia. Studies also reported on the carer relationship with the person with dementia and included spouses, siblings, children, daughter/son-in-law, nieces and nephews, grandchildren, neighbours and friends. Where studies included paid carers and participants who lived in long-term care facilities alongside carers of someone who has dementia living at home, this review only included data related to family carers and persons with dementia who lived at home.

A complete list of references of the included studies is provided in Appendix 7.

3.4.2 Quality of included studies:

The included studies are qualitative, quantitative and mixed-method in design, hence the Mixed Methods Appraisal Tool [97–99] was used for assessing quality of the included studies.

The Mixed Methods Appraisal Tool (MMAT) score is a subjective appraisal of a study's methodological quality. For qualitative and quantitative studies, the percentage of appraisal criteria that have been met is stated. For mixed-methods studies, scores are given to the quantitative and qualitative components of the study. The overall score, however, cannot exceed the lowest score of a component, so if one part (e.g., quantitative) received 100% but the other (e.g., qualitative) got 50%, the overall score would be 50%. This means it would be possible for a study to have a strong quantitative section and a weaker qualitative section (or vice-versa), but the overall score would be low, suggesting the study might be less valuable [99].

All the included studies were critically evaluated using the MMAT by VS. Scores and quality of the included studies were discussed with reviewers MP and CJ and discrepancies resolved through discussion. The MMAT scores as well as reasons for the low scores for the included studies are provided in Table 3-1. Twenty-five of the included publications scored over 50% on the MMAT. Six of the qualitative studies [71, 100–104] scored highly for due consideration of results in context and for researchers' own influence on data collection and interpretation of results. The RCTs [89, 90] and the controlled clinical trial [91] scored poorly on allocation concealment and blinding. One of the studies was a RCT pilot trial [90] and had a high attrition rate.

3.4.3 Data synthesis:

The included studies were a mixture of quantitative, qualitative and mixed-methods studies. Due to the heterogeneity of the studies, data collection methods and outcome measures, a narrative synthesis [84, 85, 105–107] of the included studies was completed.

Lins et al describe that when "descriptive qualitative studies that are characterised by 'thin descriptions' are available, an aggregative method is more appropriate; if the identified evidence includes a high proportion of in-depth qualitative studies characterised by 'thick descriptions', an interpretative method can be applied" [108]. Since all of the qualitative studies in this systematic review had 'thin descriptions' an aggregative method for qualitative synthesis was used.

For data synthesis, the method described by Timulak [109] was followed. Data from the data extraction table was transferred into data analysis software NVivo Version 12 [18] and synthesis was completed in three steps.

1) The first step of the analysis was to read and get familiar with the included studies.
2) The second step was to create a conceptual framework of categories on carers' experiences as an emerging process using a few studies. Subsequent studies were then coded into pre-existing concepts, and new categories were created as necessary.
3) The third step involved creating themes of meaningful units from these categories and describing them.

Extraction and summarising data from the results was done by VS. MP and CJ reviewed and highlighted potential/unclear categories. Final themes were subsequently arrived at through mutual discussions. As this was an aggregative synthesis, reflexivity [110, 111] was

maintained throughout the review process through discussions and reflections on extracted data and coding.

The characteristics of the included studies is provided in Table 3-1.

Table 3-1 Systematic review - characteristics of included studies:

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
	Qualitative studies							
1	Altus DE et al [112] 2000	USA	2- Spouses (2 men)	Not reported	Interviews Case study	GPS tracker/Mobile locator	50 (Findings within context and researcher influence on results unclear)	AT use provided increased confidence and peace of mind
2	Cahill S [100] 2007	Ireland	20 – Spouses + Children + Sibling + Daughter-in-law + Friend (5 men; 15 women)	34-79	Semi-structured interviews Thematic Analysis	Automatic night and day calendar; lost item locator; automatic night lamp; gas cooker device; picture button telephone	100	Low technical difficulty had highest use; carer willingness to remind person with dementia to use the AT enabled better use; Familiarity of AT to an older person with dementia influenced use
3	Starkhamar S et all [113] 2008	Sweden	14 Spouses + Daughters (5 men; 9 women)	Not reported	Interviews and Observations Grounded Theory	Stove timer	50 (Findings within context and researcher influence on results unclear)	Safety issues were of concern for carers
4	Faucounau V et al [114]	France	1 – Spouse (1 woman)	68	Interviews	GPS tracker	75	Aesthetic aspects of the device; knowing how to

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
	2009				Single dyad case study		(Researchers' influence on results unclear)	use the internet; dissensions between patient and carer on carrying the device all influenced use of AT
5	Spring HJ [94] 2009	USA	14 – Spouses + Daughters + Grand daughter (1 men; 13 women)	38-86	Semi-structured interviews Full conceptual description- grounded theory	In-home night time monitoring system	75 (Consideration of researchers' influence on results unclear)	Peace of mind. Some increase in caregiver worry; balance between personal space and remain connected with person with dementia; worry decreased with trust in the AT; better sleep; energy for self-care and care for person with dementia. Financial benefits and positive impact on other family members
6	Landau R et al [115] 2010	Israel	36 – Spouses + Children (12 men; 24 women)	Not reported	Focus groups Thematic framework approach	GPS electronic tracking device	50 (Process for analysing data unclear and researchers' influence on	Safety and peace of mind; use after first time getting lost; staying in the community and safety more important than

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
							results unclear)	patient autonomy; get patient consent
7	Powell J et al [95] 2010	England	34 – Spouses + Children + Grandchildren + Friend (12 men; 22 women)	23-91	Semi-structured interviews Framework approach	Movement sensors; cameras; automatic water and gas switch off devices; tracking devices	50 (Findings within context and researcher influence on results unclear)	Personal nature of human contact versus impersonal nature of technology; AT for others than themselves; useful for next generation of carers; trade-off between privacy, autonomy and safety; low tech solutions as important as advanced technology
8	White EB et al [116] 2010	England	10 – Spouses + Son+ Daughter (4 men; 6 women)	44-73	Interviews and survey Grounded Theory	GPS tracker	75 (Researchers' influence on results not explained)	Enable people to participate in meaningful activities; tracking as a secondary intervention; reassurance and enhanced independence
9	Rosenberg L et al [117] 2011	Sweden	4 – Son +Daughters +Neighbour	55-78	Observations and In-Depth interviews Grounded Theory	Night and Day Calendar, Forget-Me-Not	75 (Researchers' influence on	Issues relating to who has power to decide on AT

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
			(1male; 3 women)			Calendar, MeDose watch	results unclear)	
10	Olsson A et al [118] 2012	Sweden	14 Spouses (6men; 8 women)	62-89	Interviews Not reported	Safety alarm, bed alarm, door alarm, passage sensor, electronic tracking device, cooker monitors, talking cassette, picture button telephone, memory aid, special remote control	50 (Theoretical framework used is not reported and researcher influence on results unclear)	Important to let person with dementia be involved in decisions about information and communication technology use
11	Rosenberg L et al [119] 2012	Sweden	16 – Spouses + Son +Daughter+ Neighbour (5 men; 11 women)	45-78	Interviews and Focus groups Grounded Theory	GPS monitor, electronic pill dispenser	75 (Researchers' influence on results unclear)	Safety issues overshadowed ethical dilemmas

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
12	Martin S et al [120] 2013	Northern Ireland	8 (Gender not reported separately)	Not reported	Semi-structured interviews Phenomenological approach	NOCTURNAL - Sensors, communication devices, tablet PC	75 (Researchers' influence on results unclear)	High anxiety and increased time spent with person with dementia
13	Nijhof N et al [47] 2013	Netherlands	14 – Spouses + Family + Friends (Gender not reported)	Not reported	Semi-structured interviews Not reported	ADLife - gateway with alarm button, sensors	50 (Theoretical framework for analysing data not reported and researchers' influence on results unclear)	Study reports ethics was not required; anxiety from informal carers about real time video images; problems with equipment; useful if dementia deteriorates
14	Olsson A et al [121] 2013	Sweden	5 Spouses (2men; 3 women)	62-68	Participant Observation Ethnographic approach	Passive Positioning Alarm	50 (Findings within context and researcher influence on results unclear)	Being visible outweighs risk of privacy violated
15	Riikonen M et al [101] 2013	Finland	25 – Spouses + Daughters + Brothers +	Less than 65	Unstructured interviews and participant observations	Cameras, movement detectors, electronic medication	100	Technology can become a member of the social network making it stronger; crisis following

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
			Son-in-law + Niece (12 men; 13 women)		Ethnographic approach	reminder, photo memory telephone		diagnosis complicates introduction of technology
16	Hastall MR et al [122] 2014	Germany	17 - Spouses + Children (4 men; 13 women)	38-91	Semi-structured interviews Thematic Analysis	Information retrieval system; Video communication system; sensors	50 (Findings within context and researcher influence on results unclear)	Fears of dehumanised care; end user lack of experience with technology; informal carers preferred trustworthy carer related information in comparison to leisure time support
17	Jentoft R et al [73] 2014	Norway	9 – Son + Spouses +Daughters +Mother (4 men; 5 women)	19-89	In-depth interviews and Observations Not reported	Simple remote control for TV	75 (Researchers' influence on results unclear)	AT helped person with dementia and Carer experience better quality of time when together
18	Meiland F et al [123] 2014	Netherlands and Germany	13 (Gender not reported separately)	Not reported	Interviews and Focus group Not reported	COGKNOW day navigator; sensors and sensor network	50 (Theoretical framework for analysing data not reported and researchers' influence on	Carers preferred support from AT for navigation outdoors and calendar function; learning of new equipment raised as an issue

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
							results unclear)	
19	Milne H et al [124] 2014	Scotland	16 - Spouses + Sister + Son + Daughters + Son-in-law + Daughter-in-law (7men; 9 women)	Not reported	Interviews Thematic analysis with constant comparison	GPS devices - worn as watches, pendants or carried in pockets and bags	75 (Researchers' influence on results unclear)	Trust of device was low; false sense of security from use of devices; Equipment was bulky; false alerts also occurred which worried carers
20	Burstein AA et al [125] 2015	USA	34 - Spouses + Children + Grandchildren + Friend + Neighbour + Sibling + Niece + Daughter-in-law + Cousin (6 men; 28 women)	43-76	In-depth interviews Not reported	Sensor technology, GPS tracking device. emerging technology - robotic therapy seal, GPS tracking system; social contact system, health monitoring system	50 (Theoretical framework for analysing data not reported and researchers' influence on results unclear)	Carers' knowledge lags behind current technology development; Need for better education and raise awareness among carers; Future willingness outstripped current willingness to use AT; Need to alert carers of options for different stages of the disease

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
21	Gibson G et al [126] 2015	England	26 - Spouses and Daughters (Gender not reported separately)	49-82	Interviews Thematic analysis, constant comparative method	Community alarms and telecare; GPS location monitoring devices, signage, reminiscence tools, clocks to aid orientation, simplified telephones with pictures, pill dispensers	75 (Researchers' influence on results unclear)	AT accepted by person with dementia as it helped carer
22	Arntzen C et al [71] 2016	Norway	14 - Spouses +Children +Parent Gender not reported)	19-89	In-depth interviews and Observations Phenomenological conception of 'lived body'	Sensors, timers, tracking device, cooker alarm, timer on coffee machine, automatic day and night calendar, simple remote control for	100	AT had to interest and engage family carers

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
						television, electronic door lock, item locator, simple mobile phone, automatic day and date calendar, speaking arm-wrist watch, message box reading out a message when activated, memory clock, medicine dispenser with alarm		
23	Grigorovich A et al [127] 2016	Canada	20 – Sons + Son-in-law (20 men)	25-66	Semi-structured interviews Naturalistic enquiry	Cameras, baby monitors, skype	75 (Researchers' influence on results unclear)	Sons relied on other carers for support. AT used for monitoring and reassurance of safety; extension of established familial roles

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
24	Newton L et al [128] 2016	England	26 (Gender not reported separately)	49-82	Interviews Not reported	Community alarms and telecare; GPS location monitoring devices, signage, reminiscence tools, clocks to aid orientation, simplified telephones with pictures, pill dispensers	75 (Researchers' influence on results unclear)	AT useful and accepted as long as it helped person with dementia
25	Ekstrom A et al [129] 2017	Sweden	1 – Spouse (1 male)	Not reported	Video recording and observation Talk-in interaction	Tablet computer	50 (Findings within context and researcher influence on results unclear)	Carers' concern is how it supports person with dementia
26	Evans N et al [102] 2017	England	6 – Daughters +Spouses +Daughter-in-law	48-62	Interviews and Focus groups Phenomenological Analysis	Calendar	100	Little expectation from AT - does it work?

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
			(6 women)					
27	Hassan L et al [130] 2017	England	4 (Gender not reported)	Greater than 65	Focus group Not reported	Wearable sensors	25 (Theoretical framework for analysing data not reported, results not explained in context and researchers' influence on results unclear)	Carers prefer low maintenance and robust devices; carers deeply involved in everyday routines of persons with dementia; not to stereotype that older users cannot cope with technology
28	Holthe T et al [103] 2017	Norway	13 – Spouses + Daughter + Mother + son (7 men; 6 women)	19-89	Interviews Epistemology of coping	stove timer, GPS, automatic calendar, simple remote control, object locator, simple mobile phone, digital calendar, talking wrist watch, medicine dispenser,	100	"window" for successful implementation of AT may be short

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
						memory clock, message box connected to coffee machine		
29	Lorenz K et al [50] 2017	England	7 – Sons + other carers (Gender not reported)	Not reported	Email and blog reviews Not reported	Baby monitors, talking motion sensors, personalised recorded messages, cameras	50 (Theoretical framework for analysing data not reported and researchers' influence on results unclear)	Technology helps coordinate care between different family members; not many devices to support severe dementia
30	Wang RH et al [104] 2017	Canada	10 – Spouses + Son + Daughters (4 men; 6 women)	36-78	Semi-structured interviews Thematic analysis	Assistive robot - Ed - personal computer; microphones, LCD screen, speakers and web cameras	100	Robots - thought provoking and novel; did not need at present (psychological readiness) but future possibility; carers felt (incorrectly) persons with dementia were as open as they in using and integrating robots at home; useful to reduce anxiety and

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
								answer repetitive questions; robot as an appliance rather than a friend
	Quantitative studies							
31	Gitlin LN et al [89] 2010	USA	63/73 [Experimental/Control] – Spouse + Others (13 Men; 50 women – Experimental group) Dropouts not reported	53-79	Randomised controlled trial 1. Use of device (yes/no) 2. Extent to which helpful (1=not helpful, 2=somewhat helpful, 3=very helpful)	Medication dispensers, video cameras, motion detectors, lost item finders	20 (No information on randomisation, no information on attrition and blinding)	• 87.6% of devices in use at 4months • Overall somewhat to very helpful. • Lower cognitive status equated to more AT. • Devices assisted caregivers in helping to carry out specific tasks or to minimise targeted problem behaviour. • AT provided only after caregiver approval. • Device use alone may not sufficiently address problem behaviours

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
32	Rowe MA et al [90] 2009	USA	26/27 [Experimental/control] – Spouses + Daughter + Son + Granddaughter (7/4 men; 19/23 women). Dropouts = 10 in each group	38-86	Pre test-Post test repeated measures randomised pilot study 1. System reliability 2. Satisfaction with the NMS 3. Night time injuries. 4. Unattended exits from home 5. Mechanisms to manage night time activity 6. Baseline variables including short version of Zarit Burden Interview; The neuropsychiatric Inventory	Night Monitoring System	50 (No allocation concealment or blinding, high number of dropouts)	• AT is adjunct to caregiving. Experimental group 85% less likely to sustain an event • No significant differences in sleep diary variables. • Caregivers reported satisfaction and confidence in preventing night time injuries and exit
33	Rowe MA et al [91] 2010	USA	26/27 [Experimental/control] – Spouses + Daughters + Sons	38-86	Pre test-Post test Controlled Clinical Trial 1. Caregiver distress about night-time activity	Night Monitoring System (NMS)	50 (No allocation concealment or blinding)	• No significant improvement with sleep when NMS was used. • No quantifiable reduction in worry.

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
			(6/3 Men; 18/22 Women). Dropouts = 4 in each group		2. Sleep diary 3. actigraphy			• NMS not sufficient as stand-alone treatment
34	Olsson A et al [131] 2015	Sweden	3 – Spouses (3 women)	72-74	Three - Experimental single case studies (A1B1A2B2) 1. Percentage of days with independent outdoor activities 2. Spouse's worry concerning person with dementia's independent outdoor activities (1-10 not worried at all to extremely worried) 3. General wellbeing for spouses (0-10 not wellbeing at all to extremely good) 4. Caregiver burden scale (1 not at all to 4 often)	Passive Positioning Alarm	50 (convenience sample, researchers involved in data collection and provision of AT)	• Decreased level of worry about person with dementia's independent outdoor activities. • No significant changes in perceived wellbeing and burden

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
35	Pot AM et al [132] 2012	Netherlands	33- Spouses + Children (2 Men; 26 Women) Incomplete = 5	>63	Pre test-Post test Trial 1. overall global impression of device from 1 to 10 2. Acceptability using Agree, neutral, disagree 3. Self-perceived pressure from informal care scale	GPS tracking device	60 (Researchers involved in data collection and provision of AT)	• 77% of carers would recommend use of GPS. • 30% carers reported more time for other things; use of GPS rated at 7.2/10. • Role overload feelings not significantly reduced. • Decrease in the feelings of worry when they could reach person with dementia. • Forgetting to take device was not a problem as carers mainly lived with person with dementia
36	Kinney J M et al [92] 2004	USA	19 – Spouses + Son + Daughter + Sister + Great Niece.	36-82	Survey and exit interview 1. Family obligation, competence, role captivity, loss of self,	Smart home management system (Xanboo); cameras and sensors, cell phone	40 (Incomplete reporting of outcomes, high detection and	• Caregivers able to learn to use technology. • Majority indicated having the system made lives easier.

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
			(8 men; 11 women). Incomplete = 6.		overload, expressive support in caregiving 2. Retrospective time budget 3. Exit interview questions		performance bias)	• 11/16 report positive change in how they spend their time. • 3/3 individuals report a positive change in relationship with person with dementia • Caregivers interested in continuing to use the system. • Technology needed constant monitoring, which made it difficult for carers
37	Duff P et al [133] 2007	Ireland, England, Finland, Lithuania Norway	127 (Gender not reported) Incomplete = 47	Not reported	Before and After Survey 1. Usefulness. 2. Levels of satisfaction 3. Recommend device to a friend 4. Willing to pay for device 5. Carer wellbeing score	Calendar, lamp, gas cooker monitor, locator, picture telephone, medicine reminder	40 (sampling strategy unclear and detection bias unclear)	• 63.5% used AT. • 77.8% felt the AT was useful for person with dementia. • 90.1% satisfied with AT. • 94.5% recommend the device. • 81.3% willing to pay for device. • Slight decrease in overall level of carer burden during trial.

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
								• Calendar, cooker monitor and picture telephone gave most satisfaction and most useful
38	Rialle V et al [134] 2008	France	350 – Spouses + Siblings + Relatives + Other (89 men; 181 women) Incomplete = 80	54-98	Cluster sample survey 1. Questionnaire in three sections a. general information; b. Current skills and practice and viewpoints on specific technologies; c. Economical effort and support. (not at all, little, moderately, very much). Included 'mini' Zarit score	Smart home technologies - fall sensor; oral call identification; video surveillance; tracking device; robot care; video conferencing	75 (unclear information on detection bias)	• Among helpful devices, tracking devices most appreciated, especially by women and younger caregivers n=195,196 • Videoconferencing was second most appreciated. • Least appreciated was fall sensors inserted inside the body, under the skin. • Younger caregivers found technology more useful than elderly
39	Landau R et al [135] 2009	Germany and Israel	69 – Spouses + Sons + Daughters +	Not reported	Survey	GPS tracking device	75 (convenience sample)	• GPS device used for sake of patients' safety or for carers' peace of mind.

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
			Other family members (16 men; 53 women)		1. Attitude towards use of electronic tracking 2. Who should make decisions regarding use of GPS 3. Six Items adapted from Quebec User Evaluation of Satisfaction with Assistive Technology scale			• Tracking device can be viewed as contrary to human dignity. • Tracking a person with dementia in the community is an intra-family issue. • Carers want 'user-friendly' device
40	Chen Y-C et al [136] 2012	Taiwan	3 – Spouses (1 man; 2 women)	28-86	Survey 1. Lost seeking devices used. 2. Wandering behaviour. 3. Functions in lost seeking devices. 4. Faults in lost seeking devices. 5. Importance of the information 6. Importance of purchase consideration	Electronic GPS	25 (convenience sample, high detection and performance bias)	• Computer skills of carers was important in deciding use of technology. • Acceptance of product. • Carers wanted products that are not easy to dismantle by persons with dementia

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
41	Alwin J et al [137] 2013	Sweden	47 – Spouses + Children (16 men; 31 women)	46-77	Survey 1. Carers of Older People in Europe (COPE index) 2. Patient perspective on Care and Rehabilitation process instrument (POCR) 3. How do you value the significance of the intervention? (1= of no significance, 5= of greatest possible significance)	Easy-to-use telephones, door alarms, alarms and emergency transmitters	60 (Detection and performance bias unclear)	• 33/47 (70%) perceived AT as having great significance • Alarms and safety AT may have a positive effect on sense of security for carers. • AT may not achieve major improvements but instead smaller changes that could lead to slight improvements of the situation
42	Lim F S et al [138] 2013	Australia	24 – Family + Friend (3 men; 21 women) Dropouts = 3	34-85	Before, during and after survey 1. Previous experience of use of technology 2. Person with dementia using device independently 3. Carer's perspectives on	iPad	50 (Detection and performance bias unclear and some selective reporting)	• 48% carers reported they would use the iPad regularly with person with dementia. • 50% of person with dementia used device independently providing relief for carers

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
					usefulness of the device			
43	McKenzie B et al [43] 2013	USA	60 (7 men; 53 women) incomplete = 1	Not reported	Before and after survey 1. Safety assessment Scale 2. Caregiver Vigilance Scale 3. Peace of Mind scale 4. Sleep Disorders inventory	Motion sensor with remote alarm, wireless camera with handheld liquid crystal display night vision, proximity range alarm, wireless home security system, medication organiser, locating technologies, bed occupancy sensor, touchpad key locks, window alerts, water detector alert	80 (some selective reporting)	• Technology that was perceived as institutional was resisted. • New door locks were considered intrusive and resisted by all carers. • Medication organiser was most used. • AT provided immediate relief, reduced stress and helped carers provide care more easily and safely

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
44	Schulz R et al [93] 2016	USA	512 – Spouses + Sons +Daughters + Other family members + Friends (251 men; 261 women) Incomplete = 75	18-64	Survey 1. General technology attitudes -10-point scale	Emergency response system; sensors;	50 (convenience sample)	• Carers willing to pay and are receptive to AT. • Combined government and private pay arrangements help disseminate AT.
45	Kamimura T [139] 2017	Japan	5 – Spouse + Daughter + Daughter-in-law (Gender not reported)	52-65	Survey 1. Carer Burden (1=no burden; 2= little burden; 3=mild burden; 4=moderate to severe burden)	Automatic Medication Dispenser	25 (high detection and performance bias)	• Caregiver burden reduced compared to before device use. • Caregivers-maintained score of little burden or less and one caregiver had a score of mild burden throughout. • Continued caregiver support is main factor for medication adherence using the device

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
46	Korchut A et al [140] 2017	Poland Spain	81- (26 men; 54 women) incomplete = 1	Not reported	Survey 1. Social acceptance 2. Human-robot interaction	Robotic assistants	50 (Convenience sample)	• AT needed for handling emergencies at home. • Reminders for medication was a high priority. • Carers viewed robotic technology positively
47	Megges H et al [141] 2017	Germany	18 – Spouses + daughters (10 men; 8 women) Dropout = 1	41-78	Before and after survey 1. Zarit Burden Interview 2. General self-efficacy scale 3. User diary 4. How satisfied they were with the prototype (1=not at all satisfied to 4= very satisfied)	Mobile locating system with GPS	40 (high performance and detection bias)	• No significant difference in caregiver burden or self-efficacy from T1 to T2. • 76.5% willing to purchase prototype. • Recommend using qualitative methods for further research
	Mixed-method studies							
48	Topo P et al [44] 2007	Lithuania Norway Ireland United Kingdom	50 - Spouses + Children + Grandchildr	29-84	1. Burden of care questionnaire 2. Interviews	Night and Day Calendar (NDC)	40 (High performance and detection	• Most carers benefitted if person with dementia used the NDC.

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
		Finland	en + Friends. (4 men; 21 women). Incomplete = 25		1. The need for care and treatment 2. Use of services and quality of life 3. Greene's Relative Stress Scale		bias and large dropout rate)	• Important to balance expectations vs benefits from AT. • NDC benefits in mild to moderate stages of dementia
49	Meiland F et al [46] 2012	Netherlands Ireland Sweden	41 – Spouses + Children (25 men; 16 women)	23-79	Pre test-Post test Questionnaires 2. Semi-structured interviews. 3. Diary. 4. Observations 1. Short Sense of Competence Questionnaire 2. One question regarding overall judgement on QoL of the carer	COGKNOW Day Navigator (CDN) - touchscreen, mobile device, home based sensors, actuators	50 (high performance and detection bias, integration of qualitative and quantitative data unclear)	• Carers found time and day indication and reminders most useful. • Carers dissatisfied with technical instability of the system. • No statistical significant difference in pre and post test scores on QoL or burden. • Carers and person with dementia willing to accept AT
50	Nijhof N et al [142] 2013	Netherlands	16 – Spouses + Sons + Daughters	35-79	1. Log file of system use. 2. Interviews	PAL4 BV - Agenda for the day, diary, two-way video contact,	60 (High performance and detection bias)	• Installation of AT was sometimes too late in the process of dementia. Higher functioning clients

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
			(6 men, 10 women)		1. Log files - number of clicks and buttons pressed on the touch screen 2. interviews on uptake and impact with carers	memory games to play, Music and movies, information on dementia and the village they live in		might find the system stigmatising. Agenda reminders was most used followed by video with family. • All considered the system useful and user friendly. Some elderly caregivers (n=3) used the system for their own reminders and to play games as well. • Did not reduce burden on caregiver but provided more time for self. • Carers had to spend extra time to learn to use the system
51	Mehrabian S et al [143] 2014	France	30 – Spouses + Children (10 men; 20 women)	54-74	1. Survey 2. Semi-structured interviews 1. Questionnaire on use and usefulness. 2. Interview questions	Telecare system - sensors, videoconferencing, detecting emergencies, cognitive	25 (consideration of results in context is unclear and no clear integration of	• No differences in answers between offspring and spouses groups and between men and women carers.

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
						stimulation exercises. Medicines and task reminders	quantitative and qualitative data)	• Carers who did not live with person with dementia replied system would make them feel more secure. • Carers found emergency detection system more useful than person with dementia. • Carers also perceived the system will give them more freedom to leave person with dementia alone; they perceived it would improve their quality of life. • Carers felt the system could allow person with dementia stay at home for as long as possible. • Spouses denied the need for help to care for person with

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
								dementia more than children
52	Lewis V et al [144] 2015	Australia	59 – Spouses + Others (16 men; 35 women). Incomplete = 8	30-70	1. Pre test-Post test self-report questionnaire 2. Diary 3. Semi-structured phone interviews 1. Kessler-10 measure of psychological distress -1 =none of the time to 5 = all of the time 2. General health question-one item 3. Life satisfaction questions - 1=very dissatisfied to 11=very satisfied. 4. Family caregiver self-efficacy scale - 1= not at all certain to 10 = very certain 5. Caregiving and stress measure. 6.	MP3 player	90 (theoretical framework for qualitative data analysis not reported)	• Increase in symptom management and self-efficacy for the carer. • Reduced caregiver need for vigilance. • No significant changes in caregiver stress

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
					Self-care and healthy behaviours			
53	Hattink B J et al [40] 2016	Germany Netherlands Belgium	17/15 [Experimental/Control] – Spouses + Children + Other (7/6 men; 10/8 women) Dropouts = 9/9	29-85	1. Pre test-Post test control group design with matched groups (Netherlands, Belgium). Randomised Controlled Trial (Germany) 2. Focus Groups 1. Usefulness and user-friendliness 2. Short sense of competence questionnaire	Integrated Rosetta system: Elderly Day Navigator + The early Detection System + Unattended autonomous surveillance system	40 (Theoretical framework for qualitative data not reported, high detection, attrition and performance bias)	• The system was not always available due to technical faults and maintenance. • Carers found the system very useful (n=9 - all completers). • Carers described system as having a noticeable impact and offered a 'safer feeling' (n=3). • Carers experienced little less burden. • User friendliness not rated very high due to technical issues. • Concerns about privacy were occasionally raised. • No significant differences between control and experimental groups in outcome measures

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
54	Navarro R F et al [145] 2016	Mexico	3 – Spouses + Daughter (3 women)	43-66	1. Questionnaires 2. Diary. 3. interviews 1. Caregiver burden - Zarit Burden Interview. 2. Caregiver self-efficacy - revised Scale for caregiving Self-Efficacy	Assisted cognition system - touchscreen reminders for the day, current date and time, tracking	40 (Theoretical framework for qualitative data not reported, high detection and performance bias)	• Carers report feelings of 'safety' assurance that medicines were managed on time. • Trend of decreasing carer burden (from moderate to mild) and increasing self-efficacy -developing skills to deal with problem behaviour • Carers also note decrease in level of constant attention required, leaving carers calmer and more relaxed
55	Liu L et al [146] 2017	Canada	46 - Spouses + Children + Friend + Daughter-in-law (11 men; 35 women)	41-71	1. Pre test-Post test questionnaires 2. Focus groups 1. Questionnaire - 1=strongly disagree to 5 = strongly agree 2. Zarit Burden Scale 3. Focus groups	GPS	75 (Theoretical framework for qualitative data not reported)	• Focus group - Giving person with dementia more independence, peace of mind, highly recommend use of the device. • Some problems relate to false alarms and notifications

No	Authors Publication Year	Country	Participants	Age range	Study Design/Measures used	Assistive Technology	Mixed Methods Appraisal Tool (%)	Major Findings
56	Tyack C et al [96] 2017	England	12 (2 men, 10 women)	48-77	1. Quasi-experimental repeated measures. Questionnaire. 2. Semi-structured interviews 1. Quality of Life - Alzheimer's Disease (QoL-AD) scale. 2. Semi-structured interviews	Tablet Computer	75 (High performance and detection bias)	• Beneficial effect on wellbeing of person with dementia • Carers spent more time with person with dementia. Carers reappraised what person with dementia could do with the app more positively

The narrative synthesis presented below is a descriptive summary of findings from the included studies. The findings are grouped into themes mapped to the aims of this review. This synthesis provides new insights and understanding from different perspectives and gives an informed view of carer experience with AT.

3.4.4 Question 1: Identify the types and uses of AT in dementia:

There appeared to be no agreed way of classifying AT available for use by people with dementia. As a result, for the review, AT were classified by their use. AT was classified based on work developed by AT dementia [147] and Lorentz et al [50].

Within the included studies, AT was a mixture of active (required interaction from the person with dementia or carer) and passive devices. Some AT had multiple uses e.g., the electronic medication dispensers oriented the person with dementia to time when they needed to take their medication as well as acting as a safety device to ensure they took important medication on time.

AT was mostly used for safety and security (n=38) and included tracking and home safety devices. Other AT supported memory and orientation for the person with dementia (n=23) and social interaction and leisure activities (n=16). In this review, only three studies described AT that supported basic ADL activities such as feeding, washing, grooming, or dressing. Sixty-four of the AT products described in the included studies were commercially available with 10 studies describing AT that were research prototypes. The AT devices used (including some research prototypes) were adapted from aids/devices that many people, with and without cognitive impairment, already use. There was no AT used for advanced instrumental ADL, such as managing finances, shopping or preparing meals. None of the AT devices were used for supporting behavioural issues such as aggression or disinhibition,

which is quite common in someone who has dementia. A list of AT from the included studies is provided in Table 3-2.

Table 3-2 Systematic review - Types and uses of Assistive Technology:

Main Use	Type of Assistive Technology	Product Availability
Basic Activities of Daily Living	Assistive robot – 'Ed' - personal computer; microphones, LCD screen, speakers and web cameras [104]; Robotic assistants [134, 140]	Research prototype
Leisure and social interaction	Special remote control[118]/ Simple remote control to TV [71, 73, 103]	Commercial Product
	Wearable sensors [130]	Commercial Product
	Robotic Therapy 'seal' [125]	Commercial Product
	Talking cassette/magazine [118]	Commercial Product
	Telephones: Picture button telephone [100, 118, 133]/ Simple mobile phone [71, 103, 126, 128]/ Photo memory telephone [101]/Easy to use telephone [137]	Commercial Product
	Tablet computer [96, 129, 138] /MP3 player [144]	Commercial Product
Memory support	Memory aid [118, 143]/Memory games [142]/Information on village they live in [142]/Cognitive stimulation exercises [143]	Research prototype
	Memory Message [71, 117]	Commercial Product
	Timer to coffee machine[71, 103]	Research prototype
	Locators: Object locator [103]/ Lost item locator [89, 100, 133]/Locating technologies [43]	Commercial Product
Memory support and Orientation	Forget-Me-Not Calendar [117]	Commercial Product
	Message box connected to coffee machine [103]	Research prototype
	Information retrieval system [122]	Commercial Product
	Reminiscence tools [126, 128]	Research prototype
	Clocks and calendars: Electronic orientation clocks [126, 128]/ Night and Day Calendar [44, 71, 100, 117, 133]/ automatic day and date calendar[71]/automatic calendar [102, 103]/ Digital calendar with remote control [103]/ Memory clock [71, 103]/	Commercial Product
	MeDose watch [117]	Commercial Product

Main Use	Type of Assistive Technology	Product Availability
Memory support; Orientation; Safety and security	Integrated Rosetta system: Elderly Day Navigator + The Early Detection System + Unattended autonomous surveillance system [40]	Research Prototype
	Assisted cognition system - touchscreen reminders for the day, current date and time, tracking [145]	Research Prototype
	Smart home management system (Xanboo) [92]/Smart home technologies [134]	Commercial Product
	Personalised recorded messages [50]	Commercial Product
Orientation; Safety and security	*Medicine reminders:* Electronic medication reminder [100, 101, 133, 143]; electronic pill dispensers [89, 119, 126, 128, 139]/ Medicine dispenser with alarm [71, 103]/Medication organiser [43]	Commercial Product
	COGKNOW day navigator - sensors and sensor network [46, 123]	Research prototype
	Talking motion sensors [50]	Commercial Product
Safety and security	Passive positioning alarm package [121, 131]	Commercial Product
	Safety alarm [118]	Commercial Product
	Bed alarm[118]/Bed occupancy sensor [43]	Commercial Product
	Door alarm [118, 137]	Commercial Product
	Sensors: Passage sensor [118]/Sensors [71, 92, 93, 122, 143]/Movement detectors [95, 101]/ Movement sensors [43, 89]/Proximity alarms [43]/Fall sensor [134]	Commercial Product
	Global Positioning Systems: Electronic tracking device [118]/ GPS [103, 119, 136, 146]/ GPS Location monitoring devices [124, 126, 128, 141]/Tracking devices [71, 95, 134]/GPS Tracking system [112, 114–116, 125, 132, 135]	Commercial Product/Research prototype
	Stove timer [103, 113]/ Cooker alarm [71]/Gas cooker device [100, 133]/ Automatic gas switch off devices [95]/Cooker monitors [118]	Commercial Product
	Electronic door lock [71, 103]/Touchpad key locks [43]	Commercial Product

Main Use	Type of Assistive Technology	Product Availability
	Talking wrist watch [71, 103]	Commercial Product
	ADLife - gateway with alarm button, sensors [47]	Research prototype
	In-home night time monitoring system [90, 91, 94]	Research prototype
	Automatic night lamp [100, 133]	Commercial Product
	Automatic water switch off devices [95]/Water detector alerts [43]	Commercial Product
	Baby monitors [50, 127]	Commercial Product
	Health monitoring system [125]	Commercial Product
	Emergency response system [93, 143]/Emergency transmitters [137]	Commercial Product
Safety and security, Social interaction	Skype (on computer/tablet PC) [127]; Social contact system [125]	Commercial Product
	NOCTURNAL - Sensors, communication devices, tablet PC [120]	Research prototype
	Cameras [43, 50, 89, 95, 101, 127]/ Video communication system [122, 134, 142, 143]/Video surveillance [134]	Commercial Product

3.4.5 Question 2: Describe the effectiveness of AT for carers:

A wide range of carer-oriented measures (Zarit Burden Interview, satisfaction with AT, carer wellbeing score etc.,) were reported in the studies with some of the measures specifically created for use in the reported study.

From the 16 quantitative studies (17 publications), ATs were reported as 'somewhat' or 'very useful' and AT was viewed as an adjunct to caring. None of the studies considered or reported adverse events from using AT. Carers reported they would recommend use of AT to others in similar situations, especially AT that supported safety and security for people with dementia. Where this was specifically asked, carers reported wanting to continue to use the AT, after the trial period. AT for safety, including tracking devices were the most used and appreciated by carers. A descriptive summary of the changes reported in these studies is presented in Table 3-3.

Table 3-3 Systematic review Reported changes in carers using Assistive Technology:

Studies	Positive change	Negative change	No change	Statistically significant change
Gitlin LN et al [89]	Overall, somewhat to very helpful.			
Rowe MA et al [90]	• Experimental group 85% less likely to sustain an event. • Caregivers reported satisfaction and confidence in preventing night time injuries and exit using the NMS.			
Rowe MA et al [91]			• No significant improvement in sleep for caregivers. • Night time Monitoring System not sufficient as standalone treatment.	
Olsson A et al [131]	• Decreased level of worry about person with dementia's independent outdoor activities.		• No significant changes in perceived well-being and burden.	
Pot AM et al [132]	• Decrease in the feelings of worry when they could reach person with dementia. • 30% of carers reported they got time for other things since using the GPS.		• Feelings of role-overload were not significantly reduced during the study period.	
Kinney JM et al [92]	• 87.5% of carers reported that the monitoring system made life easier (peace of mind, added	• 43.75% of carers report that the system made life more difficult (cell		

Studies	Positive change	Negative change	No change	Statistically significant change
	security, easier to keep track of person with dementia). • 68.75% report that the system gave carers more free time and more time for self.	phone alerts can be annoying; one more thing to worry about)		
Duff P et al [133]	• Carer burden decreased very slightly during the course of the trial. • 100% of carers using picture telephone and cooker monitor reported satisfaction. • Over 75% of carers reported satisfaction with other AT used in the trial.			
Rialle V et al [134]	• Tracking devices were better appreciated by women. • Younger caregivers found AT more useful than elderly.			
Landau R et al [135]	• GPS device used for sake of patients' safety or for carers' peace of mind.			
Chen Y-C et al [136]	• Most caregivers hope technological products (lost seeking devices) would increase the efficiency and safety			
Alwin J et al [137]			• AT for time orientation, day planning and memory devices were more	• Carers receiving alarm/security devices reported

Studies	Positive change	Negative change	No change	Statistically significant change
			frequently associated with group of carers who reported some/no significant fulfilment and importance.	high fulfilment and importance.
Lim F S et al [138]	• 47.63% of carers reported AT (iPad) was helpful			
McKenzie B et al [43]	• AT devices provided immediate relief, reduce stress and helped carers provide care more easily and safely.			
Schulz R et al [93]			• Caregivers balance costs against potential benefits such as improved functioning, increased autonomy, reduced burden, better health and enhanced safety.	
Kamimura T [139]	• Three caregivers maintained score of little burden or less and one caregiver had a score of mild burden throughout.			
Korchut A et al [140]			• Reminders for medication was a high priority. • Carers viewed robotic technology positively.	
Topo P et al [44]	• 78% of carers found the night and day calendar useful 3 weeks after			

Studies	Positive change	Negative change	No change	Statistically significant change
	use and 82% after 6 months of use.			
Meiland F et al [46]			• No effect on burden or quality of life of the carers.	
Nijhof N et al [142]	• The cost analysis showed that it is more cost-effective for clients with dementia to live at home with the system [PAL4-dementia system] than to stay in a nursing home.			
Mehrabian S et al [143]	• 83% of carers felt the system [telecare prototype] had potential for helping in urgent situations. • 70% of carers felt that they would be ready and accept testing the system at home.			
Lewis V et al [144]	• 65% of carers' comments were positive with respect to utility of the MP3 player.		• No change in self-rated general health. • No change in overall level of satisfaction	• Significant increase in the total Symptom Management Self-Efficacy score (a measure of how confident the caregiver is that they will be able to manage problems that come up and deal with the

Studies	Positive change	Negative change	No change	Statistically significant change
				frustrations of caring). Mean at baseline was 23.5 (SD = 6.1) and 27.0 after 4 weeks (SD = 7.5) (t = −3.1, df= 47, p < 0.01).
Hattink B J et al [40]	• All informal carers felt the system [Rosetta] despite technical difficulties, is very useful and that they were happy with it.		• No significant differences in quality of life, perceived autonomy and feeling of competence between participants who used the Rosetta system and those who received usual care (the control group).	
Navarro R F et al [145]	• Caregiver burden levels show a decreasing trend, while levels of self-efficacy in caregivers increased by using the ambient assisted intervention system.			
Liu L et al [146]		• Some problems relate to false alarms and notifications.		
Tyack C et al [96]			• No significant change of quality of life or well-being across the intervention [tablet computer].	

3.4.6 Question 3: Describe carers' experiences of using AT in dementia care:

Thematic synthesis from the qualitative data generated 4 themes and 15 sub-themes.

3.4.6.1 Positive aspects of using AT:

All the studies reported that the experience of carers using AT was generally positive.

Relationships: The use of AT for leisure and social interaction, memory support, orientation, safety and security strengthened relationships between the person with dementia and their carers. AT was perceived as helping the carer in their caring role and became a 'member' of the wider social network of the person with dementia. For example, the use of a picture button telephone assisted a person with dementia to maintain social contacts with neighbours, friends and family.

Freedom and autonomy: AT offered persons with dementia an alternative solution to being restricted to their home and enabled them to become independent and participate in meaningful activities at home and outdoors. This in turn had a positive effect on the carers. AT also provided carers with additional personal time, which was highly valued and, in many instances, helped create a balance between carers' own personal space and independence with that of staying connected with the person with dementia.

Safety: Carers felt the person with dementia's ability to stay in the community and their physical safety as more important than privacy and autonomy. Tracking devices that supported safety were enthusiastically accepted and AT provided carers reassurance and in some instances, enhanced independence.

Quality of life: AT was perceived by carers as removing worries and was associated with improved mental wellbeing, especially when the carer was living away from the person with dementia.

Competence: AT was perceived as improving independence in a person with dementia. This had a positive effect on the carer, with some elderly carers reporting benefits from using the AT themselves, such as the simple remote control for TV and memory aids.

3.4.6.2 Negative aspects of using AT:

Even if the overall experience of using AT was perceived as positive by carers, some important negative aspects were also raised.

Relationships: When AT failed or the person with dementia was unable to use the AT, this caused constraints in the carer relationship. Some carers worried that the AT would replace the 'in-person' component of caring.

Freedom and autonomy: Carers perceived that the person with dementia's declining abilities could be further worsened by using AT as they would no longer be 'actively' cognitively challenged. Carers also believed that persons with dementia who did not have adequate social support could be left alone/abandoned with the reliance on AT and the person with dementia left without additional opportunities for social contact.

Competence: Carers seemed willing to consider using AT in the future rather than currently. Elderly carers worried about their competence and familiarity with AT, especially when there were technical failings or when AT needed to be replaced with newer devices, as the illness progressed.

Quality of life: Occasionally, the use of AT seemed to create more dependence of the person with dementia on the carer, which led to increased stress for the carer. The attitude of the person with dementia towards the AT (from hostility to indifference) also led to additional carer burden, while choosing and using the AT.

3.4.6.3 Use of AT:

Ethical issues: Carers weighed the needs of personal reassurance and sense of security with that of autonomy of a person with dementia while deciding on use of AT. Often there was no perceived ethical dilemma where the safety of the person with dementia was concerned. There was a consensus among carers that people with dementia must be involved as much as possible to select and use AT. Ethical issues around who held the power of choice of use and abandonment of AT and whether the needs of the person with dementia were altered to match the capability of the currently available AT were also reported in the studies with no definitive conclusions.

Help and support from carers: Carers' continuous engagement and willingness to provide support in using AT was reported as being crucial. Carers' attitude, commitment and willingness to learn about AT were vital if the equipment was to be useful and functional.

Raising issues of using AT: Carers used different methods to convince people with dementia to accept and use AT, especially when the person with dementia was hostile towards or did not understand the need for AT. Carers especially had difficulty convincing someone who has dementia where monitoring and safety devices were to be used compared to using AT for leisure and social interaction.

3.4.6.4 Acceptance and Knowledge of AT:

Costs and resource: Carers noted that AT was expensive. Most of the studies included in this review either provided the technology to the participants or participants did not mind spending on AT that could support the person with dementia to stay for longer, in their own home.

Acceptance of AT: Many of the carers accepted AT as useful. Adoption of AT depended on perceived usefulness. Carers would also recommend its use to other carers and people with dementia. Carers saw technological innovations as inevitable and expected the use of AT to increase and future generations of carers would have better skills and motivation to adopt them.

Knowledge of Technology: Carers felt that information regarding AT should be provided early in the process of diagnosis, especially as the progress of dementia was unpredictable. The main need of information was on simple and practical AT solutions with most carers unaware of new AT devices and solutions available.

Additional illustrative quotes from the included studies supporting the themes and sub-themes is listed in Appendix 8.

3.5. Discussion:

The aim of this systematic review was to identify the types and uses of AT in dementia care and the effectiveness and experience of AT use among carers. The included studies covered the previous 20 years and highlighted how AT was useful in dementia care. Caring for persons with dementia in the community is unplanned and unpaid work carried out by carers. Caring can be rewarding, but can also be damaging to a person's wellbeing and can

put carers under stress [6, 148], especially for a carer who has little prior experience. AT is considered by carers as supplementing support for people with dementia and for them to stay for longer in the community.

The symptoms which have the highest impact on carers of persons with dementia are repetitive questions, apathy, getting lost, aggression and incontinence [91, 94, 124] but the AT solutions from the studies in this review did not effectively address behavioural problems except safety/alert devices for wandering and getting lost.

Fuhrer et al [149] argue that effectiveness, efficiency and satisfaction are essential outcomes for continued use of AT. Findings from this review highlight that carers of people with dementia may prefer a specific type of AT (such as a GPS tracker, movement sensor or medication reminder) and perceive it as useful but it may not have any real effect on outcomes of burden, satisfaction or wellbeing. This is similar to findings from other reviews on AT [38, 150]. A possible explanation for this could be that existing outcome measures that are used in AT studies are not sensitive enough to measure change when using AT, or are not valid in this context, especially as some of the measures were developed before AT started being used more widely.

This review highlighted the lack of consistency in describing or classifying AT [151]. Other studies [75, 149, 152–154] have attempted various ways of classifying AT used in dementia care. This review created a classification system based on use (with more than one use per AT) from the perspective of the person with dementia and carer. This could improve consistency of reporting and enhance synthesis of findings from trials and reviews. AT was classified based on (i) name of AT (ii) type of AT (iii) function assisted (use or intended impact) and (iv) availability (commercial/prototype).

Some of the research described in studies included in this review involved robotic technology in institutional and simulation/lab based settings [155, 156], but this review identified the lack of sufficient number of AT devices to support basic and instrumental ADL for people with dementia. This could be because it is difficult to develop and deploy potentially bulky/expensive AT in a non-institutional setting. Technological advances in miniaturisation and artificial intelligence have not yet caught up with this area of need. Also, human/assisted care is seen as easier and a less expensive way of providing this care [157].

Installation of AT at home for dementia care was often wrongly seen as a one-off event, rather than an ongoing process for getting the best out of AT. Similar to other findings [158–161], this review found that carers often struggle to understand and engage with the AT in their homes, due to poor understanding, a lack of knowledge, lack of on-going support from professionals and design flaws in the AT itself.

This review also highlighted perceived fear among some carers that reliance on AT could lead to social isolation. However, AT such as tablet computers and monitoring devices that alert carers gave them a sense of participating in the life of a person with dementia, even when the carer was not physically present, this led to AT being viewed as a positive addition. There was no evidence within the included studies that multiple ATs were being harnessed to bring them together for an integrated solution that could assist both people with dementia and their carers. AT devices were used in isolation for specific problems/solutions rather than combined use of the devices. With the rise of the internet of things [54, 162] and connected devices, combining multiple ATs is feasible and in most instances desirable [163].

All the studies in this review considered the introduction of AT after a diagnosis of dementia. The timing of introducing AT may be important. Safety/tracking devices were introduced pre-emptively to prevent falls and wandering [75, 150], which in turn could potentially reduce admissions into long-term care [164].

Co-creating AT with users has steadily improved over time. Carers need to be involved in the design and testing of AT solutions and to prioritise the problems that need to be addressed. This will allow AT to be accepted as a solution in dementia care in the community [165, 166]. Many of the AT did not meet the needs of the user. Even if no adverse events were reported, some of the negative reactions to AT were because they were 'off the shelf' devices and were rarely useful in the long-term, especially with a progressive condition like dementia. The AT needed to be adapted or customised for the carers and people with dementia's individual needs and when this was not the case, led to abandonment of the AT [26, 57, 163] .

3.6 Limitations:

Due to the variety of AT devices and outcome measures used results could not be pooled, nor a meta-analysis be completed, but instead a narrative review was undertaken. Due to financial constraints, research studies in languages other than English were not included within this review, and this could have potentially led to some suitable studies being missed. However, a scan of reference lists of all studies that were included for full-text review was undertaken and there is high confidence that this review captures all suitable studies that met the inclusion criteria.

3.7 Conclusions:

The quality of research focusing on AT use in dementia care is low. This highlights the difficulty in learning about carers using AT in the care of a person with dementia at home, as this is a complex social intervention [60, 167]. AT is an adjunct to helping carers provide care to a person with dementia, yet not enough is known about their experiences in using this AT. Technology is advancing at an extremely rapid pace, especially within the fields of artificial intelligence and machine learning with their resultant healthcare applications. It is likely that AT powered by artificial intelligence will become ubiquitous soon. Further study is needed on integrating multiple AT devices to work together, more emphasis should be placed on co-designing AT with carers and persons with dementia and further research is needed to understand the lived experiences of carers of persons with dementia who use AT to support them at home.

3.8 Addendum:

While completing the work on this thesis, an updated literature search was performed on 04 April 2021 to cover the period of June 2018 (when the previous search was performed) – March 2021. This search was performed to ensure no new research studies had been omitted and to continue to monitor for updates on similar work on carers' use of AT in dementia care at home. The results found 844 publications. However, apart from publications authored by the researcher (discussed in subsequent chapters in this thesis) no new published research was found that met the inclusion criteria or varied the conclusions from the systematic review presented in this chapter.

3.9 Summary:

This systematic review highlights the gaps in knowledge and how further investigations from the carers' perspective of using AT in dementia care is needed. The themes from this systematic review were used to inform the interview topic guide for the next phase of the study, which is detailed in the next chapter.

The next chapter describes the exploratory qualitative investigation with carers who use AT in the UK, to understand their experiences, how they use AT and what support they need to use the AT while providing care for a person with dementia at home.

Chapter 4 : Exploration of carers' use of Assistive Technology in dementia care

4.1 Introduction:

Caring for a person with dementia can have a positive or negative influence on the health and wellbeing of the carer. Contextual and environmental factors affect functioning, health and long-term outcomes for a person with dementia as well as their carer [168]. As evidenced from the systematic review [79] described in the previous chapter, AT is one way to support persons with dementia, to enhance their independence when living at home and can assist carers by reassuring them about the welfare of the person with dementia and support communication, cognition, and leisure activities that the carer engages in with the person with dementia. However, despite several recommendations to do so [48, 57, 126], carers are still not placed at the centre of design, prescription and use of AT in dementia care.

Knowledge of carers' experience with AT, which types of AT carers use and prefer and how they use the AT as well as how it helps them, could provide information to those who procure health services (commissioners), health and care professionals and charities who prescribe/recommend AT, and industry partners who develop new AT. Thus, carer experiences with using AT should be investigated further. This in turn would enable tailored advice, information, better care delivery and support for carers of persons with dementia, which subsequently may improve carers' quality of life.

To explore the perceptions and understand the experiences of using AT among carers of persons with dementia living at home in the UK, an exploratory qualitative study was completed.

4.2 Methods:

Qualitative research methods are valuable in providing rich descriptions of complex phenomena [169]. Qualitative research can help illuminate and track the experiences and impact of using AT by carers, giving voice to those whose views are seldom heard. Using qualitative research can help in conducting initial explorations to better understand and later move toward explanations of carers' experiences [170]. To capture the perspectives on AT and explore this based on the lived experience of carers using AT in dementia care, a qualitative design with semi-structured interviews with carers was chosen.

4.2.1 Interview topic guide and publication:

The interview topic guide for this phase of the study was developed from the findings of the systematic review described in Chapter 3. This interview topic guide was reviewed by the research advisory group and confirmed as enabling participants to answer the research questions for this study.

The results from this study were published in a peer-reviewed journal and most sections of this chapter will reflect the publication[1].

4.2.2 Study design:

This study used hermeneutic phenomenology [171–173] as a qualitative methodology [73, 174]. Thematic analysis [170, 175–177] of responses to the semi-structured interview questions was used to identify patterns and report the results.

[1] **Sriram V**, Jenkinson C, Peters M. Carers' experience of using assistive technology for dementia care at home: a qualitative study. BMJ Open. 2020;10:e034460.

4.2.2.1 Hermeneutic phenomenology:

Edmund Husserl is considered the father of phenomenology [178]. Phenomenology deals with the lived experience or the life world. The emphasis is on the world as lived by a person, not the world or reality as something separate from the person [171]. By intentionally directing one's focus, Husserl suggested that a researcher could develop a description of particular realities and come face to face with the ultimate structures of consciousness (essences). Husserl proposed that researchers needed to separate out the outer world as well as individual biases in order to successfully achieve contact with essences [179]. He recommended putting this reality on hold 'bracketing out' all extraneous thoughts to clarify how objects appear to consciousness. This is considered as descriptive phenomenology [180]. Martin Heidegger succeeded Husserl but countered his ideas and described human experience as 'already within the world' and thus 'bracketing' was not possible. He suggested that pre-understanding is not something a researcher can step outside of (or put aside). Heidegger went as far as to claim that nothing can be encountered without reference to a person's background understanding [171]. He developed interpretive phenomenology by extending hermeneutics, the philosophy of interpretation [181], as an interpretive process that seeks to bring understanding and disclosure of phenomena through language [171]. Hermeneutics could be seen as 'the study of human cultural activity as texts with a view towards interpretation to find intended or expressed meanings' [179]. Heidegger concentrated on understanding and our interpretation of phenomena – he developed a notion of how humans give meaning to experience, behaviour and action through understanding and the clarification of speech and language [182].

Susan Crowther [183] describes that

'hermeneutic phenomenology aims to reveal, enhance and extend understandings of a human experience as it is lived; to explore the structures of various types of experiences ranging from perception, emotions, actions and behaviors'.

Hermeneutic phenomenology thus deals with the way in which the world is understood and interpreted in relation to cultural, social and historical contexts [171]. This method is designed to interpret meaning not just of stated facts but of understanding the lived experience in context and to then consider important themes and characteristics of these expressed facts. Lindseth et al [184] use the example of a chair to illustrate this – a chair could be a familiar concept, as a place to sit, for some - chairs are where people are enthroned and for others such as in an academic setting, a chair could be a position held for teaching or research. Thus, the lived experience of an individual must be interpreted in context from the statement(s) they make.

In qualitative research different approaches are used to thematize meaning [185]. In hermeneutic phenomenology themes are developed by understanding and interpretation of data, clarifying the underlying or unspoken meanings that are embodied in lived experiences [180]. The experiences of participants are subjected to descriptive and then a deeper interpretive analysis to identify and develop themes on the qualities and commonalities of those experiences revealing what is beneath and behind the taken-for-granted and obvious subjective accounts of the participants. In addition, the interpretation of data in hermeneutic phenomenology appreciates the dialogical nature of data and how any interpreted meaning by a researcher (interpreter), and then subsequent readers of the work, are provisional; any interpretation will give way to the possibility of new

interpretations over time in an ongoing dialogue [186] and the researcher's experiences and reflections are considered alongside participants' experiences [182].

For this study, personal experience of using hermeneutic phenomenology in previous research (data collection, analysis and interpretation), provided the researcher with a methodology that helped describe the experiences of carers and 'give voice' by interpreting their experiences of using assistive technology in the care of a person with dementia. The researcher however acknowledges that the methodology described in this study is informed by hermeneutic phenomenology and may not be totally distinct from other phenomenological research approaches.

4.2.3 Recruitment:

Participants were recruited from *Join Dementia Research* [13] and the *OxDARE* [14] database. For this study, the inclusion criteria were, participants who are:

- adult carers – spouse, partner, family, friend or neighbour;
- providing at least 10 hours of care (e.g., shopping, leisure, personal care, finance) per week to a person with dementia living at home;
- using at least one AT device at home in the previous year;
- able to speak English.

An email with the participant information sheet (Appendix 9) was sent to volunteers who met the inclusion criteria. From those volunteers who replied to the email, expressing an interest in participating, a purposive sample [187, 188] of participants reflecting variations in gender, age, ethnicity, living arrangements, rurality and relationship with the person with dementia was selected. The recruitment commenced in August 2018 and the final interview was completed in June 2019.

4.2.4 Data collection:

Face to face semi-structured interviews were conducted at the participant's own home or at the researcher's office. Informed consent was gained from each participant before the interview questions were put to the participant. The consent form used is provided in Appendix 10.

The interview used open ended questions following the interview topic guide. The questions explored the participants' experiences of caring for someone with dementia, the types of AT used and their experience of using AT. The questions were followed by additional verbal probing questions that sought to clarify or add to the information provided by the carer. The questions in the interview topic guide and pre-interview preparation are given in Box 4-1.

Saturation is often described as the point in data collection and analysis when new incoming data produces little or no new information to address the research question [189]. Different models of saturation are described in literature including theoretical saturation, inductive thematic saturation, a priori thematic saturation and data saturation [190] and various combinations of these [191]. In theoretical and a priori thematic saturation the focus is on sampling, in inductive thematic saturation the focus is on analysis and data saturation relates to the degree to which new data repeat what was expressed in previous data, with the principal focus on data collection [192]. The researcher is mindful of the conceptual differences in saturation and is not using data saturation within this research as a marker for quality.

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Box 4-1 Exploratory interviews - interview topic guide:

Pre-interview:

Participant to re-receive the information sheet and asked to read it through. Participant will be given a brief introduction to the research that includes a description of Assistive Technology.

- *Show University Card for ID of Researcher and introduce self*
- *Participant to be told what will happen during the interview process and reminded that the interview will also be audio recorded. Participant to be told that an anonymised transcript will be made from the audio recording.*
- *Participant to be reminded that they will remain anonymous, and that their data will be confidential.*
- *Participant given time to ask questions*
- *Participant will be asked to sign two copies of the consent form, one of which is to be retained by the researcher.*

Questions:

Background:

1. Can you tell me a bit about yourself and your current situation and living arrangements? – You have the option of not providing this information if you do not wish to.
2. How long have you been helping or caring for [person with dementia]? How did it start?
3. How is your day to day life affected by helping or caring for [person with dementia]? What tasks do you help or support them with?
4. How is your health generally?
5. How has your caring role changed since you first took on the role? In what way?
6. What support, if any, do you receive from other people?
7. What would help you on a day to day basis? This could be something (or many things) to support your own health and wellbeing, or to help you care for [person with dementia]?
8. What tasks that you help or support [person with dementia] with do you find challenging?

Use of Assistive Technology:

As you know we are particularly interested in your experiences of Assistive Technology use for [person with dementia] Give examples of AT.

1. What do you think are helpful and unhelpful about the use of ATs?
2. What AT do you use with [person with dementia]? Can you tell me why these types of ATs were chosen and used? How do you and/or [person with dementia] use AT?
3. What is your main purpose for using the AT (ask for each type of AT)? Are the any other purposes?
4. What was particularly helpful or unhelpful about the use of each AT? If you are using multiple types of AT, is there one that is more helpful than others (and if so why)?
5. Do you think using this AT helps/helped you in caring for [person with dementia]?
6. What would you do to support [person with dementia] if this AT was not available?
7. If you have used an AT before and no longer are using it, what do you think prevented you or [person with dementia] from using it?

Experience of using Assistive Technology:

1. Can you tell me more about your experiences with this (these) AT(s)?
2. Can you tell me your views or experiences regarding the use of or non-use of AT as [person with dementia] dementia progresses?
3. How do you feel about using AT to support [person with dementia]? And Yourself?
4. Do you feel the AT is integrated in your daily life/help/care that you provide for [person with dementia]?
5. What support have you needed to use the AT? Where did you get the support from?
6. How has use of AT impacted on your wellbeing/QoL?

Is there anything else you would like to add about your caregiving experience or AT?

The background of the interviewer as an Occupational Therapist and consequent interest in the research topic was discussed with participants when it came up. The participants were not known to the interviewer before recruitment. The researcher acknowledged that being interviewed is an unfamiliar experience to many participants and they look to the researcher to help them feel 'comfortable'. Participant being at ease is important for data quality, helping the participant to answer honestly and openly [193]. For the interviews in this study, rapport was built with the participants to establish a feeling of connection, comfort and conversational ease. The researcher approached all participants politely, used humour with pleasant and courteous conversation over tea (when it was offered by the participant), avoided jargon and used a conversational tone throughout the interview. The researcher listened attentively and respectfully throughout the interview and acknowledged the sensitive nature of the discussion. In addition, the researcher also checked with the participant that they were comfortable before and after the interview as well as answered questions regarding the research project as a whole and the experience of doing doctoral research. The interviews lasted between 30-55 minutes, were audio-recorded, and later transcribed verbatim with names of participants/the person with dementia and any towns/cities mentioned in the interviews pseudonymised to ensure confidentiality.

4.2.5 Data analysis:

The data were analysed using NVivo version 12 [18]. The data analysis was ongoing throughout data collection, this allowed modification of the interview guide to focus on emerging patterns.

The process for data analysis was in three steps and inspired by Lindseth and Norberg's method [73, 184].

1. The interviewer listened to each of the interviews (naïve understanding) and transcribed them with assistance from a professional transcriber.
2. 'Meaning units' that captured carers' experience of caring and using AT were then identified (structural analysis). These groups of statements from the transcribed text were labelled with a code.
3. The identifying and coding of meaningful units was repeatedly re-evaluated, and earlier transcripts were recoded to reflect new codes. All the coded units were grouped into themes and underlying sub-themes by a 'comprehensive understanding' of how to interpret the findings in relation to the everyday experience of carers.

This understanding was achieved using a circular process (i.e., a hermeneutic circle) that involved moving from the whole (naïve understanding) to the individual parts (structural analysis) and from the individual parts back to the whole (themes).

Carers' own words with an understanding of the context (relationships, caring tasks, living arrangements etc.) were used to illustrate themes that retained the voice of the carers' personal experiences and perspectives.

There is no practical way to get at what is going on inside someone's head, data collection methods such as interviews are necessarily interpretive and mediated by language and the participant's background. The interpretation of carer's experiences in this study is layered and complex as the carer must interpret their experience and the researcher must then interpret that interpretation. While this research sought to understand the subjective experience of carers using AT, the qualitative interviews relied on carers' ability to accurately and honestly recall details about their lives, circumstances, thoughts, opinions

and behaviours and communicate this to the researcher. Building rapport could have helped with thoughtful and honest responses but the researcher was aware that participants may be answering questions in a way that is socially acceptable, especially on a sensitive topic that involves social, behavioural and personal questions.

4.2.5.1 Reflexivity and integrity:

The researcher positioned himself in a hermeneutic phenomenological stance and analysis and interpreting data from the interviews was done in collaboration with others. The interviews, initial analysis, coding of transcripts and themes were completed by the researcher VS. MP and CJ (supervisors of the researcher for this DPhil) read selected transcripts and coded meaning units and themes. Regular meetings between VS, MP and CJ supported discussion, data collection, analyses and interpretation of themes.

Reflexivity [194] and integrity of the research process was maintained throughout the data collection and analysis stages. Reflexivity acknowledges the role of the researcher as a participant in the process of knowledge construction and not merely an outsider-observer of a phenomenon [194] and for this research, it is acknowledged that this experience and prior conceptions on long-term care and carer experiences could have influenced the coding and interpretation of the themes. The researcher's experience as an occupational therapist and MP and CJ as health services researchers, including experience of research with people with long-term conditions, such as dementia, and their carers, provided the necessary expertise for this research. The interview topic guide was informed by the results of the systematic review and there was active participation from the participants in the interviews, all of which assisted with triangulation. The purpose of triangulation was to bring together interpretation of meaning from multiple participant perspectives. The researcher recognises

the criticisms of triangulation in qualitative research and acknowledged that triangulation in this instance was a strategy for deeper understanding of the experiences of carers of persons with dementia when using AT rather than for validity or objectivity of the interpretation of data [109] . The experience of VS, MP and CJ enabled appropriate ethical conduct during the study.

4.3. Results:

4.3.1 Participant characteristics:

A total of 387 emails were sent to volunteers in the *Join Dementia Research* and *OxDARE* databases. Of the 112 responses received, 61 carers did not meet the eligibility criteria (mainly from carers providing care for a person with dementia who had moved into a long-term care facility). Twenty-three carers (14 women and 9 men), with varying types of relationship to a person with dementia, finally took part in interviews. Every participant had used at least one AT device in the previous year. Participants were aged between 42 to 91.

Towards the 21st interview, new data repeated what participants expressed in previous interviews and no new codes were emerging. Data collection continued with two more interviews to ensure and confirm that there were no new codes identified. . Table 4-1 provides further details on participant characteristics and the AT used.

Table 4-1 Exploratory interviews - characteristics of interview participants:

ID	Age Range	Gender	Relationship	Ethnicity	Occupation	Living arrangements	Assistive Technology used
1	71-85	Male	Husband	White British	Retired	Not currently living with person with dementia [hospital admission at time of interview]	iPad; Motion sensor alarm
2	86-100	Male	Husband	White British	Retired	Living with spouse/partner	Pendant alarm; Large picture button telephone; Call monitoring app; Emergency alarm; Stair lift
3	40-55	Male	Son	Asian or Asian British Indian	Full-time Work	Not currently living with person with dementia	iPad; Pendant alarm
4	56-70	Female	Daughter	White British	Part-time Work	Not currently living with person with dementia	Three rings plug; Motion sensor system; Pendant alarm
5	40-55	Female	Daughter	White British	Part-time Work	Not currently living with person with dementia	iPad with messenger app; WhatsApp group; Lost item locator fobs; Smart mobile phone; Picture button telephone; Alexa spot
6	40-55	Female	Daughter	White British	Part-time Work	Not currently living with person with dementia	Simple button mobile phone; CCTV cameras; Talking clock; Automatic medication dispenser
7	40-55	Male	Son	White British	Part-time Work	Not currently living with person with dementia	Dementia clock; Simple remote control; Pendant alarm; Movement sensors; CCTV camera
8	71-85	Male	Husband	White British	Retired	Living with spouse/partner	GPS tracker; Electronic pillow raiser; Dementia clock; Pendant alarm

ID	Age Range	Gender	Relationship	Ethnicity	Occupation	Living arrangements	Assistive Technology used
9	56-70	Female	Niece	White British	Retired	Not currently living with person with dementia	Motion sensors; Pendant alarm; Digital cash box
10	56-70	Female	Daughter	White British	Full-time Work	Not currently living with person with dementia	Pendant alarm; Dementia clock; Smart gas meter
11	71-85	Female	Wife	White British	Retired	Living with spouse/partner	iPad; Fitbit watch; smart mobile phone; Laptop
12	56-70	Female	Daughter	White British	Retired	Not currently living with person with dementia	Pendant alarm; Falls monitor; Motion sensor system; Dementia clock; Call screening telephone
13	71-85	Female	Daughter	White British	Retired	Live-in carer	Hospital bed; Electric hoist; Dementia clock; Automatic sensor light; Baby monitor; Mattress alarm
14	71-85	Female	Wife	White British	Retired	Living with spouse/partner	Automatic night/day light; Satnav system in car; GPS tracker; Smart mobile phone; Automatic medicine dispenser
15	56-70	Male	Husband	White British	Retired	Living with spouse/partner	Dementia clock; GPS tracker; Lost item locator
16	40-55	Female	Grand daughter	White British	Part-time work	Not currently living with person with dementia	Door entry fob; Automatic sensor lights; Pendant alarm
17	56-70	Male	Husband	White British	Retired	Living with spouse/partner	Riser recliner chair; Flood detector; Automatic switch off taps; Door exit alarm; Electronic pillow raiser
18	56-70	Female	Daughter	White British	Full-time carer	Live-in carer	Smart gas meter; Electric hoist; Electric bed; Bed movement sensor; Airflow mattress; Air floss; Touch and dry auto sensor hair dryer

ID	Age Range	Gender	Relationship	Ethnicity	Occupation	Living arrangements	Assistive Technology used
19	40-55	Female	Daughter	White British	Part-time Work	Not currently living with person with dementia	Alexa spot; Alexa show
20	40-55	Male	Son	Asian or Asian British	Part-time work	Living with person with dementia	Fall alarm; Simple button remote control; large button telephone; iPad
21	40-55	Female	Daughter	White British	Part-time work	Living with person with dementia	Automatic medication dispenser; Reminder clock and calendar; Door exit alarm; Pendant alarm
22	71-85	Female	Wife	White British	Part-time work	Living with spouse/partner	iPad; Pendant alarm; Door exit alarm; Smart mobile phone
23	56-70	Male	Son	White British	Retired	Not currently living with person with dementia	Automatic medication dispenser; Three rings plug; Movement sensor system; Pendant alarm

Analyses generated five major themes that reflected carers' experience of using AT and the impact it had on their everyday life.

4.3.2. Theme 1: Providing care for a person with dementia while using AT:

Carers expressed a mixed picture of additional responsibilities because of caring for someone with dementia. Some of these responsibilities acted as a trigger for considering and using AT. Some of the non-spousal carers moved either themselves or the person with dementia to be geographically closer; where this was not possible there was a reliance on using remote monitoring AT. Other participants relied on increasing the number of physical visits to the person with dementia and used additional paid carers.

4.3.2.1 Caring role:

Carers provided support with personal care, including continence management; leisure activities; domestic tasks, household support; financial management and help with transport for essential appointments.

> *"…So, I help her, so basically, with like really fundamental carer activity. So, literally like washing, cleaning, all the glamorous stuff and I provide company for her as well. I help her with watching media or organising things around the home; that sort of stuff"* (participant 7, Son, not living with person with dementia).

The amount of care provided, was for some participants dependent on other responsibilities they had. For example, children of persons with dementia had caring responsibilities for their own children. As one carer put it, they saw themselves as 'a sandwich generation'.

> *"I suppose I'm a typical sandwich generation person; the combination of dealing with my own family['s] needs and knowing that I need to sort of check up on, sort out, shop, cook for my mum as well…. I feel like I have a third child"* (participant 6, Daughter, not living with person with dementia).

AT was used as an additional layer of support while providing care for a person with dementia. AT was used for support with personal care tasks, safety, orientation to date and time, leisure and social interaction and to improve safety and security.

4.3.2.2. Financial considerations in using AT:

Carers invariably made the decisions on purchasing and using the AT. In most instances, these decisions were made without consultation with the person with dementia. Some participants had access to pendant alarms from their local authority social services, but most participants purchased AT devices currently in use by themselves. The costs of the AT were perceived as being expensive, with decisions to try/trial a particular AT determined by the cost.

> *"A particular application can be developed and promoted and looks sexy and relatively…you know, can be sold for a price; doesn't mean to say it's actually going to be much added value"* (participant 15, Husband, Living with person with dementia).

> *"I don't know. It is an expensive thing to experiment with…Do I buy that?' even though it's maybe another hundred pounds. I can imagine that being a tough decision"* (participant 5, Daughter, Not living with person with dementia).

Carers expressed concern that slightly modified AT were being marketed and priced higher simply because they were aimed at people with dementia who are likely to require the use of AT.

> *"You know, the clock [Dementia clock] that I bought her; this clock that's got Monday to Friday on it, cost me fifty pounds. And if it's just a normal clock which normally would probably cost a tenner if it's for you and me"* (participant 10, Daughter, Not living with person with dementia).

4.3.2.3. Unanticipated issues arising from the use of AT:

Carers used AT for reassurance and to provide additional support for the person with dementia, however, occasionally there were incidences where the AT failed or increased inconvenience for the carer.

> *"…it [movement sensor] alerted me in the night. It also alerted me if a spider walked across, which wasn't ideal"* (participant 13, Daughter, Live-in carer).

> *"With the bed mattress [air-flow mattress], I couldn't really get it [bed sensor] to work anyway with this alternating mattress because every time the cycle went round it set off the alarm because it thought there'd been an epileptic fit happening"* (participant 18, Daughter, Live-in carer).

Occasionally, the AT could assist a carer in ways other than what it was intended for, which helped the carer provide an improved level of care for the person with dementia.

> *"Although it [a movement sensor system with remote alerts] wasn't set up to check up on them [paid carers] in any way. We did find that a couple of the carers were saying that they had done things and with writing them in mum's record book. Yes, we found that one carer who was saying she was bathing mum but the monitors showing that nobody's been upstairs to the bathroom"* (participant 4, Daughter, Not living with person with dementia).

4.3.3 Theme 2: Motivation for using AT:

Carers gave various reasons for considering use of AT. The initial motivator seemed to be to problem solve for concerns or issues that the person with dementia was having. This included considerations of safety for the person with dementia, reassurance for carers and ease of use of a particular AT.

4.3.3.1 Freedom and autonomy:

Carers used AT to enhance freedom and autonomy for a person with dementia, which resulted in additional time for the carers themselves to carry out other tasks.

> *"I mean if there's a film on it [iPad] he likes to watch, then I can get on if I'm here and not at work; I can get on with chores like ironing or doing something"* (participant 22, Wife, Living with person with dementia).

4.3.3.2 Quality of life and wellbeing:

Carers surprisingly did not consider their own quality of life or wellbeing as reason for choosing AT. In essence the initial choice of AT was dependant on the functional needs of the person with dementia. However, reasons for reassurance to the carer of safety and welfare of the person with dementia was mentioned often. Once the AT was in place, carers were able to appreciate the positive influence of the AT on their wellbeing, and this did vary over time depending on the progressive nature of dementia.

> *"She was on the phone constantly day and night ringing up to see what day it was, what time it was; what was she supposed to be doing at that time. Well…we don't get that anymore because she just looks at the clock [Dementia Clock] and she knows. So yes, definitely, it's cut my workload, if you like, down a lot"* (participant 12, Daughter, Not living with person with dementia).

> *"I think it's [wrist fall alarm, simple button remote, large button telephone, iPad] absolutely been a life changer for me as a carer, for me as a son, and as a family member as well"* (participant 20, Son, Living with person with dementia).

Occasionally the increased anxiety over safety, especially for a carer who lived further away from the person with dementia, resulted in over-use of AT that exacerbated their need for constant reassurance of the welfare of the person with dementia.

> *"My husband used to worry that I was checking too much [participant using motion sensors in the home of person with dementia that could be viewed on a smart phone]. Say…I didn't switch off"* (participant 4, Daughter, Not living with person with dementia).

4.3.3.3 Ease of using AT:

There were differing opinions on how easy it was for a person with dementia or for the carer to use an AT device. Even though ease of using AT was a factor that was considered before the purchase of an AT device, it was only during use at home that some of the issues on ease of using the AT surfaced.

> *"…it's an easy phone to use [picture button telephone]. So, if [person with dementia] wanted to dial out, err…she presses the A button, and she presses that [points to his picture on the phone] and she talks. Anyway, it's a nice bit of kit that* (participant 2, Husband, Living with person with dementia).

> *"He hears the phone [smart phone] ringing [video call]. He realises it's me because nobody else phones him because he never switches it on. And he'll come indoors to see what I want rather than pick it up and answer it because I'm not sure he knows how to do it"* (participant 11, Wife, Living with person with dementia).

4.3.3.4 Reassurance:

For many carers, AT provided a useful additional layer of reassurance, even if it was technology that was not often used.

> *"…and it's sort of like an extra level of reassurance. But I mean because she was wandering, so it is kind of good to know that there's a thing there [door exit alarm]. I don't know... yeah, it's not really been used but it's sort of good to have, so yeah"* (participant 21, Daughter, Living with person with dementia).

Carers who lived away consistently expressed the need to have reassurance that the person with dementia was safe at home, even if the person with dementia did not require physical

help or verbal prompting. Occasionally this reassurance was provided through 'check-visits' by professional carers. Where this was not available from public/private funded services carers instead relied on remote monitoring systems.

> *"When we had the sensors on [motion sensor system], that was the most helpful for me because it was a real peace of mind knowing that she was moving about from room to room and that, you know, obviously then she was fine"* (participant 12, Daughter, Not living with person with dementia).

4.3.4 Theme 3: Changes to roles and routines:

Carers frequently referred to a range of lifestyle adjustments that they had to make in caring for a person with dementia and this extended to using the AT.

4.3.4.1 Additional tasks and responsibilities:

When AT was used, as part of caring responsibilities, carers had to take on additional responsibilities and adjust their routines. Carers did not consider this an onerous change and the benefits that the AT provided appeared to out-weigh these additional tasks and changes to routines.

> *"He [person with dementia] likes me to set it [GPS satellite navigation system for use in a car and for walks] for him now. I don't know whether he's...that's because...I think that's because he's had problems setting it himself"* (participant 14, Wife, Living with person with dementia).

> *"It's almost second nature now just to have a quick check on the motion sensors and a quick check on her location"* (participant 23, Son, Not living with person with dementia).

4.3.4.2 Active and passive AT:

Carers expressed a need for devices that actively anticipated the requirements of a person with dementia. This was mainly because cognitive decline in someone with dementia usually necessitated devices that could predict and react to what the person with dementia wanted, rather than having to wait for the person with dementia or the carer to verbalise the need. At the time of the interviews, none of the carers used an artificial intelligence driven device that could provide this function.

> *"...but for my wife and her particular presentation of the dementia, any assistive technology would have been, has to be absolutely passive and require no input whatsoever from her"* (participant 1, Husband, Person with dementia temporarily in hospital).

> *"…it has to be something passive. Passive sensors or even understanding in our absence from a location perspective, where is she…and how often is she...so, in those kinds of situations when somebody is alone, what would be [sic] those passive sensors that actually come alive and create a real time alert for the caregivers"* (participant 3, Son, Not living with person with dementia).

Carers sometimes had to modify/change AT, when a device that required active engagement from the person with dementia was no longer adequate. A frequent issue raised by carers was regarding *pendant alarms* that were issued to persons with dementia by social services, to alert a carer or a call centre. Often, the person with dementia was not aware of how to use the pendant alarm when required, especially when their cognitive abilities worsened. Consequently, some participants indicated that they purchased falls alarms instead, which triggered an automatic alert to a call centre.

> *"Mum [now] has a falls monitor that she wears round her neck. We did have a standard call alarm that you press a button or a pendant round her neck, but Mum had a couple of falls and had no idea what this thing round her neck was for"* (participant 12, Daughter, Not living with person with dementia).

> *"Yes, he has the pendant alarm but sometimes he forgets to... you know, he forgets about it"* (participant 9, Niece, Not living with person with dementia).

4.3.4.3 Considering AT for use in the future:

Carers felt that the younger generation was getting better at using technology and the use of AT in the care of persons with dementia was likely to increase in the future. In addition to currently supporting a person with dementia using AT, carers had to anticipate future problems that the person with dementia could have and how to support them.

> *"I could get sensors in and I could see what she's doing. And I could also put something on her front door which would enable me to see who's... you know, use that app that's come out where you can see, well who's actually getting into the house and stop them getting in"* (participant 10, Daughter, Not living with person with dementia).

> *"I will get some sort of tracker thing with his agreement so that when he gets lost, if he gets lost when we're on holiday, we're going out for a walk or something and somehow we've got separated and we'll be able to find each other"* (participant 14, Wife, Living with person with dementia).

4.3.5 Theme 4: Knowledge and skills for using AT:

Carers used a variety of sources for information on accessing support for a person with dementia. For information regarding AT, personal knowledge, shared knowledge from other family members, support groups, public and third sector organisations as well as internet

searches were used. Carers also had to rely on their skills to adapt and adopt AT for use by someone with dementia.

4.3.5.1 Sources of information about AT:

All of the interviewed carers reported using dementia specific charities as a source of information on AT. Information was gathered either by the main carer or a family member from websites as well as through their involvement in local dementia or carer support groups.

> *"I belong to a carers group in [name of town] and we have had a couple of presentations from people who have come along to tell the carers about technology, which is available"* (participant 1, Husband, person with dementia temporarily in hospital).

> *"[National Charity] were quite good and they have some quite good websites, and so I did quite a lot of reading beforehand and also dementia [town] and [they] have leaflets and stuff"* (participant 4, Daughter Not living with person with dementia).

4.3.5.2 Support from public services and others:

The AT products themselves were overwhelmingly purchased with private funds by family, carers or persons with dementia themselves. Some AT devices such as pendant alarms and hospital beds were provided through health or social care services, based on the functional needs of the person with dementia.

> *"[I] think they were all items that were suggested by somebody [family]…they came up with the calendar...clock/calendar thing, and they were quite proactive in coming up with various things"* (participant 13, Daughter, Live-in carer).

> *"The emergency pendant, the social workers there were very good and suggested things like that. The TV remote control, we saw that at a meeting at a local charity near us that has a meeting for people with young onset dementia"* (participant 14, Wife, Living with person with dementia).

However, carers perceived that the support from public services was not always satisfactory. Sometimes, they were only provided with information or sign-posted to charities and this often was not sufficient for some carers.

> *"It takes a bit of imagination and confidence to find the help that you need from [local council]. I think it's really difficult for people. But I think an awful lot of people don't and have to... and kind of give up in desperation and people end up in care homes and then everybody's unhappy"* (participant 13, Daughter, Live-in carer).

4.3.5.3 Adapting AT for use in dementia care:

Carers or others had to adapt/modify some of the AT for successful use. This depended in part on the skill, including sometimes by trial and error and confidence of the carer in enabling this to happen. Carers also had to change routines or adapt the physical environment so that the AT could be successfully used.

> *"…the reason for that is, is that bit on here [points to the pendant button and elevated ring around it] is not part of the original kit. It's something I have put on it…the button protrudes, well as you can imagine, the minute you put it on, brush your hand against it, it goes off. So, I went and bought a piece of…I think it was a piece of plumbing fitting. Cut the end of it and glued it onto there, so that you have to…press it"* (participant 2, Husband, Living with person with dementia).

> *"Having the app [connected to movement sensors] was brilliant. I think if you had to find a laptop and logging and all that, it would have been a bind. I think the fact that most people have smartphones and you just do that and it's like 30 seconds, you know*

you've got all the information you need" (participant 4, Daughter, Not living with person with dementia).

4.3.5.4 Use of AT over time:

New AT devices were tried, or AT was abandoned due to the unpredictable and progressive nature of dementia, which dictated the ability of the person with dementia. This meant carers had to be constantly aware of and looking for additional information on AT.

"We had little monitors set up round the house that could tell where she was moving and when she'd gone into the kitchen and we could access it from our iPads and see what she was doing. We only [had] that for a short period of time…But it was really valuable when we did have it" (participant 12, Daughter, Not living with person with dementia).

"It can be a bit discouraging as well when you, you know, keep buying new stuff and then it gets kind of put to one side. It's just trial and error" (participant 5, Daughter, Not living with person with dementia).

4.3.6 Theme 5: Social, environmental and ethical considerations in using AT:

Dementia, like any other long-term conditions, can be viewed from a bio-psycho-social model perspective. AT use by and for people with dementia is linked to the social and environment context of use. These include attitudes to technology of carers and persons with dementia, as well as how technology systems are integrated into everyday care. Social structures including age, gender, previous experience of using technology and coping styles when technology breaks down are also relevant.

4.3.6.1 Social pressure to use AT:

Carers expressed that caring for a person with dementia introduced pressures on carers to buy or provide care, including AT, that they would otherwise not have chosen. Carers were compelled by peer pressure or they wanted to be seen as doing the right thing for the person with dementia.

> *"Whenever you go to see the doctors or you see the mental health team.. and they all say to you, 'Has she got this, has she got that, has she got... do that, has she done this?' And you think to yourself, 'Well, I'd better have it then because it's obviously something that people think they're useful.' So, to a certain extent she has the [pendant] alarm because everyone expected to have the alarm because she [is] older"* (participant 10, Daughter, Not living with person with dementia).

> *"[I bought] a baby alarm, which was something I had to buy. I suppose... I think that's because of confidentiality and that the [professional] carers could be feel [sic] they were being spied on [by putting in a camera], isn't it?"* (participant 13, Daughter, Live-in carer).

4.3.6.2 Integrated AT:

The provision, purchase and use of AT does not happen in a vacuum. Carers revealed that most AT devices need the support of other technology or solutions to be available to work in the intended manner, and occasionally these were unavailable or had additional cost implications. From the interviews, it was clear that carers also had to use multiple ATs in isolation as they were manufactured by different providers and did not integrate and work well with each other.

> *"I'm also a little bit worried…I'm very concerned that a lot of stuff [movement sensors] are wireless route [sic]. Well, that concerns me a little bit because if there's a*

breakdown in the internet, which [rural community in Scotland] is a bit renown for" (participant 16, Granddaughter, Not living with person with dementia).

"…the sense of longevity and also the entire patient journey, that same piece of equipment does not solve the problem and they are not integrated. There are very discrete pieces, but they are not matching with disease progression as they only solve one problem at a time and do not match up to condition that progresses" (participant 3, Son, Not living with person with dementia).

4.3.6.3 Co-morbidities associated with dementia affecting choice and use of AT:

The use of AT by carers whilst they cared for persons with dementia was the main focus of this study. The interviews revealed that carers often were having to make decisions for someone with dementia who had other multiple co-morbidities. When the abilities of the person with dementia deteriorated, AT use was reduced, and additional formal carers were employed. In other instances, AT was purchased to support issues that arose as a result of these co-morbidities, other than those related purely to dementia.

"That's made it...I wouldn't say more difficult, but it's changed the nature [of care]. In fact, to be honest, in some ways it's [i.e. the person with dementia having a stroke] made it easier because we now have carers coming in twice a day as well" (participant 23, Son, Not living with person with dementia).

"She's got a pillow lifter. Because of the extreme arthritis in her shoulder she has this pillow lifter that can raise up or down...the other arm… because of the extreme arthritis in the shoulder is… she can't really put much strength on it you see…and the pillow lifter handset, she has to be prompted to use them" (participant 17, Husband, Living with person with dementia).

4.3.6.4 Ethical considerations in the use of AT:

Carers actively reflected on ethical issues when using AT, especially when its use was considered to be intrusive, particularly those that allowed remote monitoring.

> *"We stopped having it [movement sensors in every room] because I felt it was an infringement of her privacy. I felt quite awkward about it, so we didn't have it anymore"* (participant 12, Daughter, Not living with person with dementia).

> *"We have [had] been thinking of putting cameras in our house for security purposes, but we have not yet done that. I don't think she'll have a problem with that at all…but We don't have a camera and we decided not to use it"* (participant 3, Son, Not living with person with dementia).

Decisions regarding purchase and continued use of AT did not always involve the person with dementia. Even when a person with dementia initially consented to use of intrusive/privacy-reducing technology at home, it was not always followed up over time, especially when the condition of the person with dementia deteriorated. Carers considered issues of privacy, dignity and beneficence and non-malfeasance as important when using AT. However, these considerations were often supplanted by issues of safety, vulnerability and autonomy of the person with dementia.

> "*We don't... there's nothing observing what she's up to in the bathroom or in the bedroom, but we can see that she's up and moving around, so that is very useful"* (participant 6, Daughter, Not living with person with dementia).

Carers also actively chose not to use certain types of AT, as they felt it would further socially isolate a person with dementia.

> *"It [remote video monitoring] might give people an excuse to do less and less talking and less and less face to face, and I know that's, for her, is definitely one of the things*

that brings her most happiness and joy, is actually the human stuff" (participant 7, Son, Not living with person with dementia).

A couple of the carers also expressed concerns of third-party data sharing and potential hacking into private devices.

"We put a very strong password on and all that kind of thing, but we saw these... well, I saw these websites where they had photographs of people on webcams, ladies in beds and things and a little bit worrying really when you think someone might be hacking in and looking at your Mum" (participant 18, Daughter, Live-in carer).

"*Yeh, it's the technology. There's all this thing, 'Oh, it's listening into everything we say' [speaking about concerns from other family members on using Alexa – a cloud-based voice service]"* (participant 19, Daughter, Not living with person with dementia).

Further illustrative quotes aligned to the themes and sub-themes is given in Table 4-2.

Table 4-2 Exploratory interviews - Themes and sub-themes with illustrative quotes:

Theme	Sub-theme	Example quote 1	Example quote 2	Example quote 3
Providing care for a person with dementia while using AT	Caring role	When you are dealing with anything like dementia, for example, it doesn't actually impact one person; it impacts the whole family (participant 20, Son, Living with person with dementia).	I needed the agency [private care provider], social services and the incontinence nurses to just kind of back me up that I'm doing the right thing. Because to take over someone's life it's not easy (participant 10, Daughter, Not living with person with dementia).	It means that every day I have to sort of... I can't really go out anywhere or do anything for the whole day because I have to be here some time of the day to call on my mum and check that she's OK (participant 12, Daughter, Not living with person with dementia).
	Financial considerations in using AT	Most of the equipment that we had has been supplied by the Red Cross and so it hasn't cost a fortune to be able to, you know, keep them at home (participant 13, Daughter, Live-in carer).	So, I thought, well we need to get these automatic stop taps in. I knew they existed; it was just a case of getting the right sort of… the right price (participant 17, Husband, Living with person with dementia).	My sister, my other sister paid for that (participant 19, Daughter, Not living with person with dementia).
	Unanticipated issues from the use of AT	Sometimes it [automatic medication dispenser] doesn't work very well because he's doing something when it rings so he just turns it off and then he doesn't get up and get his pills straight away, so then he forgets because he knows he's heard the alarm, so he assumes he's taken his pill	It was that device [three rings adaptor plug with kettle plugged in] which alerted us to the fact that she'd had her stroke (participant 23, Son, Not living with person with dementia).	So, he couldn't ring for help. And he was there for a couple of hours. And for some reason the sensors didn't alert the care link (participant 9, Niece, Not living with person with dementia).

Theme	Sub-theme	Example quote 1	Example quote 2	Example quote 3
		(participant 14, Wife, Living with person with dementia).		
Motivation for using AT	Freedom and autonomy	If he didn't have a satnav I would just have to go with him more; it would really reduce his independence and make it harder for me (participant 14, Wife, Living with person with dementia).	I think it's brilliant because what I didn't mention with the falls pendant is, say for example, I just go right now to the shops to go and grab some groceries (participant 20, Son, Living with person with dementia).	She watched TV and we got a very simple remote. She was able to use that (participant 4, Daughter, not living with person with dementia).
	Quality of life and wellbeing	I think, any form of video communication is very helpful…The conversation…the quality of the conversation is very different when she's seen me on the video chat (participant 3, Son, Not living with person with dementia).	Well, you know, you get interrupted on what you're doing. It's very wearing; draining I mean, to have to keep stopping and answering all these questions. So, yeh, it's just... it's [calendar clock] made things easier because somebody else can do it for themselves (participant 8, Husband, Living with person with dementia)	So all those bits of technology [falls alarm, mattress sensor, calendar clock] were very helpful. Well, it's... you know, it's solving a problem. Without it, it would be impossible (participant 13, Daughter, Live-in carer).
	Ease of using AT	Even though I drew a note and I drew those two symbols and wrote against them pause and play, she no longer had the cognitive capacity to follow the instructions to use the assistive technology [simple button remote	She does have difficulty remembering to… how to switch it off. So, you know, the commands, like you say, 'Alexa, stop,' and stuff like that. So, she will forget, or panic and she'll unplug it because it's	Of course voice calls are always available, but when we started finding that the iPad was easy for her to operate than the phone, we just moved from voice to video (participant 3,

Theme	Sub-theme	Example quote 1	Example quote 2	Example quote 3
		control] (participant 1, Husband, Person with dementia temporarily in hospital).	easier for her to… rather than say, 'Alexa, stop.' (participant 19, Daughter, Not living with person with dementia).	Son, Not living with person with dementia).
	Reassurance	So, from a reassurance point of view of not living in the same town or not… even if I was in the same town I wouldn't know she's had a fall; it's [falls monitor and alarm] been absolutely fantastic (participant 16, Granddaughter, Not living with person with dementia).	I didn't have to ring mum up every morning to make sure she was up. I could look when she has used it [three rings plug attached to a kettle] and think oh yeah, she had a cup of tea at 9 o'clock and put the kettle on at 11, so she is ok (participant 4, Daughter, Not living with person with dementia).	Confidence, that she's safe and well looked after because we've got the equipment [falls alarm, key safe] that we've got (participant 13, Daughter, Live-in carer).
Changes to roles and routines in using AT	Additional tasks and responsibilities	I have to remember…I must and I do forget sometimes of course. So, if I go to the gym or something like that, I always have to remember to take the phone in my pocket (participant 2, Husband, Living with person with dementia).	It's something we're working on as a family to sort of build a schedule [using whatsApp groups] so that we know who's available to help (participant 5, Daughter, Not living with person with dementia).	The remote control [simple button remote control] means I don't get those phone calls saying the TV's broken and I don't have to respond to that (participant 7, Son, Not living with person with dementia).
	Active and passive AT	I suppose it's been a consideration around message... you know, voice messaging back and forth, that it's difficult for her to do anything active that's got any level of complexity to it. Yeh, that's definitely a consideration	My mother, wears this on her wrist, so should she fall this triggers an automatic response, and the phone rings and we can physically speak to somebody through the gadget, the box in the hallway, and they can actually call out an ambulance	What we're going to do is monitor your [person with dementia] habits and from that we can send people [carer] a message…'look in on this person'…and 'they still haven't been to their medicine cabinet', or whatever it might

Theme	Sub-theme	Example quote 1	Example quote 2	Example quote 3
		(participant 7, Son, Not living with person with dementia)	or the relevant emergency services if required. (participant 20, Son, Living with person with dementia).	be…So, it's kind of like what can you do that doesn't require an action from the person (participant 5, Daughter, Not living with person with dementia).
	Considering AT for use in the future	Things where people get out of bed... a little mat tells you when someone's got out of bed and things like that, I think would be very useful. And I'm sure I will be using things like that, yes (participant 11, Wife, Living with person with dementia).	Therefore, as we all get older we'll perhaps be better at using modern technology, but the older generation are struggling with that I would say (participant 13, Daughter, Live-in carer).	I think there could be improved apps that could be designed around use for people with dementia, and their families (participant 19, Daughter, Not living with person with dementia).
Knowledge and skills for using AT	Sources of information about AT	The [National charity] sent me a load of stuff about... because it's about things asking advice for Mum for Alzheimer's (participant 10, Daughter, Not living with person with dementia).	Basically, we're quite good at finding information on the... you know, Googling things (participant 14, Wife, Living with person with dementia).	I am very familiar with digital technology. I just went online and found the appropriate devices there. So, yeah, I mean there are... there's at least one company that focuses on supplying those kinds of things to people with dementia (participant 8, Husband, Living with person with dementia).
	Support from public services and others	As far as the pendant stuff [pendant alarm] goes, that was actually provided to us by social	So, I found it so the social services side was pretty useless, really down to me to research what I needed (participant 4,	If you've got over a certain amount of money they're not interested in you. They just send you a leaflet, you know, a

Theme	Sub-theme	Example quote 1	Example quote 2	Example quote 3
		services (participant 20, Son, Living with person with dementia).	Daughter, Not living with person with dementia).	booklet telling you, 'Ere are, here's all the services,' and they call it Help Yourself (participant 10, Daughter, Not living with person with dementia).
	Adapting AT for use in dementia care	So it's like you have to make big icons that say family pictures, just have the picture on the icon itself [modifying app styles on an iPad] (participant 3, Son, Not living with person with dementia).	So, then I've got to try to explain to her I'm on my mobile, so I call it my work phone now. So, I say, 'That's my work phone if you need me; I'm always on that phone' (participant 10, Daughter, Not living with person with dementia).	Initially when I used it, they didn't have the emergency bypass on your phone setup because they used a third-party phone company but when I fed back to them that it would be really useful to be able to do that, because I often have to turn my phone off but I want to know if there's a problem, you know, so we managed to set up so that it would come through to my phone in an emergency (participant 4, Daughter, Not living with person with dementia).
	Use of AT over time	He can't really use that now [GPS navigator]; he doesn't remember how to use it (participant 14, Wife, Living with person with dementia).	Basically, it's too complicated for her to use [pendant alarm], so despite it having a single SOS button that... she could do that, but what she couldn't do was understand the next step,	So, she won't use the electricity one [electric bath lift] which of course is nothing to do with electricity [in water] but she doesn't realise that…So, that was a bit

Theme	Sub-theme	Example quote 1	Example quote 2	Example quote 3
			which is don't do anything else (participant 8, Husband, Living with person with dementia).	difficult. So, we've got a [bath lift] which she doesn't use…it doesn't let her into the bath because she likes to sit in the bath to have a proper wash (participant 10, Daughter, Not living with person with dementia).
Social, environmental and ethical considerations in using AT	Social pressure to use AT	I mean, I tried really hard with a mobile phone to show how that works. It's just a plain simple one. No, she never got it round, she just could not understand that at all (participant 10, Daughter, Not living with person with dementia).	I think it's because she doesn't have a method for way of looking for things anymore. She would just be like running around the house wondering where buzzers are going off from. I think anything sounding an alert and alarming, it's more of a problem [using a motion sensor alarm] (participant 5, Daughter, Not living with person with dementia).	It cuts out the...like the nuisance calls [call monitoring system]. But it's been good in that it's stopped Mum giving out details, bank details and things, to these cold callers that have been calling. That's been excellent (participant 12, Daughter, Not living with person with dementia).
	Integrated AT	They [district nurses] changed the bed mattress, I couldn't really get it to work anyway with this alternating mattress because every time the cycle went round it set off the alarm because it thought there'd been an epileptic fit happening.. (Participant 18, Daughter, Live in carer).	Sometimes it's difficult to get all three things to synchronise together [calendar app] but, you know, we don't have too much of a problem (participant 15, Husband, Living with person with dementia).	She's also got an alarm round her neck, which she can press if she falls. That's been one of the hardest things to get her to understand because it's a range... it works within a range of her telephone (participant 10, Daughter, Not living with person with dementia).

Theme	Sub-theme	Example quote 1	Example quote 2	Example quote 3
	Co-morbidities associated with dementia affecting choice and use of AT	We're in the process of getting a room ready to accommodate a profiling bed; hospital bed [post fall and fracture of hip of person with dementia] (participant 17, Husband, Living with person with dementia).	So, you just press a button and the head comes up or we can raise the legs as well [4part profiling bed], yes, it's definitely been better for my wellbeing because I haven't had to worry about heavy lifting (participant 18, Daughter, Live-in carer).	It [automatic medication dispenser] was also really useful when she had the carers in because you'd know if they'd given her her tablets or not. And that for me just, you know, because you know just to know that you've given her the right dose [for epilepsy]; she's not given two lots or anything like that (participant 21, Daughter, Living with person with dementia).
	Ethical considerations in the use of AT	A baby alarm, which was something I had to buy. I suppose... I think that's because of confidentiality and that the [formal] carers could feel they were being spied on. It's almost like putting in a camera, isn't it? (participant 13, Daughter, Live-in carer).	[About Alexa] and there's no password or lock on the account, so you know, anyone can access it and do what they like to it (participant 19, Daughter, Not living with person with dementia).	It's giving more ability to the carer to do stuff remotely, but it might also be reducing the control that the person with dementia has because they don't understand how it all works (participant 5, Daughter, Not living with person with dementia).

4.4. Discussion:

This study explored experiences of carers currently using AT in dementia care at home. Most of the participants expressed a positive experience in the use of AT. The findings were similar to previous research [50, 79, 134], which has suggested ease of using AT, AT providing reassurance, and AT improving the safety and autonomy of a person with dementia and the carer, were all reasons for carers to use AT. Similar to other accounts on caring for an elderly population in the community [195, 196], this study found that carers continued to use AT regardless of an increase in formal care services or taking on additional responsibilities of finding information and funding the purchase of the AT themselves.

AT complemented carer support by enabling redistribution of carer time to additional meaningful activities and interactions with the person with dementia. Carers generally consider AT as helping the person with dementia and when prompted were able to consider the impact of AT on their own quality of life and wellbeing [104].

Carers were troubled by the financial costs involved in testing new AT devices, especially as dementia progressed; this appears to be a neglected area in research and policy [75, 126]. All of the carers in this study are from the UK, while the devolved nations have differing policies on access and funding for health and social care, in general health services for individuals are provided free at the point of use. In England, the majority of the AT (when provided by public funded services) is provided through local authority social care services, this funding is means tested and invariably restricted to those with substantial needs and the least assets. In fact only about 25% of the people applying for social care actually get it [197] and most persons with dementia may not qualify [198]. Use of AT in dementia care is not a one-off event but is an on-going process [48]. Having a repository of AT devices, that

carers could borrow, trial and return when the AT is no longer useful for a person with dementia may help overcome some of the financial concerns of carers. This could also reduce waste and improve the re-use of resources.

The functional capabilities of a person with dementia worsen over time. As a result, some AT solutions that worked for a person with dementia and their carer, might not continue to do so over time. Pendant alarms are one such common example, where the AT was not keeping pace with the progress of dementia and the person with dementia no longer able to actively use the device leading to frequent abandonment of the AT [163, 199].

Other studies on AT have reported on how existing or 'off-the-shelf' AT is frequently modified for newer purposes [26, 57]. Very few studies have actually considered the use of AT in dementia care, to support co-morbidities not associated with dementia [200]. In this study, carers reported this as a common occurrence, however, this was not always possible for all carers and care situations and very much depended on the carers' previous knowledge and skills in using, adapting/modifying AT.

The progress of dementia is dynamic and the context (e.g., availability of wider support systems or formal carers) and the environment (e.g., person with dementia living alone), in which AT is being used were one of the prime motivations for using AT. Carers who lived away from the person with dementia, expressed the need for a 'check-in' for reassurance that someone with dementia was safe and well [201, 202] and this function was mostly fulfilled by AT. This matches the findings from the systematic review [79] described in the previous chapter of how safety of the person with dementia is a major reason for why AT was used.

There was concern among some carers that the reliance and use of AT may usurp the need for human interaction and worsen social isolation [95, 203] of persons with dementia. This is echoed in findings from other studies on AT [117, 134, 154].

Intrusive data sharing or data loss were not a concern for the majority of the carers in this study. Some carers however have started expressing concerns with integrated AT. This is likely to require further research and policy interventions, as AT devices become increasingly sophisticated, available on the 'cloud' and artificial intelligence driven [104, 204]. Carers considered the person with dementia when selecting AT. However when safety and security became a concern, carers made independent decisions that did not always involve discussions with the person with dementia [205–207].

4.5 Strengths and limitations of this study:

This study explored the use of AT among carers of persons with dementia in the UK. As participants were from across the UK, geographical limitations of procuring and using AT did not limit the transferability of this study's findings. The interviews used open ended questions and the researchers were not known to the participants and ongoing data analysis showed that satisfactory data saturation was achieved. This study aimed to recruit carers from various and diverse ethnic backgrounds, but participation in the interviews was voluntary and due to financial constraints only English language speakers were included in the study. This meant recruiting from some seldom heard groups, especially from ethnic minorities could not be fully achieved.

4.6 Conclusions:

AT can play an important role in supporting carers and persons with dementia who continue to live at home. AT is seen by carers as an adjunct to the support they provide. This study highlights important gaps in the understanding of carers' experiences of AT use in dementia care in the community. Individual and social contexts should be considered in the prescribing, purchase and use of AT. AT can provide support that is less intrusive, provides reassurance and improves wellbeing of carers. However, there continue to be issues that need to be understood and addressed, such as ethical considerations in the continued use of AT when the dementia progresses, the costs involved, and additional tasks, role and routine changes that carers need to take-on while using AT to provide care for a person with dementia.

4.7 Summary:

This chapter describes the methods of data collection and analysis, as well as the results from the qualitative exploration of the experiences of carers who use AT in dementia care. The results are discussed in context of the existing literature on AT in dementia care as well as other literature pertaining to the care of the elderly. Previous research has considered experience of using AT devices or the experience of its use mainly from the perspective of persons with dementia. The study described in this chapter explores the experience of AT use in the community from the perspective of carers, without restriction on the type, use, costs or amount of AT being used. The next chapter describes the steps involved in creating the Carers' Assistive Technology Experience Questionnaire (CATEQ), which was used to survey carers' experiences with and the impact of AT on them.

Chapter 5 : Developing the Carers' Assistive Technology Experience Questionnaire

5.1 Introduction:

Caring for a person with dementia can be demanding for carers and can affect their mental and physical health as well as influence their social lives [208]. Carers use AT to support persons with dementia to continue to live at home. However, more research is needed in understanding carers' experiences while using AT and the impact AT has on them [79, 209]. A survey of carers using AT would help in understanding the use and impact of AT on them.

In a survey, the data collection tool that is typically used is a structured questionnaire and the measurements obtained are the respondent's answers to survey questions [210]. This type of data collection assumes that all participants understand the questions in a consistent way. The questions in a survey are asking for information that participants have and can retrieve from memory and the questions are phrased in a way that the participants are able to answer as intended by the researcher.

In order to provide a valid and reliable questionnaire the wording, structure, and layout of the questionnaire must make allowance for the nature and characteristics of the typical population that would complete the survey [211]. One way of ensuring the questionnaire is understood by participants as intended, is by interviewing potential respondents and pre-testing the questionnaire using cognitive interviews.

This chapter describes how a draft version of the Carers' Assistive Technology Experience Questionnaire (CATEQ) was developed based on the systematic review described in Chapter 3 and the themes from the exploratory qualitative study descried in Chapter 4, and how the drafts were iteratively revised using cognitive interviews to arrive at the final version.

The results from this study were published in a peer-reviewed journal and most sections of this chapter will reflect the published version[1] of this part of the study.

5.2 Cognitive interviews:

Survey participants engage in four types of information processing before responding to survey questions. Participants must [212]:

a) interpret the question;
b) retrieve the information from their memory;
c) decide how to respond;
d) select an answer from among the response categories that matches their "internally generated answer".

Cognitive interviews can identify problems in item interpretation, memory retrieval, decision processes, and selection and so are commonly used for pre-testing survey questions [210, 213]. They can give information on how the questions are understood and answered by typical participants. Cognitive interviews can help detect problems participants may have in understanding survey instructions, questions, and in formulating answers [214]. Cognitive interviews can identify problems in item interpretation, memory retrieval, decision processes, and response selection [212].

The process of cognitive interviewing involves creating a draft questionnaire with candidate items. Cognitive interviewing with participants representing the target population is then used to revise the questionnaire. Cognitive interviews also help detect other problems in a

[1] **Sriram V**, Jenkinson C, Peters M. Using rapid cycle tests of change to develop the Carers Assistive Technology Experience Questionnaire: a cognitive interview study in the UK. BMJ Open. 2021;11:e042361. doi:10.1136/bmjopen-2020-042361.

questionnaire, such as instructions, design, and organisation of items in the questionnaire [215].

Cognitive interviews consist of one-to-one interviews in which the respondents describe their thoughts while answering the survey questions. Cognitive interviews can be undertaken by different methods such as think aloud, verbal probing, confidence rating, card sorting and paraphrasing [211].

Learning from each cognitive interview is used to inform the modifications that need to be carried out to the questionnaire [216, 217]. If a question or instruction is changed based on a detected problem, there is a validation of this change through subsequent cognitive interviews [214, 218]. This process continues until a questionnaire suitable for quantitative evaluation is derived.

Cognitive interviews are usually undertaken in rounds, with several participants interviewed in each round, their responses analysed and changes to the questionnaire made after each round [219–221]. This process is generally burdensome for respondents and involves higher costs during questionnaire development for researchers. In order to decrease this additional burden and speed up the process of pre-testing the questionnaire, a series of cognitive interviews were carried out using the quality improvement methodology of Plan-Do-Study-Act cycles, which is described in the next section.

5.3 Plan-Do-Study-Act Cycles:

Plan-Do-Study-Act (PDSA) cycles are an iterative action-oriented learning process used in improving healthcare process and outcomes [222, 223]. PDSA cycles consist of four phases [222, 224] and are described in Box 5-1.

Box 5-1 Plan-Do-Study-Act cycles:

Plan	State the objective of the test and the planed change. Make predictions of what will happen and why. Develop a plan to test the change.
Do	Carry out the test/intervention, document problems and unexpected observations. Begin analysis of the data.
Study	Complete the analysis of the data. Compare the data to earlier predictions in the plan phase and summarise and reflect on what was learnt.
Act	Determine what modifications should be made. Decide what the plan phase has achieved. Decide what additional or new change is required. Prepare a plan for the next test.

PDSA cycles are frequently used in improving service delivery of clinical care but few clinical research trials have documented its use for implementation [225] and none have used PDSA cycles as a framework for cognitive interviews for pre-testing questionnaires. PDSA cycles can be used as rapid cycle tests of change, for conducting cognitive interviews in pre-testing questionnaire items. This is an alternative and resource efficient way of developing and pre-testing a questionnaire.

5.4 Methods:

The steps followed in designing the CATEQ and recruitment process are described under the methods section of this chapter. The way in which PDSA cycles were used to iteratively change the CATEQ is described under the results section.

5.4.1 Developing items for the questionnaire:

The CATEQ was intended to be administered as an electronic survey. The initial item set for CATEQ was established from the results of the systematic review [79] and the themes from the exploratory qualitative study [209]. The CATEQ was designed to explore themes that carers described as relevant for use of AT in dementia care. An iterative process of drafting, evaluation, revision and content checking was followed. Attention was taken to draft the items in the questionnaire:

1. to capture the intended concept of experience of using AT and their impact on carers;
2. to be relevant to all carers irrespective of age, living arrangements and relationship with the person with dementia;
3. to ensure the response choices in CATEQ were ordered in a meaningful way;
4. to ensure the questions were worded throughout CATEQ in a manner consistent with best practice style guide by Alzheimer's society [12];
5. to ensure each item in CATEQ represented a single concept, rather than a multidimensional concept;
6. to ensure the content of the items was appropriate for a recall period of the previous 4 weeks;
7. to ensure the items could be answered in a self-administered questionnaire.

The questionnaire items were designed to be mainly closed questions with multiple choice answers. Some of the questions were partially closed with "other" as an open-ended text option.

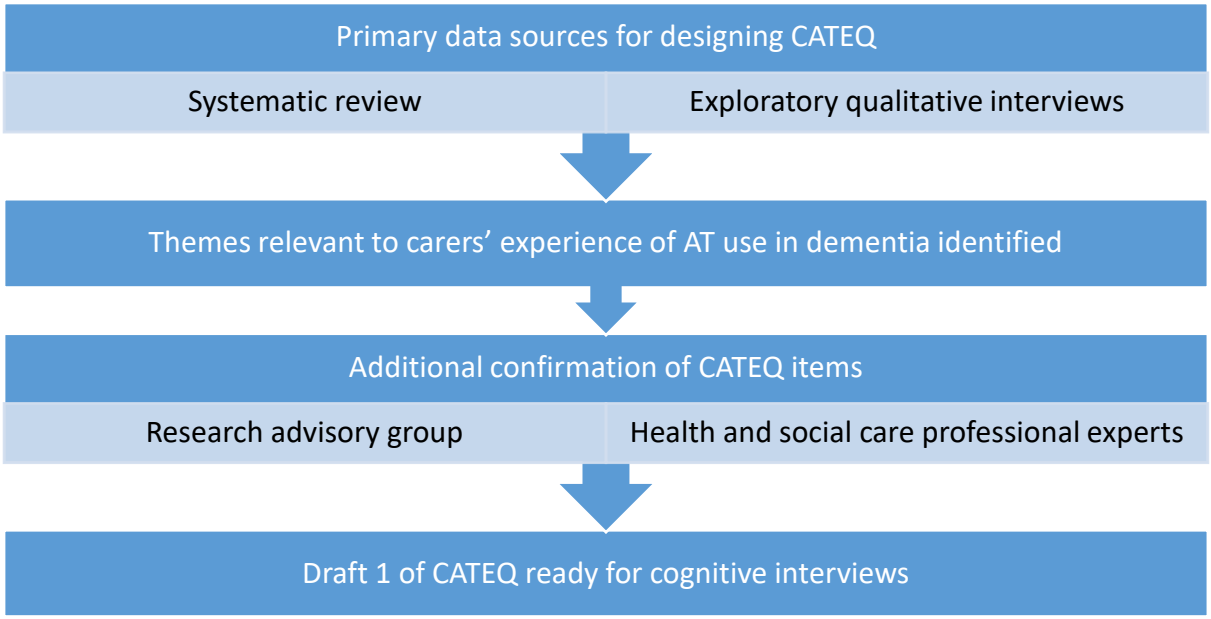
The questions were a mixture of:

- Behavioural: e.g., *What input is required from you for using the assistive technology? How often are you able to solve problems with the assistive technology by yourself?*
- Opinion: e.g., *How helpful is the assistive technology in reducing your stress? How helpful is the assistive technology in giving you more time for yourself?* and
- Factual: e.g., *age; gender; who was involved in the choice of AT?*

The survey included questions to capture demographic information of participant carers and their health-related quality of life. A question asking for an expression of interest in potential participation of follow-up qualitative interviews was also included. None of the questions except for the consent question at the beginning of the survey had a forced-choice response (i.e., respondents could omit answers to questions). The questionnaire items had a Likert type rating scale as response choices.

This questionnaire version was commented on by the research advisory group and minor changes were made to the instructions section. This version was then circulated to three clinical and social care experts in England, who were involved in prescribing AT for use by persons with dementia at home. A couple of minor changes to the order of the questions were made. This modified CATEQ version was labelled draft 1 and was used in the first cognitive interview. Figure 5-1 provides a visual overview of these steps.

Figure 5-1 Cognitive interviews - steps taken to generate and refine items for CATEQ draft 1:



5.4.2 Cognitive interview process:

Cognitive interviews were used to assess participants' comprehension of the items in CATEQ as well as establish that no important items were missing. An interview guide with think aloud questions and verbal probing questions was developed to elicit this information from the participants. The cognitive interview topic guide is provided in Box 5-2.

Box 5-2 Cognitive interviews - interview topic guide:

Pre-interview:

Participant to re-receive the information sheet and asked to read it through. Participant will be given a brief introduction to the research that includes a description of Assistive Technology.

- *Show University Card for ID of Researcher and introduce self*
- *Participant to be told what will happen during the interview process and reminded that the interview will also be audio recorded.*
- *Participant to be told the method of analysis and reminded that they will remain anonymous, and that their data will be confidential.*
- *Participant given time to ask questions*
- *Participant will be asked to sign two copies of the consent form, one of which is to be retained by the researcher.*

Instructions:

Based on our research, we have the following questions as part of the Carers Assistive Technology Experience Questionnaire. Please look at each page and the questions in this survey. During the interview, we will ask you to speak aloud about what you are thinking as you respond to questions. I am also going to ask you additional questions about individual items in this questionnaire. Remember, the purpose of this interview is to test the questionnaire and not to test you. Are you ready to begin?

We will start with the instructions for the survey:

Example verbal probes used to test the questions:

(For every question) ….

1. What to you, is "……."?
2. Tell me more about "....."?
3. Can you repeat this question in your own words?
4. What does "……." mean to you?
5. Would you mind providing some examples about "…."?
6. When you think about "……" what comes to your mind?

Overall for the survey….

7. Are there additional questions you believe should be asked?
8. Are there questions you believe should be deleted?
9. Are there questions you believe should be modified?
10. Are there words used in the questions that you think could be changed to make it more understandable to others who help/look after those with dementia?

Do you have any questions for me?

5.4.2.1 Recruitment:

Similar to the exploratory qualitative interviews described in Chapter 4, participants for the cognitive interviews were recruited through the *Join Dementia Research* database [13].

The inclusion criteria were:

- adult carers – spouse, partner, family, friend or neighbour;
- providing at least 10 hours of care (e.g., shopping, leisure, personal care, finance) per week to a person with dementia who lives in their own home;
- carer could be living together with or away from the person with dementia;
- carer should have used at least one AT device at home in the previous year;
- able to read and communicate in English.

Participants were emailed a copy of the participant information sheet (Appendix 11) and a purposive sample of participants reflecting variations in gender, age, ethnicity, living arrangements and relationship with persons with dementia were selected. The recruitment commenced in October 2019 and the final interview was completed in February 2020. A target sample size of 7-10 participants was deemed enough to complete cognitive interviews for items in the CATEQ. This was based on previous estimates [221, 226, 227] but the intention at the start was to continue with cognitive interviews until no further amendments to the CATEQ were necessary [228].

5.4.3 Conducting cognitive interviews:

The cognitive interviews were conducted through think aloud and verbal probing questions, following the interview topic guide.

In the think aloud method, the participant was asked to speak all thoughts aloud as he/she answered the question. For verbal probing, the researcher asked specific questions or

probes which were designed to elicit how the participant went about answering the question. For example, how the participant made their choice among the response options or how they interpreted an instruction [210, 211].

5.4.3.1 Data collection:

The interviews were conducted face-to-face at the participant's own home, workplace or at the researcher's office, taking into consideration the carer's geographical location and preference. Informed consent was gained from each participant before the cognitive interview questions were put to the participant. The consent form used is provided in Appendix 12.

The interview involved asking the carer how they went about answering a particular survey question [215]. For the cognitive interviews, carers used the electronic version of CATEQ developed using Qualtrics software [15] on a laptop. Participant 8 also tested the questionnaire on a smart mobile phone. The final participant in addition to the electronic version, also commented on a paper version of CATEQ [226]. As only minor modifications were made to the survey between the electronic and paper versions, the properties of the electronic version will still hold for the paper version and would not introduce significant response bias, hence a cognitive interview alone was deemed sufficient for usability testing of the paper version converted from the electronic version of the survey [226].

The carers were not known to the researcher prior to recruitment. Trust and easing into the think aloud interview was built by establishing rapport (as discussed in Chapter 4) with the carers. The researcher explained that the purpose for this set of interviews was to make the questionnaire better by identifying items that were difficult to answer.

Interviews were undertaken using concurrent think aloud and verbal probing questions and lasted between 55-95 minutes; all interviews were audio-recorded along with field notes and the use of a PDSA template (Appendix 13). The field notes noted verbal and nonverbal cues from the carers, as well as their perception of the items in CATEQ. Confidentiality of the carers was maintained throughout the process by avoiding reference to their names, or that of the person with dementia, cities and other person identifiable information.

5.4.4 Revising the questionnaire:

5.4.4.1 Data Analysis:

The PDSA template was used to document the changes needed, results of the cognitive interview process and to iteratively make changes to the CATEQ.

To ensure quality, decrease personal bias and strengthen the interpretation of recommended changes to CATEQ from the analyses of data from the cognitive interviews, this study was done in collaboration with others. The interviews, initial analysis and initial changes to the drafts of CATEQ were completed by the researcher VS. MP and CJ (Supervisors of the researcher for this DPhil) met regularly with the researcher to discuss data collection, analyses and iterative changes to the drafts of the CATEQ. The questionnaire items were changed in line with suggestions from each participant as well as accounting for any difficulty encountered by the participant with specific items during the cognitive interview.

Changes to CATEQ were made after every cognitive interview instead of waiting for rounds of interviews to finish, which is the process in traditional cognitive interview methods [221]. This rapid cycle of change method permitted decreasing the time between data collection, analysis and changes made to the questionnaire. The researcher ensured each subsequent

participant, in addition to “thinking-aloud” on a focused section of the CATEQ, also commented on the latest iteration of the full questionnaire. This helped to determine if the latest version of the CATEQ could be understood as intended, without introducing further difficulties in comprehension or changes needed to the questionnaire.

Subsequent CATEQ questionnaire drafts were numbered draft 2, draft 3 etc. which were used contiguously for the progressive set of cognitive interviews.

5.4.5 Final test of the questionnaire:

Towards the end of questionnaire revision, the final version of CATEQ was tested on three volunteers and the research advisory group to check time taken to complete the questionnaire, issues with formatting, skip logic on the online Qualtrics platform, and ease of understanding of the instructions. It was then deemed ready to be used in a cross-sectional survey.

5.5 Results:

Thirty-eight emails were sent to potential participants. From the 22 responses received, 11 carers did not meet the eligibility criteria and 9 carers (5 women and 4 men), with varying types of relationship to a person with dementia, took part in the cognitive interviews. Every carer had used at least one AT device in the last year. Carers’ ages ranged between 42 to 75 years.

Characteristics of the participants is given in Table 5-1.

Table 5-1 Cognitive interviews - characteristics of interview participants:

ID	Age Range	Gender	Relationship with person with dementia	Ethnicity	Living arrangements
1	56-70	Female	Wife	White British	Living with spouse/partner
2	56-70	Male	Son	White British	Live-in carer
3	40-55	Female	Daughter	White British	Live-in carer
4	40-55	Male	Son	Asian British	Not currently living with person with dementia
5	71-85	Male	Husband	White British	Living with spouse/partner
6	56-70	Female	Daughter	Caribbean British	Not currently living with person with dementia
7	40-55	Male	Nephew	White British	Not currently living with person with dementia
8	40-55	Female	Daughter	Mixed White British	Live-in carer
9	40-55	Female	Granddaughter	Asian British	Living with person with dementia

5.5.1 PDSA cycle 1: Testing instructions and questionnaire items:

Draft 1 of the CATEQ had instructions for participating in the survey, eligibility criteria and a consent statement at the start. It had 29 items (21 items in matrix format) about carers' current experiences and impact of using AT with a person with dementia at home. During PDSA 1, participant 1 was able to comprehend and understand the instructions and commented on the font and layout of the instructions that could be improved. The eligibility criteria and consent statements were easy to understand and overall participant 1 took less time than anticipated to complete these sections.

On verbal probing, participant 1 stated that most instructions only carried information regarding data protection and use which were standard statements.

> *"…these are what…err…you'll find in a product agreement you know…and who reads these through fully? I always click agree, so I can start using the thing, err…you know…like the cookie thing on websites"*

Participant 1 answered items on the questionnaire and commented that the layout was easy to follow, the questions were easy to understand, and appreciated the use of questions with the option of "other" where extra information was needed.

During the think aloud interview for item 1 on the CATEQ, it was observed that there was some difficulty in sorting through AT devices that the carer had used but was no longer using. It was suggested by the carer that additional instructions and questionnaire items to provide details of these devices might be helpful.

At the end of this PDSA cycle, modifications to the layout of the questionnaire and participant instructions were made by adjusting font size and paragraph spacing. Question item for current AT was modified and four additional questions on previously used AT and reason for abandonment were added. Additional information on accessing the research website at the end of survey message was also added. This version of the CATEQ draft was then labelled draft 2.

5.5.2 PDSA cycle 2: Testing questionnaire items:

Cognitive interviews with Participants 2 and 3 were carried out separately using the electronic version of draft 2 of the CATEQ. Both participants thought that the image at the start of the instructions with examples of common AT was helpful.

The think aloud interviews for the questionnaire items highlighted confusion regarding the phrasing of the questions on cost of AT. The question was phrased as:

> "Can you give the approximate cost (in pounds) associated with the assistive technology currently used, paid for by the person with dementia or by you or another carer (family, friend or neighbour)?"

Participant 2 had difficulty in separating out initial cost in purchasing the AT with that of ongoing costs for maintenance.

Participant 3 also had difficulty with another question on the cost of AT

> "Are you concerned about cost of the assistive technology?"

This was because the AT the participant was using was provided by social care services without a cost to them. Both participants were able to differentiate questions on *anxiety* and *stress* presented as separate questions. On verbal probing both participants wanted a "*does not apply*" option to matrix questions such as:

> "How helpful is the assistive technology in giving you additional time for tasks that you have to do?" and
>
> "How helpful is the assistive technology in maintaining dignity of the person with dementia?"

These cognitive interviews also gave the unsolicited confirmation that the CATEQ could be self-administered.

> *"You'll get more out of me doing this (answering the questions) on a laptop or on the phone than if I were sat in front of you and answering them…these are personal questions and [I] might be feeling guilty answering them honestly if you were in the room, you know what I mean"* [Participant 2]

At the end of this PDSA cycle the questionnaire items were modified to change the wording on items on cost and add a "*does not apply*" option to the Likert type scale choice for the matrix questions and the new draft of the CATEQ was labelled draft 3.

5.5.3 PDSA cycle 3: Testing questionnaire items and skip logic:

The cognitive interview with Participant 4 tested the modified items in draft 3, as well as the layout and format of the electronic version of the questionnaire. The think aloud interview confirmed that the revised items on cost was better understood by the carer. On verbal probing participant 4 appreciated the option of "*does not apply*" as a choice. He also commented that the layout of the questionnaire was easy to understand and suggested a change in colour scheme for the button at the bottom of the page, which indicated progress with the questionnaire.

> *"You know this arrow button in the bottom (indicates on screen), it is blue now, but if this were in green, other carers who do your survey would think they are good to go, sort of like…you know...like…like a traffic light system and make good headway with your questionnaire".*

At the end of this PDSA cycle, the colour scheme for the questionnaire was changed. Items to collect demographic data of participants were added and this version of the CATEQ was labelled draft 4.

5.5.4 PDSA cycle 4: Testing questionnaire items and demographic questions:

Cognitive interview with participant 5 concentrated on the nine demographic questions. Verbal probing and think aloud interview were used to check comprehension, recall and ease of answering these demographic questions.

The carer understood the questions readily enough but had some hesitation in answering the question on income. On verbal probing the carer disclosed that he and the person with dementia pooled their income for household expenses and some of the hesitation was in disclosing this in a survey, even if it was anonymous.

At the end of this PDSA cycle, it was decided to reframe the question on income to 'family income' and add an option of "do not wish to disclose" as part of the response options for this question.

On the advice of the research ethics committee further modifications to the instructions for survey participants were made. This included further detailed information on use of data, data protection and contact details of all the study researchers. The revised version of the questionnaire incorporating all these changes was labelled draft 5.

5.5.5 PDSA cycle 5: Testing modified instructions and questionnaire items:

Participants 6 and 7 participated in cognitive interviews that tested the modified instructions and questionnaire items. Both carers completed the questionnaire items without difficulty and on verbal probing commented that the instructions were long but easy to understand and, in any case, they were not spending too much time on them.
On verbal probing participant 7 also felt the order in which items on stress, anxiety, time for self and effort on caring were presented could be rearranged in the questionnaire and grouped together as they helped the participant think through them better and maintain '*flow of thought*'. Participant 6 recommended testing the questionnaire on participants using a smart phone device, as this might be the way some participants would choose to complete the questionnaire during their commute into work.
At the end of this PDSA cycle, items in the CATEQ were regrouped to facilitate ease of recall. Items on health-related quality of life based on the validated 12 item Short Form survey (SF-12) version 1 [229, 230], plus three questions on coping with caring and carer relationship with the person with dementia were added to the CATEQ . This revised version of the questionnaire was labelled draft 6.

5.5.6 PDSA cycle 6: Testing items on quality of life and testing using a smart phone:

Cognitive interview with participant 8, focused on testing items on the questionnaire from the SF-12. The SF-12 contains items covering physical functioning, social functioning, role functioning (physical and mental), vitality, bodily pain, mental health and general health. The SF-12 generates two summary scores: The Physical Component Score and the Mental Component Score. A higher score indicates better quality of life.

The SF-12 is a validated instrument, so the cognitive interview was limited to comprehension of the questions and answer choices as well as the layout of the electronic version of the questionnaire. The carer also completed the questionnaire using a smart phone device to check ease of use and layout of the questionnaire in a smart phone device. The carer was able to complete the CATEQ with ease and had no specific difficulty in comprehension or recall of information required for completion of the entire questionnaire. The smart phone layout of the CATEQ was reported as being easy to follow. The questions were presented one after the other and was completed without difficulty or the need for increased time.

At the end of this PDSA cycle, the questionnaire was deemed to be ready for a test to include the electronic and paper versions to check ease of completion. The paper version would require a check for minor modifications to instructions, as skip logic could not be applied for the question on “consent to participate in future interviews” and the removal of references in the instructions such as, “IP address will not be collected”.

The revised version of CATEQ was labelled draft 7.

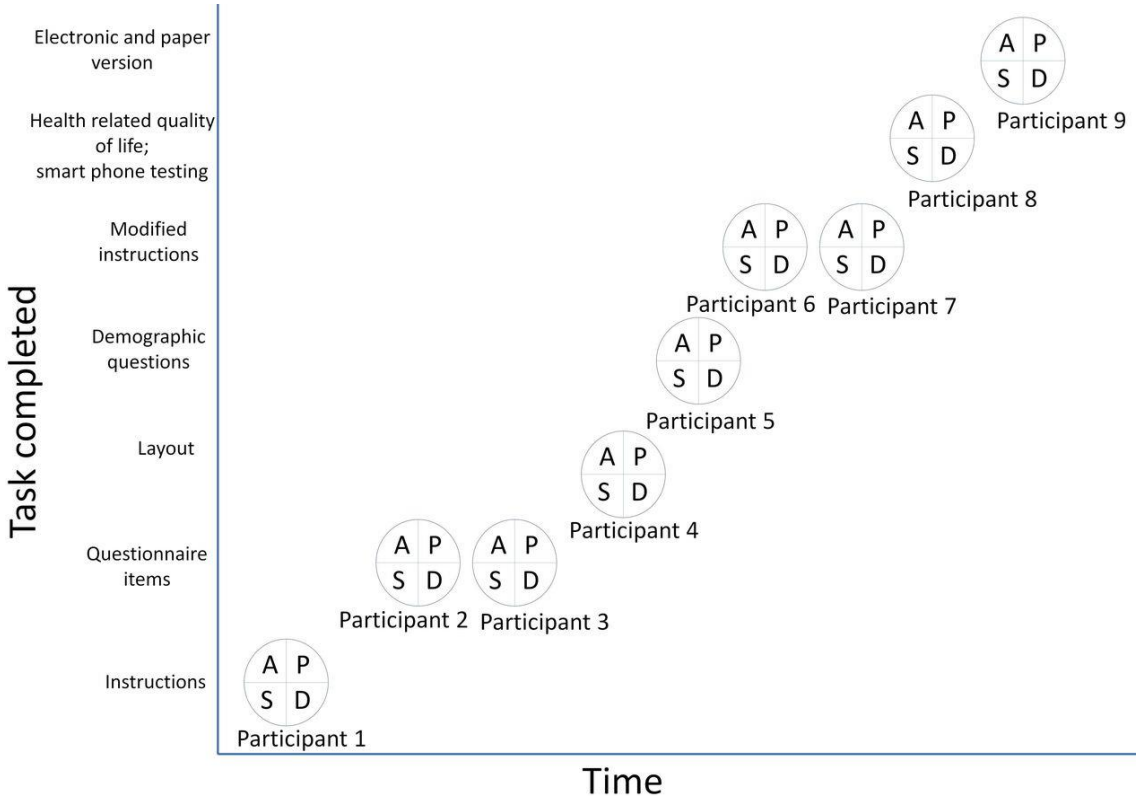
5.5.7 PDSA cycle 7: Testing the electronic and paper version of CATEQ:

Participant 9 completed the CATEQ initially on a tablet computer and then as a paper version. Time taken by the carer to complete the questionnaire without prompts was 19 minutes and 23 minutes, respectively. The additional time taken to complete the paper version was because the carer had to flip back and forth between the pages as the matrix questions asked about three AT devices that were currently used, and the carer needed to remind themselves in which order they were answering this question.

At the end of this PDSA cycle the CATEQ was deemed ready to be used in a survey and was confirmed with the research advisory group.

A visual illustration of the PDSA cycles and the focused areas of the questionnaire items that the cognitive interviews targeted is shown in Figure 5-2.

Figure 5-2 PDSA cycles and tasks involved in the cognitive interviews:



The changes made to the questionnaire from draft version 1 to the final version is shown in Table 5-2.

Table 5-2 Cognitive interviews - Changes to the questionnaire between versions 1 and 7:

	Questionnaire structure	Draft 1 of questionnaire	Draft 7 of questionnaire
1.	Instructions Line numbers: Paragraphs:	 16 12	 41 12
2.	Questions on Assistive Technology Questions on Previous Assistive Technology	9 0	10 5
3.	Matrix questions on experience and impact	21	20
4.	Demographic questions	0	9
5	Health-related quality of life questions	0	15
6.	End of survey response line number	1	1 + research website details
7.	Layout and structure of questionnaire Colour scheme: Font Size:	 Blue progress bar 12	 Green progress bar 15

5.6 Discussion:

Cognitive interviews have helped develop better questionnaires and survey instruments and are increasingly being used routinely to pre-test questionnaires [217, 231]. Rapid cycle tests of change using PDSA cycles as a format can be used as an alternate way of conducting these cognitive interviews. Each cycle made modifications to the questionnaire and tested this in subsequent cognitive interviews without increasing participant burden.

Cognitive interviews are usually undertaken in rounds, with several participants interviewed and changes to the questionnaire only made after each round [219, 220]. Problems in comprehension, recall or response choices to the questionnaire items emerge from the interviews themselves [227], without the interviewer anticipating or having a hypothesis of which items or layout in the questionnaire may require change.

Using small tests for change through PDSA cycles enabled better structuring of questionnaire items with improved ease of comprehension, recall and response choices to items within the CATEQ. The use of PDSA cycles as a learning mechanism for cognitive interviews resulted in predicting potential problems (what are we expecting to happen?) with questionnaire items and layout. This allowed the focus to be on potentially problematic items (e.g., questions on costs and freeing up carer time). Learning from each cognitive interview was used to inform the modifications that need to be carried out to the questionnaire and changes to the probing questions [216, 217]. Making changes to the questionnaire after every cognitive interview as a result became easier to manage and learning from each PDSA cycle was applied to the next [232, 233].

In the seven PDSA cycles, the think aloud interviews helped indicate problems with a questionnaire item or instruction other than the ones that were considered problematic. This unanticipated learning helped re-frame and re-test the CATEQ until it was satisfactory. Focusing on different items in the questionnaire and building up the testing helped reduce fatigue among the participants and gave better insight into item comprehension, language used and layout. Using PDSA cycles enabled changes to questionnaire items, which not only provided information on problems in a question but also its possible source(s), as well as information toward the problem's solution.

5.6.1 Advantage of using PDSA cycles for cognitive interviews:

The use of PDSA cycles in pre-testing the CATEQ allowed testing on as small a scale as possible before building confidence and scaling up to test additional items in the questionnaire and with different devices and a paper version.

The questionnaire items for cognitive interviews were divided into parts – instructions, CATEQ items, demographic data, and health-related quality of life questions. This was done for pragmatic reasons and to allow carers to focus on specific sections in detail, while also commenting on the questionnaire in its entirety.

Planning and anticipating problems with questionnaire items, splitting the tasks into small manageable parts and increasing its complexity over the course of the seven PDSA cycles helped maximise learning opportunities, decrease overall costs and time taken to complete cognitive interviews and reduced participant fatigue and burden. The PDSA cycles allowed the ability to break issues down and focus on making small, measurable changes [222, 233].

Testing using a paper version, a laptop and a smart phone helped identify if the wording of each question communicated the objective of the question, and quickly identify problems such as redundancy, missing skip instructions and awkward wording with only a few interviews, instead of waiting for multiple participants in each round of interviews in the typical way cognitive interviews are conducted.

PDSA cycles are a learning methodology whose "simplicity belies its sophistication" [223]. The use of iterative PDSA cycles for cognitive interviews provided information that would otherwise have been unseen before launch of the survey, for example, questions on AT devices that are no longer being used/abandoned by carers. The PDSA cycles also helped learning from unsolicited information such as the questionnaire being self-administered instead of interviewer administered.

Cognitive interviewing is one of a multitude of ways for pre-testing a questionnaire. It helped to assess if the CATEQ collected the information that it is intended to capture. Using PDSA cycles allowed for planning, and researcher hypothesis of the difficulty of the various

questions in the questionnaire. This allowed rapid and iterative pre-testing of the questionnaire without having to wait for multiple rounds of cognitive interviews before changes to the questionnaire could be made and re-tested again. This study evidenced the use of PDSA cycles to inform cognitive interviews in questionnaire development as another use for PDSA cycles and could be one way of pre-testing questionnaires in the future.

5.7 Strengths and limitations of this study:

The extent to which carers could verbalise their thought processes during the cognitive interviews varied amongst the participants. However, a combination of think aloud and verbal probing interviews helped achieve the intended aim for each PDSA cycle of improving instructions and comprehension, recall and answering of items within the CATEQ. The cognitive interviews included participants from different ethnic backgrounds, which added confidence that the questionnaire could be understood by participants from diverse ethnicities during the survey. Cognitive interviews are used to evaluate existing questions, and to test proposed revisions to the original questions. Cognitive interviews cannot provide quantitative evidence on whether the revised version of the question is better than the original. However, the revision in each PDSA cycle built on the learning from the previous cycle and consequently there is a high degree of confidence that the final version of the questionnaire is superior to the first draft.

5.8 Conclusions:

PDSA cycles are widely used and familiar to many involved in healthcare. It can be an appropriate mechanism for pre-testing questionnaires before deploying them in large scale surveys in healthcare. The use of PDSA cycles to frame the process of cognitive interviews

was an alternative way to pre-testing the CATEQ. This minimised risks by using rapid small-scale tests of the changes introduced to layout and items in the questionnaire as well as helping reduce fatigue and burden to researchers and participants. The addition of cognitive interviews as an extra step in the questionnaire development process assured the instrument would provide data covering the intended issues to be assessed by the measure.

5.9 Summary:

This chapter summarises the development of the CATEQ as a questionnaire that could be used to collect data from carers who support persons with dementia, from across the UK, on their experience with AT and the impact of the AT on them. The next chapter describes the methods of conducting the cross-sectional survey (as the quantitative phase of the mixed-methods study) and the results on how carers use AT.

Chapter 6 : Quantitative phase of the sequential explanatory mixed-methods study: Cross-sectional survey of carers' experiences of AT use in dementia care

6.1 Introduction:

Technology is suggested as a widespread solution to supporting carers and persons with dementia to live for longer in the community [150, 234, 235], yet there have been very few attempts to understand the experiences of carers, who use and support the use of AT and their perceptions of the impact of these ATs [57, 79]. Additionally, in the UK, there continues to be a lack of understanding of the number of AT devices available and what they are used for, as well as the ethical implications of choice and continued use of certain AT where privacy and confidentiality is a concern. The perceived satisfaction with and benefits of using AT from the perspective of carers is also not well understood [209].

A survey of carers who use AT will provide a broader understanding of the experiences of carers using or supporting a person with dementia to use AT, and provide information on the current use, satisfaction and impact of AT among carers of persons with dementia. The diverse perspectives from carers and the relationships that exist between the intricate layers of the research questions cannot be obtained from a survey alone. Additional qualitative methods would be useful to explain and uncover nuances from the findings of the survey.

6.2 Sequential explanatory mixed-method study:

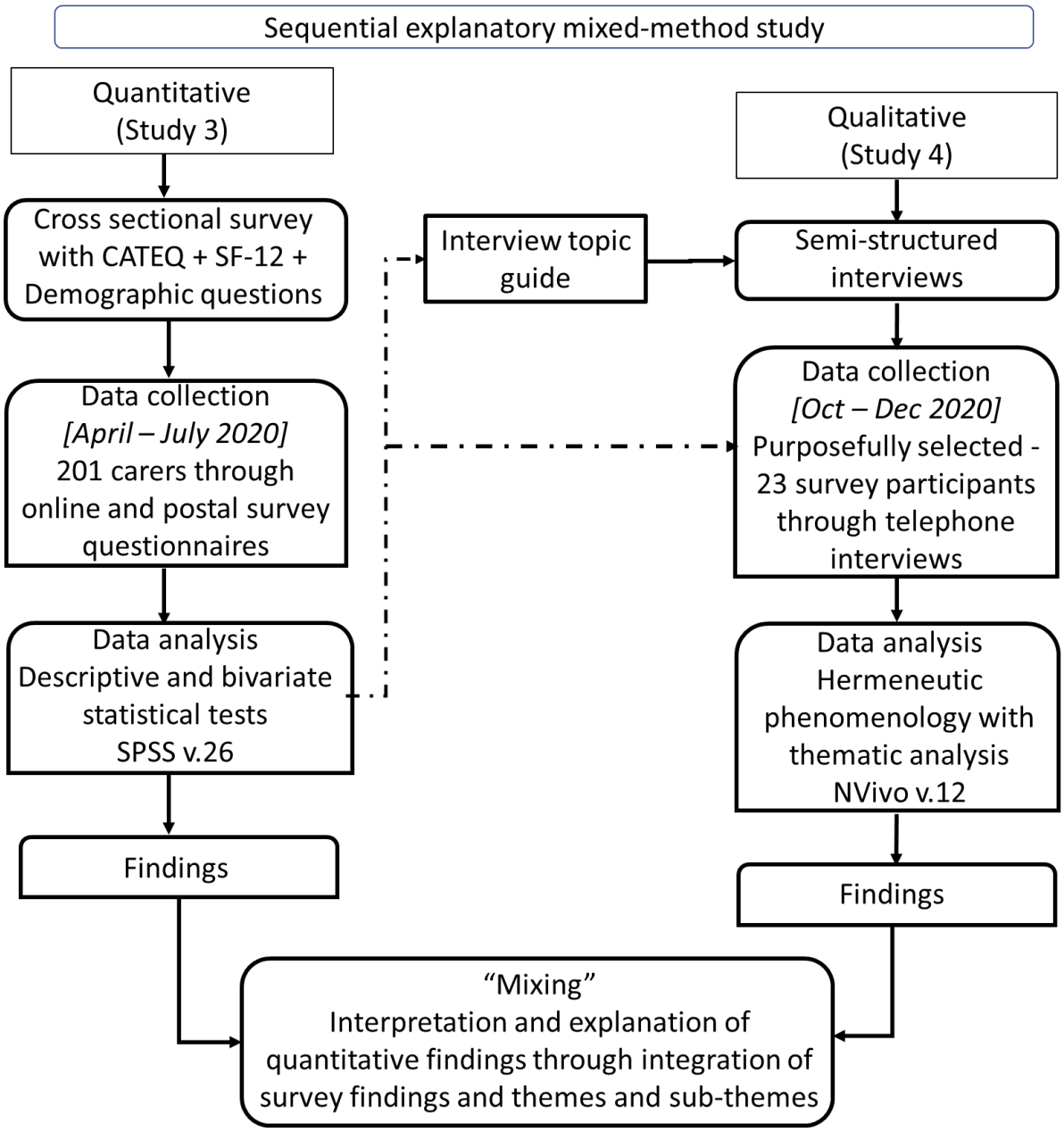
The combined use of quantitative and qualitative approaches would provide a better understanding of carers' experiences and impact of using AT than either approach alone. A better understanding can be obtained by combining survey (quantitative) data results with interview (qualitative) data to thereby enhance the validity of any inferences that are made [170].

Collection of quantitative data and analysis of the results followed by collection of qualitative data and analysis of the results and "mixing" the analysis of the qualitative data to explain the findings from the quantitative data is called the sequential explanatory mixed-method design [236–238]. Within a mixed-method approach, using a sequential explanatory mixed-method design provides the added advantages of [239, 240]:

- expansion (extend the breadth and range of the research inquiry by using both quantitative and qualitative methods);
- complementarity (explanation or clarification of the results from the survey (quantitative method) with the findings from additional interviews (qualitative method);
- convergence (explaining how the findings from the interviews agree with the findings from the survey).

The quantitative data for this mixed-method study was collected and analysed first by means of a cross-sectional survey, using the CATEQ, SF-12 and demographics questions. For ease of understanding, coherence and flow, this chapter describes the quantitative phase of the sequential explanatory mixed-methods study. This quantitative study was followed by collection and analysis of qualitative data through semi-structured interviews, to help explain the quantitative data, which is described in the next chapter. A visual representation of this design is shown in Figure 6-1.

Figure 6-1 Sequential explanatory mixed-method study



6.3 Study aim and objectives:

This survey aimed to investigate the experience and impact of AT use in dementia care among carers in the UK. The objectives were to use the CATEQ to investigate:

1. types and use of AT by carers in the support of persons with dementia;
2. the outlay costs, monthly on-going costs and perceived value for money of AT;
3. the perceived impact of AT on carers;
4. the general physical and mental health of carers of persons with dementia who use AT.

The results from this study have been submitted as a manuscript to a peer-reviewed journal and published as a preprint[1].

6.4 Methods:

6.4.1 Study design:

A cross-sectional survey was carried out using the CATEQ, SF-12 and demographics questions. Data was collected electronically through an anonymous link to the questionnaire using the electronic survey platform Qualtrics [15] and for those who requested it, by post, with the printed questionnaire mailed to participants, with a pre-paid return envelope.

A consent question was included at the start of the questionnaire and informed consent was required for online respondents to continue with the survey. Postal versions included the consent question as part of the paper questionnaire and, in addition, participants were

[1] **Sriram V**, Jenkinson C, Peters M. Carers' experiences of assistive technology use in dementia care: a cross sectional survey. BMC Geriatr 2021 211. 2021;21:1–12. doi:10.1186/S12877-021-02417-1.

instructed to not send back the questionnaire if they did not consent to participating in the survey.

6.4.2 Study participants:

Participants were recruited using the *Join Dementia Research* [13] and *OxDARE* [14] databases. To increase participation of carers from different ethnic backgrounds, requests were made through health care professionals who prescribe AT for persons with dementia, to pass on the link for the survey to interested participants. The inclusion criteria were:

- adult carers – spouse, partner, family, friend or neighbour;
- providing at least 10 hours of care (e.g., shopping, leisure, personal care, finance) per week to a person with dementia who lives in their own home;
- carer could be living together with or away from the person with dementia;
- carer should have used at least one AT device at home in the previous year;
- able to complete the questionnaire in English.

6.4.3 Study Questionnaire:

As described in the previous chapter, the CATEQ was developed based on themes from the systematic review [79] and exploratory qualitative interviews [209]. Draft versions of CATEQ underwent iterative revision based on the cognitive interview [241] until a final version was arrived at.

6.4.3.1 The Carers' Assistive Technology Experience Questionnaire:

The CATEQ contains questions on types and uses of AT, support provided by the AT and the impact of using AT. The CATEQ had options with free-text spaces for respondents to qualify their answers if necessary. The survey questionnaire also had questions to collect socio-

demographic information, as well as health-related quality of life of the carer through the SF-12. The time needed to complete the questionnaire was less than 30 minutes. The full questionnaire is provided in Appendix 14.

6.4.3.2 The Short Form-12 health survey:

The survey questionnaire included the SF-12 Health Survey (version1) [229, 230, 242]. The SF-12 is a generic health status measure that contains items covering physical functioning, social functioning, role functioning (physical and mental), vitality, bodily pain, mental health and general health. The SF-12 generates two summary scores: The Physical Component Score and the Mental Component Score (PCS and MCS respectively). The PCS and MCS are generated using norm-based methods and are standardised, using scores from the general population [229, 243], to have a mean of 50 (Standard Deviation (SD) 10). A higher score indicates better quality of life.

6.4.4 Independent variables:

The survey collected socio-demographic variables to describe the carers. These included age, sex, employment status, marital status, ethnicity, education level, annual family income, living arrangements and relationship with the person with dementia.

6.4.5 Dependent variables:

1. The types and use of AT by carers in the support of persons with dementia (objective 1) - The types and uses of the AT were explored using a list of AT as well as open ended questions asking participants to record AT that were not listed.
2. The outlay costs, monthly on-going costs and perceived value for money of AT (objective 2) - Carers were asked for information on approximate expenditure in

Pounds sterling (£) for the initial purchase and monthly ongoing costs of using the AT, as well as indicating who paid for the AT.

3. The perceived impact of AT on carers (objective 3) - Carers were asked to indicate perceived impact of AT in reducing harm, creating additional time for carers, reducing stress and managing anxiety, concerns about privacy and confidentiality, how AT meets their needs and overall satisfaction with AT.
4. The general physical and mental health of carers of persons with dementia who use AT (objective 4) - The quality of life of carers who completed the survey was investigated with data from the SF-12, along with one question each on the impact of caring on carer health and how carers coped.

6.4.6 Statistical methods:

Data from postal surveys were entered into Qualtrics [15] and double checked for transcription errors by the researcher. A final data set from Qualtrics was then imported as a comma separated value file and data analyses were carried out using IBM SPSS Statistics version 26 [17]. Descriptive statistics in the form of frequency distributions, percentages, means, standard deviations, and medians were used to examine the types of AT used, what the AT was used for, costs of the AT, perceived value for money and satisfaction with the AT. Bivariate analyses involving a chi-square test, a Mann-Whitney U test and a Kruskal-Wallis test were conducted to examine differences in socio-demographic variables such as education level, living arrangements and relationship status between carers and their SF-12 MCS and PCS scores. An independent-Samples Kruskal-Wallis Test was used to analyse perceived value for money and total costs and monthly costs of use of AT. The level of significance was set at $p<0.05$ for all analyses.

6.5 Results:

The survey was conducted between April 2020 – July 2020. A total of 215 questionnaires were returned by respondents. Sixty-six completed questionnaires were returned from a total of 85 participants who requested the postal questionnaire. A further 149 questionnaires were returned using the online anonymous link on the Qualtrics survey platform. Of these, 3 respondents declined to give consent at the start of the online questionnaire and did not proceed further and were excluded. A further 11 respondents had not completed the questionnaire further than listing the AT used and so their data were excluded. This left a total of 201 complete questionnaires after exclusions.

6.5.1 Description of participants:

There were 131 (65.2%) women and 65 men (32.3%) with 1 participant self-identifying as non-binary and 4 missing values. Carers' ages ranged from 33 to 92 with a mean age of 62 (SD 12) with most carers between 46-65 years (n=105; 52.2%) followed by carers between 66-85 years (n=74; 36.8%). Participants in the survey were predominantly white (n=186; 92.5%), currently married (n=158; 78.6%) and with a university degree (n=127; 63.2%). Participants were children of a person with dementia (n=110; 54.7%) or a spouse of a person with dementia (n=72; 35.8%) with others caring for in-laws, uncles, and step-parents. For those who disclosed annual family income (n=153; 76.1%), most participants earned between £10,000 - £40,000 (n=86; 42.7%). A fuller description of the participants is available in Table 6-1.

Table 6-1 Cross-sectional survey - characteristics of interview participants:

Characteristic	Category	Number of carers	Percentage
Age [Range: 33 - 92 Years]	< 45	20	10.0
	46- 65	105	52.2
	>66	76	37.8
Sex	Women	131	65.2
	Men	65	32.3
	Other	1	0.5
Living arrangements	Living with person with dementia	103	51.2
	Living away from person with dementia	98	48.8
Ethnicity	White	186	92.5
	Indian/Indian British	4	2
	Mixed/multiple ethnic groups	3	1.5
	Other	1	0.5
Marital status	Single	17	8.5
	Married/civil partnership	158	78.6
	Divorced/legally dissolved civil partnership	22	10.9
	Widowed/surviving partner	3	1.5
Highest level of education	Secondary school	8	4.0
	College (further education)	58	28.9
	Undergraduate university degree	76	37.8
	Postgraduate university degree	51	25.4
	Other	8	4.0
Annual family income	Less than £10,000	7	3.5
	£10,001 - £40,000	86	42.7
	£40,001 - £70,000	49	24.4
	Greater than £70,000	11	5.5
	I do not wish to say	47	23.4
	Parent	110	54.7

Characteristic	Category	Number of carers	Percentage
Relationship with person with dementia	Sibling	3	1.5
	Friend	2	1.0
	Neighbour	1	0.5
	Spouse	72	35.8
	Grandparent	3	1.5
	Other	10	5.0

6.5.2 Types and uses of AT:

Carers reported using a wide variety of AT. Frequently used AT were smart phones (n=91; 45.5%) and tablet computers (n=90; 45.0%), followed by video communication systems (n=89; 44.5%) and dementia clocks (n=82; 41.0%). Less frequently used AT included stair lifts, electric toothbrushes, and hoists. Carers used many different ATs (between 1 to 13), with 37.8% carers using less than four ATs and 62.2% carers using five or more ATs. There was no difference in numbers of AT used or abandoned in relation to the age of the carer.

AT were predominantly used for safety (n=157; 78.5%) and communication (n=132; 66.0%), followed by AT used to support memory and provide reminders (n=125; 62.5%). AT were least used for managing everyday spending (n=8; 4.0%) and for activities of daily living such as supporting eating, washing etc., (n=17; 8.5%).

Among those participants (n=88) who provided information on AT that were no longer in use, pendant alarms (n=35; 41.2%) and audio books (n=22; 25.9%) were the most frequently abandoned AT devices. The main reason for abandonment was reported to be because the person with dementia was no longer able to use the device (n=69; 81.2%).

Table 6-2 gives an overview of the AT in use, those that were abandoned by carers and the main reasons for use as well as why they were abandoned.

Table 6-2 Cross-sectional survey - Types and uses of Assistive Technology and reasons for abandonment:

Type of Assistive Technology	AT in use N (% of participants)	AT no longer in use N (% of participants)
Assistive robot(s)	1 (0.5%)	
Flood detector	2 (1.0%)	
Robotic pet(s)	2 (1.0%)	
Satnav in car	2 (1.0%)	
Bath lift	2 (1.0%)	
Electric toothbrush	3 (1.5%)	
Stair lift	4 (2.0%)	
Digital photo frame	4 (2.0%)	
Hoists	5 (2.5%)	
Electronic mattress	5 (2.5%)	
Automatic gas switch-off device	7 (3.0%)	2 (2.4%)
Stove timer	7 (3.0%)	
CCTV	8 (4.0%)	1 (1.2%)
Baby monitors	11 (5.5%)	1 (1.2%)
Riser recliner chair	11 (5.5%)	
Cooker alarm	12 (6.0%)	5 (5.9%)
Bed occupancy sensor	13 (6.5%)	1 (2.4%)
Electronic medicine dispensers	13 (6.5%)	8 (9.4%)
Electronic reminders	13 (6.5%)	2 (2.4%)
Electronic tracking device	14 (7.0%)	12 (14.1%)
Object locator	14 (7.0%)	
Picture button telephone	15 (7.5%)	
Smartwatch	15 (7.5)	1 (1.2%)
Movement detectors/sensors	16 (8.0%)	4 (4.7%)
Audio books	20 (10.0%)	22 (25.9%)
Voice-controlled personal assistant such as Alexa or Siri	21 (10.5%)	3 (3.5%)

Type of Assistive Technology	AT in use N (% of participants)	AT no longer in use N (% of participants)
Web camera	21 (10.5%)	2 (2.4%)
Smart lights	22 (11.0%)	
Smart plugs	27 (13.5%)	
Door alarm	28 (14.0%)	2 (2.4%)
Electric bed	28 (14.0%)	1 (1.2%)
Falls alarm	31 (15.5%)	6 (7.1%)
Automatic night lamp	32 (16.0%)	1 (1.2%)
GPS tracking device	33 (16.5%)	7 (8.2%)
Large button telephone	37 (18.5%)	8 (9.4%)
Memory clock	42 (21.0%)	7 (8.2%)
Computer/Laptop	52 (26.0%)	10 (11.8%)
Smart gas and electricity meter	56 (28.0%)	2 (2.4%)
Pendant alarm	66 (33.0%)	35 (41.2%)
Electronic day, date and time clock (Dementia clock)	82 (41.0%)	9 (10.6%)
Video communication systems such as Skype or FaceTime	89 (44.5%)	3 (3.5%)
Tablet computer	90 (45.0%)	7 (8.2%)
Smartphone	91 (45.5%)	20 (23.5%)
Use of Assistive Technology		
Managing day to day spending	8 (4.0%)	
Everyday activities such as eating, washing, dressing, toileting	17 (8.5%)	
Outdoor mobility	24 (12.0%)	
Managing finances	24 (12.0%)	
Indoor mobility	25 (12.5%)	
Reducing effort when caring for someone with dementia	60 (30.0%)	
Leisure	93 (46.5%)	
Memory or reminders	125 (62.5%)	
Communication	132 (66.0%)	

Type of Assistive Technology	AT in use N (% of participants)	AT no longer in use N (% of participants)
Safety	157 (78.5%)	
Reason why Assistive Technology is no longer in use:		
Ethical reasons		3 (3.5%)
The assistive technology is no longer working		5 (5.9%)
I or a family member support the person with dementia		11 (12.9%)
Removed assistive technology as person with dementia no longer wanted it		14 (16.5%)
Formal/paid carers support the person with dementia		15 (17.6%)
The assistive technology device has been replaced by a better device		16 (18.8%)
The person with dementia is no longer able to use it		69 (81.2%)

6.5.3 Costs of AT:

Carers chose AT predominantly by themselves (43%), followed by carers choosing along with the person with dementia (21%) and then by health or social care professionals prescribing the AT (18.9%). Only 7 participants reported that the AT was chosen exclusively by the person with dementia.

Carers (n=168) reported that initial costs for the AT ranged from £16.00 to £10,000 (median = £400) and monthly ongoing costs, when reported (n= 179) ranged from no additional costs to £150.00 a month (median =£17). The monthly costs usually involved expenditure towards pendant alarm subscriptions and monthly phone subscription and internet costs. The AT was purchased predominantly by the participant carer (54.4%), by another carer (10%), by the person with dementia (23.9%); or provided by social services/health system without a charge (9.7%).

Most of the carers stated the AT they were using was either extremely good (35.3%) or somewhat good (49.3%) for value for money. Carers would definitely (62.7%) or probably (31.3%) recommend the use of AT to other carers. None of the carers said they would not recommend AT. There was no significant difference in the initial and monthly costs of AT to the perception of value for money.

Independent-Samples Kruskal-Wallis Test Null Hypothesis	N	Test statistic	Sig.
The distribution of 'Approximate initial cost of AT' is the same across categories of value for money of assistive technology.	168	7.002	0.070
The distribution of 'Approximate monthly cost of AT' is the same across categories of value for money of assistive technology.	178	3.943	0.260

The significance level is 0.050

6.5.4 Perceived impact of AT:

Carers were asked to choose up to three currently used AT devices and respond to questions on how the nominated AT helped reduce their effort in caring for someone with dementia, the perceived impact of AT in reducing stress and managing anxiety of the carer. Carers' views on AT in reducing harm/potential harm to the person with dementia and if AT made their caring role easier were also assessed.

Carers indicated that the level of care provided to the person with dementia had not changed (48.3%) since the introduction of AT. Some carers reported that AT improved a little (32.6%) and improved a lot (11.5%) of the care provided. Carers (n=123) felt that AT was very helpful (24.9%) or helpful (21.1.%) in reducing the need for additional paid care. Carers (34.8%) reported being extremely satisfied with the AT, with carers using five or more AT devices being significantly more satisfied with AT than carers using four or less AT devices (p=0.001). There were no significant differences between the level of satisfaction with AT to age, living arrangements or relationship with the person with dementia.

Further details of the perceived impact are provided in Table 6-3.

Table 6-3 Cross-sectional survey - perceived impact of Assistive Technology:

	Percentage (%) of responses based on AT currently in use				
	Not at all helpful	A little helpful	Quite helpful	Helpful	Very helpful
AT helps in reducing effort (n=200)	8.8	27.2	16.5	25.0	22.5
AT helps in reducing stress (n=194)	5	21.1	11.0	23.9	39.0
AT helps in reducing anxiety (n=200)	7.0	19.4	12.0	23.0	38.6
AT helps make caring role easier (n=198)	7.2	26.4	10.8	30.8	24.8
AT reduces need for additional paid care (n=123)	32.2	11.9	10.0	21.1	24.9
AT helps reduce harm/potential harm (n=198)	32.5	16.4	7.4	15.7	28.0
	Deteriorated a lot	Deteriorated a little	Not changed	Improved a little	Improved a lot
Care provided for a person with dementia changed (n=198)	4.0	3.6	48.3	32.6	11.5
	Extremely dissatisfied	Somewhat dissatisfied	Neither satisfied/dissatisfied	Somewhat satisfied	Extremely satisfied
Overall satisfaction with AT (%)	1.0	1.0	7.5	55.2	34.8
Less than 5 AT used (N)	1.3 (1)	0 (0)	17.3 (13)	54.7 (41)	26.7 (20)
Five or more AT used (N)	0.8 (1)	1.6 (2)	1.6 (2)	56.0 (70)	40.0 (50)
	Value	df	Asymptotic Significance (2-sided)		
Pearson chi-square	19.200	4	**0.001**		

6.5.5 Physical and mental health of carers:

Mean PCS and MCS scores were calculated from the SF-12. The mean PCS (n=201) was 49.19 (95% CI 47.75 – 50.63) and the mean MCS (n=201) was 45.37 (95% CI 43.93 – 46.80).

PCS scores were significantly ($p<0.001$) associated with age, with older carers having lower PCS scores. MCS scores were also significantly associated with age ($p= 0.012$) with carers in the 46-65 age group having lower MCS scores than other age groups and women having lower MCS scores compared to men ($p= 0.002$). Carers who lived with the person with dementia had significantly ($p<0.001$) lower PCS scores than those who lived away. Children had better PCS scores than spouses ($p<0.001$).

MCS scores were significantly higher ($p=0.010$) in carers who expressed they were extremely satisfied with the AT but there were no significant differences in PCS and MCS scores to the amount of AT used. There was no significant difference between the number of AT devices being used to the perceived impact on caring, coping, and personal relationship with the person with dementia.

There was a significant relationship between coping with caring ($p<0.001$) and perceived relationship ($p<0.003$) with the person with dementia. Those who coped well and had a good relationship with the person with dementia had better PCS and MCS scores.

Table 6-4 gives an overview of the PCS and MCS scores with the significant differences.

Table 6-4 Cross-sectional survey - Physical and mental component scores:

		N	PCS		MCS	
		N	Mean	95% CI	Mean	95% CI
SF-12 Scores		201	49.19	47.75 – 50.63	45.37	43.93 – 46.80
Age Groups						
	<45	20	54.78	52.53 – 57.02	49.52	45.37 – 53.68
	46-65	105	51.62	49.81 – 53.43	43.76	41.70 – 45.82
	>66	76	44.37	41.88 – 46.86	46.49	44.22 – 48.75
	p		**<0.001**		**0.012**	
Sex						
	Men	65	49.28	46.67 – 51.89	49.23	47.35 – 51.10
	Women	131	49.10	47.32 – 50.88	43.37	41.46 – 45.29
	p		0.536		**0.002**	
Living arrangements						
	Living with the person with dementia	103	46.18	43.93 – 48.43	44.69	42.69 – 46.69
	Living away from the person with dementia	98	52.36	50.78 – 53.94	46.08	43.98 – 48.17
	p		**<0.001**		0.244	
Marital status						
	Single	17	52.70	46.77 – 58.63	41.65	35.49 – 47.81
	Married/civil partnership	158	49.30	47.71 – 50.88	46.11	44.53 – 47.69
	Divorced	22	45.80	40.89 – 50.71	44.00	39.24 – 48.76
	Widowed	3	54.08	47.00 – 61.17	43.42	21.34 – 65.50
	p		0.063		0.515	
Relationship with person with dementia						
	Parent	110	51.74	50.08 – 53.51	44.38	42.34 – 46.42
	Sibling	3	39.13	9.67 – 68.58	52.61	48.80 – 56.42

		N	PCS		MCS	
	Friend	2	57.48	44.27 – 70.70	51.75	29.26 – 74.24
	Spouse	72	44.86	42.17 – 47.54	46.27	44.00 – 48.54
	Grandparent	3	57.80	50.22 – 65.37	49.56	24.03 – 75.10
	Other	10	50.59	44.74 – 56.44	44.16	35.45 – 52.88
	p		**<0.001**		0.436	
Highest level of education						
	Secondary school	8	47.01	35.10 – 58.93	40.53	29.03 – 52.02
	College	58	50.45	47.80 – 53.10	43.85	41.10 – 46.60
	Undergraduate university degree	76	47.64	45.16 – 50.13	47.03	44.88 – 49.17
	Postgraduate university degree	51	49.81	47.14 – 52.47	45.38	42.32 – 48.45
	Other	8	53.07	46.63 – 59.51	45.28	36.63 – 53.94
	p		0.302		0.305	
Satisfaction with AT						
	Extremely satisfied	70	48.71	46.32 - 51.10	48.26	46.29 – 50.22
	Not extremely satisfied	130	49.38	47.54 - 51.21	43.94	42.04 – 45.85
	p		0.720		**0.010**	
Number of AT being used	Less than 5 AT	76	49.20	46.95 – 51.46	46.16	43.88 – 48.44
	5 or more AT	125	49.19	47.30 – 51.08	44.88	43.02 – 46.75
	p		0.757		0.561	
Coping with caring						
	Coped very well	45	54.52	52.85 – 56.19	49.83	47.41 – 52.26
	Coped quite well	79	49.38	47.38 – 51.39	46.86	44.98 – 48.74
	Coped ok	68	45.16	42.14 – 48.17	42.45	39.75 – 45.14
	Coped poorly	9	51.37	42.80 – 59.95	32.00	21.65 – 42.35
	p		**<0.001**		**<0.001**	

		N	PCS		MCS	
Relationship with the person with dementia						
	Very good	50	51.90	49.85 – 53.96	48.47	45.99 – 50.96
	Quite good	107	47.18	45.15 – 49.21	46.23	44.38 – 48.09
	Fair	34	51.68	47.72 – 55.64	40.59	36.83 – 44.35
	Quite poor	5	45.45	25.56 – 65.35	35.00	20.23 – 49.77
	Very poor	3	60.48	53.31 – 67.65	36.69	0.48 – 72.90
	p		**0.003**		**0.001**	

6.6 Discussion:

This survey showed carers and persons with dementia use a wide variety and multiple types of AT in the UK. Smart phones and tablet computers were the most commonly used AT, this is perhaps because they can be used for more than one purpose, such as communication, safety (e.g., tracking, medication reminders) and leisure activities. AT was largely used for safety (e.g., monitoring/tracking, movement sensors, pendant alarms, medication management), followed by communication and reminders, which is similar to earlier findings [244].

The survey showed that the age of the carer did not limit the number of AT devices used and it was not a reason for abandoning AT, which is dissimilar to previous findings [245], that older participants did not perceive AT as useful in caregiving activities and may be reluctant to adopt new technologies. This contradiction could be because the choice of AT did not depend only on the spousal (older) carer alone; other family members and health care professionals assisted with the choice and purchase of AT. In addition, older carers are now comfortable to use technology that are pervasive (such as smart phones and tablet computers) and have now started using them as AT [246, 247].

This survey provided information on the range of expenditure on AT currently being used in dementia care in the UK. Carers consider AT as good value for money, due to the perception of AT supporting safety and communication (useful for both the carer and the person with dementia) and support the person with dementia to live longer at home [163].

Carers decide on and are willing to abandon AT especially devices such as pendant alarms when it is no longer possible for the person with dementia to use them. This continues to raise the issue of the suitability of AT that are purchased, trialled, and then abandoned -

increasing waste both economically for carers and environmentally [209]. Carers did not highlight ethical reasons as a prime reason for abandoning AT. This could be because carers feel the overriding concerns of safety and welfare of the person with dementia are more important [235, 248].

Caring can be a positive experience for carers but it does have an influence on anxiety, stress and fatigue, as well as causing problems with physical health among family carers [249]. None of the carers in this survey felt they could not recommend the AT to other carers; this could be because carers, irrespective of perceived impact and personal satisfaction with the AT, felt AT enhances and/or supplements care for a person with dementia and their own quality of life.

In this survey, carers felt there was no change in the effort of caring since they started using AT. This could be because the progress of dementia is often slow and unpredictable, and perhaps AT helps to maintain the status quo of the needs of a person with dementia. In addition, the care could also be supplemented by support from formal carers. Carers felt that AT helped in reducing their stress and anxiety. This could be because AT devices for communication and safety provide a sense of reassurance for carers, especially when they lived away from the person with dementia.

Carers did not perceive most AT as being useful in reducing harm, this may be because AT devices such as smart phones and tablet computers, which are the most used AT, are seen as devices that facilitate communication and leisure, rather than used for safety and welfare. Carers reported that AT helped reduce the need for additional paid care, and whilst this survey did not quantify this, it should be an area for further investigation into the economic advantages of using AT.

This study also revealed that the larger the number of AT devices being used the greater the satisfaction with AT. While this needs to be further explored, one reason could be because carers may be sequentially adding AT, i.e., using additional AT one at a time, based on the changing needs of the person with dementia, this could consequentially lead to increased satisfaction, as the AT meets their needs.

This survey provides an insight into the quality of life of carers who are currently using AT. Carer-person with dementia relationship, carer physical and emotional wellbeing and coping with the demands of caring are all dimensions of quality of life of family carers [250–252]. Carers who felt that their relationship and ability to cope with caring for a person with dementia had better PCS and MCS scores. Older carers had lower PCS scores similar to other studies [208, 245], which could explain why spousal carers had lower PCS scores than children who care for persons with dementia. MCS scores for carers in the 46-65 age group were significantly lower. This could be because carers within this age group are likely to be the "sandwich" generation [249], with responsibilities for caring for their own children and families whilst having to care for their aged parents.

Previous research [67, 79, 244] has shown that there were fewer numbers of AT that met the needs of basic ADL such as eating and bathing etc., which is confirmed in this survey. Basic ADL could be the tasks that a person with dementia is most dependent on [67]. Carers living with persons with dementia are usually spousal carers and living with the person with dementia meant carers being called on to physically assist them more often, which could explain why PCS scores were lower for carers living with the person with dementia.

Earlier studies [253, 254] have reported that coping with care responsibilities and actual relationship with the person with dementia has a direct effect on carer quality of life. This is

confirmed in this survey. AT is perceived to help carers manage their stress and anxiety as well as making their caring role easier, which could explain why those carers who felt extremely satisfied with the AT had better MCS scores. It may also be that the reason for using the AT for reassurance (safety, communication) is important for better carer quality of life.

The amount of informal care provided to older people in England, who require additional support is unlikely to keep pace with demand [255]. For dementia care, as this study shows, AT may help bridge this gap by reducing the need for physical contact based informal care or by improving the efficiency of this care.

6.7 Strengths and limitations of this study:

This study provides insight into the current use and impact of AT in dementia care across the UK. The CATEQ includes items related to uses, costs, impact and satisfaction with AT and provides a much better understanding of carers' experience with AT. One of the limitations for this study is that the questionnaire is in English and despite intensive efforts, participation from carers from a non-white ethnic background could not be increased. This does mean that some of the findings may not fully represent the views of carers in a multicultural UK population. This survey was launched just before the lockdown and subsequent restrictions due to COVID-19 in the UK could have resulted in an inability for some carers to respond to the survey, for example being unable to go out due to shielding to post paper questionnaires or increased caring responsibilities due to reduced healthcare services or other formal support. This in turn could have led to fewer responses from carers who are using AT to look after the most vulnerable of persons with dementia.

6.8 Conclusions:

This survey provides information on carers' experiences with using AT in dementia care. Providing care using technology has been sharply highlighted, due to the restrictions and consequent increased reliance on technology brought about by the COVID-19 lockdown, during which period this survey was carried out. Safety, memory, and communication are areas where AT is most used. This study found that AT can support carers in their efforts in caring for someone with dementia. Carers reported that AT helped them in reducing the effort involved in caring, making the caring role easier as well as reducing stress. However, additional support is needed for carers in the choice, purchase, and continued use of AT. Incremental use of AT and cost-effectiveness of AT in supporting the person with dementia and their carers are areas where additional attention is needed.

6.9 Summary:

This chapter discusses the findings of the survey on the use of AT in dementia care. The findings show AT is viewed as a positive influence in the life of most carers, but additional investigation is needed to explain why certain carers had lower quality of life; how multiple AT impacts on level of satisfaction; and AT's role in carers' ability to continue to provide ongoing care as the dementia progresses. The next chapter details the explanatory qualitative interviews conducted with a sample of carers from this survey to explain the facilitators and barriers in using AT as well as the impact of AT on carers, while caring for a person with dementia living at home.

Chapter 7 : Qualitative phase of the sequential explanatory mixed-methods study: Explanatory interviews on impact of AT use on carers of persons with dementia

7.1 Introduction:

Dementia is a progressive illness, and even if functional challenges impede their ability to live independently, persons with dementia want to live at home [256]. Carers play a crucial role in supporting people living with dementia in the community. Technology is viewed as a widespread solution to supporting carers and persons with dementia to live for longer in the community [150, 234, 235]. From the survey in the previous chapter, it is clear that carers regularly make the decision on purchasing and maintaining as well as deciding on abandonment of AT. Understanding carers' perceptions of AT and the impact of these AT devices on carers is important to continue to provide support for persons with dementia and their carers.

7.2 Sequential explanatory mixed-method study:

The survey using the CATEQ provided a broad understanding of the experiences of carers using AT. It provided information on the current use, satisfaction and impact of AT use among carers of persons with dementia. As described in the previous chapter, to gain a better insight into these findings, interpret them and to enrich the understanding of the experience and impact on carers using AT, a sequential explanatory mixed-methods design [236–238] was used. The quantitative data was collected and analysed first, as described in Chapter 6, this was followed by collection and analysis of qualitative data using semi-structured interviews with a sample of survey participants to help explain the quantitative data.

Integration in a mixed-method study may take place at more than one stage of the research process, using a wide variety of strategies. For this study, integration of the quantitative and

qualitative phases of the study was made at recruitment, data collection and data analysis stages. Data collection for this study took place in separate and sequential stages [257] (i.e., quantitative survey data was collected before qualitative interview data was collected), but the results of the survey informed the recruitment of carers and questions that were used for data collection in the interviews. At the analysis and interpretation stage, integration was achieved through discussion of how the qualitative findings explain and elaborate upon the findings from the quantitative study and discussion of implications of findings from both studies for future research and support for carers and persons with dementia.

This mixed-method study allowed focused attention on responses, by comparing individual carers' responses to the survey including their SF-12 scores with their interview transcripts. This also allowed consideration of where there is agreement, partial agreement, silence (theme or finding arises in either quantitative or qualitative data but not both), or disagreement between findings from the survey and the interviews.

To aid coherence and flow, the qualitative phase of this mixed-method study is described in this chapter. For ease of understanding relevant sections of data collection, analysis and results from the survey are repeated and combined with the themes from the interviews to better explain the findings.

7.3 Study objectives:

This qualitative phase was designed to provide additional context to the findings from the survey by investigating:

1. the experience of carers in using AT in the care of persons with dementia;
2. what are the facilitators and/or barriers in using AT?

3. what impact does AT have on carers whilst caring for a person with dementia?

7.4 Methods:

7.4.1 Study design:

This chapter describes the qualitative phase of the mixed-methods study. The cross-sectional survey was carried out between April to July 2020. Following the survey analysis, interview questions were formulated to gain further understanding into carers' experiences as identified in the survey. Interview participants were recruited and interviewed between October – December 2020.

The findings from this phase of the study have been published in a peer-reviewed journal[1] and published as a preprint[2]. Most sections of this chapter will reflect the submitted versions of this study.

7.4.2 Participants and recruitment:

As described earlier, survey participants were recruited from the *Join Dementia Research* [13] and OxDARE [14] databases, as well as through health care professionals who prescribe AT for persons with dementia. For the interviews, an email with the participant information sheet (Appendix 15) was sent to survey participants who gave consent to be contacted. From those who replied expressing an interest in participating, a purposive sample, based on the survey results, reflecting variations in age, sex, living arrangements, rurality, and relationship with persons with dementia was selected for the interviews. Participants were

[1] **Sriram V**, Jenkinson C, Peters M. Impact of COVID-19 restrictions on carers of persons with dementia in the UK: a qualitative study. Age Ageing. 2021;1. doi:10.1093/AGEING/AFAB156.

[2] **Sriram V**, Jenkinson C, Peters M. Carers using assistive technology in dementia care: an explanatory sequential mixed methods study. medRxiv. 2021; doi:10.1101/2021.04.08.21255110.

then sent two copies of consent forms by post and asked to return a signed copy of one of the forms to the researcher. The consent form used for this phase of the study is provided in Appendix 16.

7.4.3 Data collection:

The qualitative phase of this study was conducted during lockdown restrictions as part of the UK wide response to the COVID-19 pandemic [258]. Semi-structured interviews were hence conducted over the telephone [259, 260]. The interview focused on the caring experience, the use and impact of AT on carers and on caring for the person with dementia. All of the questions and prompts were open ended and informed by the systematic review [79], the qualitative study [209] and the results from the survey [261]. The interview topic guide was further confirmed as meeting the needs for answering the research questions by the research advisory group. The questions in the interview topic guide and pre-interview preparation are given in Box 7-1.

A question on:

“How has the restrictions and changes from COVID-19 impacted on your caring for [person with dementia] using AT?”

was added to identify changes in caring due to the restrictions imposed as a result of the COVID-19 pandemic.

Box 7-1 Explanatory interviews - interview topic guide:

Pre-interview:

Participant to receive the information sheet and asked to read it through. Participant will be given a brief introduction to the research that includes a description of Assistive Technology.

- *Introduce self*
- *Participant to be told what will happen during the interview process and reminded that the interview will also be audio recorded. Participant to be told that an anonymised transcript will be made from the audio recording. Participant to be reminded that they will remain anonymous, and that their data will be confidential.*
- *Participant given time to ask questions*

Questions:

Background:

1. Can you tell me a bit about yourself and your current situation and living arrangements? – You have the option of not providing this information if you do not wish to.
2. How long have you been helping/looking after/caring for [person with dementia]? How did it come about?
3. How is your day to day life affected by helping, looking after, or caring for [person with dementia]?
4. Do you have health issues (physical and mental health) that has an impact on your caring for [person with dementia]?
5. What support, if any, do you receive from other people? Does the [person with dementia] get formal/paid care?
6. What tasks that you help or support [person with dementia] with do you find challenging?

Use of Assistive Technology:

1. How do you and/or [person with dementia] use AT? Do you use AT with other family members?
2. Were there any ATs you could not obtain?
3. Do you think using this AT [list AT currently or most recently used] helps/helped you in caring for [person with dementia]?
4. If you have used an AT before and no longer are using it, what do you think prevented you or [person with dementia] from using it?
5. How happy are you with using this AT? Why do you say that?
6. Did you buy/use AT devices (when more than one) in any particular order, did that help you meet your/[person with dementia's] needs?

Impact of AT:

1. To what extent is AT integrated in your daily life/help/care that you provide for [person with dementia]?
2. How often do you use the AT?
3. When you consider all the help you are providing to [person with dementia], how does the AT help you? Do the AT cause any problems?
4. With which aspects of care has AT helped you?
5. What impact has the use of AT had on you and your quality of life or the burden experienced through your caring role? -
    a. Manage physical effects – sleep, health, aches and pains?
    b. Manage psychological effects – mood? Exhaustion, stress, anxiety, depression?
    c. Emotionally – Spending more time with person with dementia, frustration, confidence?
    d. Socially – friends, time for self, hobbies, vacation?
    e. Manage employment or education (e.g. University) – Time away from work/study
    f. With relationships – Strengthened caring for person with dementia, more time
    g. Provide better choice and control in everyday life
6. What type of AT, that you are not using but have heard of or may want others to develop - do you think would be useful and why when helping or caring for [person with dementia]?

Is there anything else you would like to add about your caregiving experience or AT?

The background of the interviewer as an Occupational Therapist and consequent interest in the research topic was discussed with carers. The carers were not known to the interviewer before recruitment and trust was built by establishing rapport with the participants. The interviews lasted between 30-50 minutes, were all audio-recorded, and later transcribed verbatim with names of participants/the person with dementia and any towns/cities mentioned in the interviews pseudonymised to ensure confidentiality.

7.4.4 Data analysis:

7.4.4.1 Quantitative data analysis:

Survey data was analysed as detailed in the previous chapter, using SPSS version 26 [17]. Descriptive statistics were used to examine the types of AT used, what the AT was used for, costs of the AT, perceived value for money and satisfaction with the AT. Bivariate analyses were conducted to examine differences in socio-demographic variables between respondents and the SF-12 scores. The level of significance was set at $p<0.05$ for all analyses.

7.4.4.2 Qualitative data analysis:

The data was analysed using Hermeneutic Phenomenology and thematic analysis, a process outlined in Chapter 4. In brief, the methodology of hermeneutic phenomenology focuses on the subjective accounts of individuals' own experiences in context. The process as described by Lindseth and Norberg and others [171, 173, 184] was followed. Thematic analysis was used to identify and describe topic categories raised by carers in describing and explaining the survey results in three steps.

1. The researcher (VS) listened to each of the interviews and read the transcripts multiple times.

2. Line by line coding of each transcript was carried out using the software package NVivo 12 [18]. The data analysis was ongoing throughout the period of data collection, this ongoing method allowed earlier transcripts to be recoded to reflect new codes as well as ask new questions to subsequent carers during interviews.
3. All the coded units were grouped into themes and underlying sub-themes.

Carers' own words, within the context of the results from the survey were then used to illustrate themes that retained the voice of the carers' personal experience and perspective. Data collection continued beyond 20 interviews to ensure no new codes were developed.

7.4.4.3 Reflexivity and integrity:

This study was conducted in collaboration with others. The interviews, initial analysis, coding of transcripts and themes were completed by the researcher VS. MP and CJ (Supervisors of the researcher for this DPhil) read selected transcripts and coded meaning units and themes.

Reflexivity [194] and integrity of the research process was maintained throughout the data collection and analysis stages. The researcher's experience provided the necessary expertise for this research. The interview topic guide was informed by the results of the systematic review [79], the exploratory qualitative interviews [209] and the survey [261] and there was active participation from the participants in the interviews.

7.4.4.4 Mixing analysis:

The themes from the qualitative interviews were developed, regularly compared and interpreted in context of the survey results [257]. VS, MP and CJ met regularly to discuss and agree ongoing data collection, agree on themes, interpret and integrate data analysis with the survey results.

7.5 Results:

Full results from the survey are reported in the previous chapter. Some of the findings are repeated in this chapter, as needed, to provide context. AT were predominantly used for safety, communication, and reminders. Multiple AT were used in the care of persons with dementia and the number of AT devices used was associated with perceived satisfaction. Carers reported that AT helped them reduce the effort of caring for a person with dementia and reduced perceived stress. Additional support was needed to support purchase and continued use of AT, and AT devices were abandoned when the person with dementia could no longer use them.

For the qualitative study, carers were purposively chosen from the survey participants. Due to the small number of participants from ethnic minority backgrounds in the survey, the qualitative interviews only included one carer from a non-white ethnic background.

Twenty-three carers (18 women, 4 men, and 1 non-binary) participated in the interviews. Participants' ages ranged from 51 to 85. Table 7-1 provides further details of the interview participants including their Physical Component Score (PCS) and Mental Component Score (MCS) from the survey. The PCS and MCS are generated using norm-based methods and are standardised, using scores from the general population to have a mean of 50 (Standard Deviation 10). A higher score indicates better quality of life. Although the scores are not meaningful at the individual level, scores below 35 are very low and would place respondents in the bottom 10% of the working age population [243, 262].

Table 7-1 Explanatory interviews - characteristics of interview participants:

ID	Age Range	Gender	Relationship	Ethnicity	Living arrangements	Assistive Technology used	PCS Score	MCS Score	Type of dementia	Years/months since diagnosis
1	71-80	Female	Wife	White	Living with person with dementia	Laptop; cooker alarm; smart phone; stove timer	23.11	52.03	Vascular dementia	Two years
2	51-60	Male	Son	White	Weekly visits	Audio books; automatic night lamp; dementia clock; GPS tracker; large button telephone; object locator; pendant alarm; picture button telephone; smart phone; web camera	57.23	55.92	Alzheimer's dementia	Eighteen months
3	71-80	Female	Wife	White	Living with person with dementia	Audio books; laptop; dementia clock; falls alarm; GPS tracker; pendant alarm; tablet computer; Alexa; web camera	54.37	42.29	Alzheimer's dementia	Three years
4	51-60	Female	Daughter	White	Living with person with dementia	Automatic night lamp; laptop; smart gas meter; smart lights; tablet computer; web camera	38.48	22.51	Unsure	Ten years
5	71-80	Female	Wife	White	Living with person with dementia	Electronic reminders; large button telephone; smart phone; tablet computer; video communication	39.90	35.17	Alzheimer's dementia	Four years
6	61-70	Female	Daughter	White	Living with person with dementia	Falls alarm; CCTV; GPS tracker; door alarm; memory clock; movement sensor;	57.12	26.40	Mixed dementia	Eight years

ID	Age Range	Gender	Relationship	Ethnicity	Living arrangements	Assistive Technology used	PCS Score	MCS Score	Type of dementia	Years/months since diagnosis
						picture button telephone; web camera				
7	81-90	Male	Husband	White	Living with person with dementia	Laptop; dementia clock; community alarm; smartphone; video communications	52.83	47.95	Alzheimer's dementia	Three years, six months
8	61-70	Female	Daughter	White	Living with person with dementia	Laptop; memory clock; tablet computer; video communications	55.91	55.86	Mixed dementia	One year
9	61-70	Female	Wife	White	Living with person with dementia	Automatic night lamp; baby monitor; laptop; cooker alarm; dementia clock; smart phone; stove timer; video communications; web camera; satnav in car	53.95	47.56	Mixed dementia	Six years
10	61-70	Female	Daughter	White	Daily visits	Electric bed; dementia clock; falls alarm; GPS tracker; Large button telephone; simple radio	62.47	28.33	Alzheimer's dementia	Four years
11	61-70	Female	Wife	White	Living with person with dementia	Electric bed; memory clock; pendant alarm	34.54	47.69	Vascular dementia	Three years
12	61-70	Female	Daughter	White	Visits every three weeks	Electric bed; stand aid	50.91	50.12	Unsure	Four years
13	71-80	Male	Husband	White	Living with person with dementia	Baby monitor; laptop; electric bed; smart gas meter; smart phone; video	55.50	57.82	Fronto-temporal dementia	Eleven years

ID	Age Range	Gender	Relationship	Ethnicity	Living arrangements	Assistive Technology used	PCS Score	MCS Score	Type of dementia	Years/months since diagnosis
						comms; Hoist; Wheelchair; WAV vehicle				
14	61-70	Female	Daughter	White	Daily visits	Laptop; dementia clock; GPS tracker; large button telephone; memory clock; pendant alarm; smart gas meter; smart phone; smart watch; video communications	57.99	43.30	Alzheimer's dementia	Seven years
15	51-60	Non-binary	Friend	Other	Daily visits	Laptop; electronic reminders; large button telephone; video communications; web camera	56.44	49.98	Parkinson's Dementia	One year, three months
16	61-70	Female	Wife	White	Living with person with dementia	Assistive robot; automatic night lamp; laptop; electronic reminders; GPS tracker; smart phone; tablet computer; video communications; Alexa	24.31	35.38	Alzheimer's dementia	Four years
17	71-80	Female	Wife	White	Living with person with dementia	Laptop; cooker alarm; falls alarm; pendant alarm; smart gas meter; smart phone; smart plugs; stove timer; tablet computer; video	33.30	27.00	Vascular dementia	Twelve years

ID	Age Range	Gender	Relationship	Ethnicity	Living arrangements	Assistive Technology used	PCS Score	MCS Score	Type of dementia	Years/months since diagnosis
						communications; Alexa; web camera				
18	71-80	Female	Wife	White	Living with person with dementia	Pendant alarm	44.47	38.91	Lewy body dementia	Seven years
19	51-60	Female	Daughter	White	Living with person with dementia	Audio book; laptop; dementia clock; GPS tracker; object locator; smart gas meter; smart phone; tablet computer	62.85	26.05	Alzheimer's dementia	Two years
20	71-80	Male	Husband + Son-in-law	White	Living with person with dementia (wife). Mother-in-law recently moved to nursing home	Cooker alarm; dementia clock; GPS tracker; smart gas meter; smart lights; smartphone; tablet computer; video communications; ELK lifting cushion	51.21	33.58	Behaviour variant fronto-temporal dementia (wife) + Vascular dementia (mother-in-law).	Four years (wife) Unsure (mother-in-law)
21	51-60	Female	Daughter + Stepdaughter	White	Weekly visits (mother recently moved to nursing home)	Falls alarm; Large button phone; memory clock; pendant alarm; picture button telephone; Video communications	60.39	27.12	Alzheimer's dementia (mother) + Vascular dementia (stepdad)	Five years

ID	Age Range	Gender	Relationship	Ethnicity	Living arrangements	Assistive Technology used	PCS Score	MCS Score	Type of dementia	Years/months since diagnosis
22	51-60	Female	Daughter	White	Daily visits	Dementia clock; door alarm; tracking device; GPS tracker; memory clock; smart phone	49.85	43.63	Alzheimer's dementia	Four years, six months
23	51-60	Female	Daughter	White	Daily visits	Electric bed; smart lights; tablet comp; video communications; Alexa; movement detector	50.88	17.41	Mixed dementia	Two years

7.5.0 Themes:

Five themes and 14 sub-themes were identified from the analysis of the qualitative interviews. The themes from the qualitative interviews are described in this chapter by putting them in context of the survey results. These explanatory interviews took place during the restrictions imposed across the UK due to the COVID-19 pandemic [263, 264]. Carers' responses in using AT in the context of COVID-19 are interwoven into the themes described below.

7.5.1 Theme 1: Use of AT:

In the survey, carers indicated use of a wide variety of AT including smart phones, tablet computers and video monitoring systems. They also reported staggered purchase and use of AT. Some AT devices such as pendant alarms and audio books were frequently abandoned as the person with dementia was no longer able to use them.

7.5.1.1 Staggered purchase and use of AT:

Interview participants confirmed that as a person with dementia's needs worsened, AT devices were added to support them and as these AT devices were purchased to meet specific needs, the satisfaction with these devices was higher.

> *"The clock was one of the first things that I got because she really struggled with time and day"* (Participant 19, Daughter, Living with person with dementia).

Computers and tablet computers were already in use by carers or the person with dementia and were adapted to support caring needs.

> *"Well, I already had the laptop…and she started using it for memory [games]"* (Participant 13, Husband, Living with person with dementia).

Carers had to constantly anticipate the future needs of the person with dementia and additional AT was added to support them as and when a need arose.

> *"The increase in [motion sensor] alarms has gone on as he has deteriorated and that is really because of the danger of him falling downstairs...it's had to be a gradual, a gradual putting-in and I've still, you know, I've still got one or two things, one or two plugs that I need to change on the Hive [smart home technology] system"* (Participant 17, Wife, Living with person with dementia).

Some of the purchase of AT was constrained due to the carers' own knowledge of the AT available and which devices could support the person with dementia.

> *"I think in all honesty I'd have liked to have had that one [CCTV cameras] before but didn't really know what would be suitable and again, lacked the technological know-how to say how do I sort this out"* (Participant 9, Wife, Living with person with dementia).

7.5.1.2 Ease of using AT:

The ease of using AT had an impact on satisfaction, continued use or abandonment of AT. This in turn affected the impact the AT had on carers.

Carers found some of the AT helped a person with dementia, even when the carer lived away. This provided the carer with a sense of reassurance.

> *"The tile [object locator] certainly helped so that remotely we could make them [objects connected to the object locator] buzz for her [person with dementia] and that made it easier to find things"* (Participant 2, Son, Visits weekly).

Carers reported that persons with dementia struggled to use AT such as pendant alarms, as intended.

> *"She's supposed to press [pendant alarm] if she falls? But she, she can't remember what it's there for. She puts it on religiously, it's like putting on jewellery. But twice she has fallen in the house, she's never pressed it"* (Participant 10, Daughter, Visits daily).

Elderly carers who were not used to technology and digital devices, initially struggled with AT and described the need for access to support and education regarding AT and using it in the care of a person with dementia.

> *"I think I've done extremely well with it [AT] but I've possibly … It, it would have been useful to have some access to education about that" (*Participant 9, Wife, Living with person with dementia).

Carers who were comfortable with using technology continued to use AT to communicate and stay in touch with the extended family and social networks where they could, when regular face-face visits were not possible during the COVID-19 pandemic restrictions.

> *"As I say, we're both pretty adept with technology, so it's, it's not something that's just come into our lives because of the COVID, I do not think so"* (Participant 16, Wife, Living with person with dementia).

7.5.1.3 Problems using AT:

While most of the AT devices that were currently in use were perceived as being user-friendly, carers also reported problems in the AT themselves or in their design. Some of the AT equipment such as electric beds and electric hoists were large and unwieldy in a home environment.

> *"I mean, all the equipment's large, but that [electric hoist] is really cumbersome" (*Participant 18, Wife, Living with person with dementia).

Some of the problems encountered with AT was a result of the ability of the person with dementia to look after the devices. Damage to the AT was frequent and the added responsibility of fixing or maintaining the AT fell on the carer.

> *"Now the problem with the electronic alarm, the electronical alarm watch lasted about four months and then it got dropped in the bath by [person with dementia]"* (Participant 15, Friend, Visits daily).

The design features of some of the AT also caused problems, did not serve their intended purpose or caused additional confusion in the person with dementia.

> *"The GPS [tracker], that is a right pain because it has to be charged up every night"* (Participant 20, Husband, Living with person with dementia).

> *"But, again, because, you know, you've got to have the angles and, and everything right and sitting comfortably, that [video phone call] works up to an extent, but I think after a while when we've, we've done the [video] call she's sort of asking, "Well ..." you know, "... where are they?" She can't sort of understand the concept of what's going on*" (Participant 8, Daughter, Living with person with dementia).

Carers wanted AT developers to involve them as end users, to ensure devices are easy to use and are accessible to those who are technologically challenged.

> *"Perhaps if they [AT developers] just sought a bit of feedback, we could help them just alter things a little bit, you know, not, not greatly, just to make things even more accessible for people and, and for us"* (Participant 10, Daughter, Visits daily).

7.5.2 Theme 2: Satisfaction with AT:

The survey showed that carers who used five or more types of AT expressed greater satisfaction with the AT. During the interview, carers confirmed that they made decisions to use AT based on the immediate needs of the person with dementia, which included other

co-morbidities not associated with dementia. Carers also described how the use of AT strengthened their relationship with the person with dementia, and this explained the increased level of satisfaction with the AT.

7.5.2.1 Ability of the person with dementia:

While AT was generally used to support difficulties a person experienced, because of dementia, some of the AT was used to support a person with dementia for other illnesses.

> *"We use it [electric bed] as unfortunately she's also got severe osteoarthritis"* (Participant 12, Daughter, Visits every three weeks).

Persons with dementia benefitted from AT that supported them with cognitive issues. However, as they were still physically active, carers continued to struggle with providing adequate care. Additional AT devices were used when the situation of the person with dementia deteriorated.

> *"The first years [since diagnosis] were in some ways more difficult because she was still active and would go walkabout…She then broke her hip and that was it, her mobility went. She wouldn't bear weight thereafter…so we had to use these equipment [electric bed and hoist]"* (Participant 13, Husband, Living with person with dementia).

Carers also used AT to support persons with dementia when their own abilities meant they could no longer participate in activities with the person with dementia.

> *"So, he quite likes walking and getting about and I can't no longer do the length of walk that he would like so we use the tracker [GPS tracker device]"* (Participant 3, Wife, Living with person with dementia).

AT was abandoned when the person with dementia's situation worsened due to non-dementia related reasons.

> *"He used, he really lost the ability to use a computer [cognitive reasons]. But he could, he did until maybe 18 months ago [now no longer using], cause his eyesight really was getting worse, he used a Kindle [eBook reader]"* (Participant 18, Wife, Living with person with dementia).

7.5.2.2 Ability of the carer to problem solve:

Carers described how their ability to problem solve assisted them in the continued use of the technology.

> *"So, she has one friend where he phones her up and he painstakingly talks her through how to get into Skype on the computer…then he can hang up and they can have a conversation 'cause he lives in Germany'"* (Participant 15, Friend, Visits, Daily).

Carers also simplified the use of some off-the shelf devices to suit the specific needs of the person with dementia.

> *"He's got some, a couple of photographs and my number, and my daughter's number [on the smart phone]. And we had other things on it but we've had to limit it to that [two numbers] because he can manage to, to press and ring with those two [being] very visible, but that's now what we've had to reduce it down to"* (Participant 17, Wife, Living with person with dementia).

7.5.2.3 AT supporting strengthened relationships:

Carers (75.21%) in the survey described that AT gave additional time for themselves and 46.05% of carers indicated that the use of AT helped to improve the care they provided to the person with dementia, and 78.9% of carers felt that their relationship with the person with dementia was very good (25.1%) or quite good (53.8%). These findings were confirmed in the interview by carers as another reason for their increased satisfaction with using AT.

Carers felt that the AT helped provide reassurance to the person with dementia that the carer was still trying to keep them safe.

> *"I suppose he [person with dementia], because it's, he's not able to communicate that well now, but hopefully it helps him to realise that I am coping and keeping him safe with the equipment that we use"* (Participant 11, Wife, Living with person with dementia).

AT also helped carers spend more time together with the person with dementia

> *"We can sit down and watch something together [on tablet computer] and, and engage with it, and, you know…and stuff and we can have a giggle and then you end up talking about old neighbours or old family members. So, yes, it does help"* (Participant 19, Daughter, Living with person with dementia).

7.5.3 Theme 3: Impact of AT on carers:

In the survey, carers in the 46-65 age group and carers who were not extremely satisfied with AT had lower MCS scores. Carers who lived with the person with dementia and older carers had lower PCS scores on the SF-12. The interviews attempted to explain the impact of AT on carers and to explain the variations in SF-12 physical and mental health component scores.

7.5.3.1 Physical wellbeing of carers:

Carers had multiple physical health problems. These physical health issues were not always a result of caring or looking after a person with dementia. Carers' age and other illness were attributed to their physical health problems. Carers reflected on their own poor health, which explained the lower physical component scores, especially among older carers.

> *"As for myself, I haven't got very good health. I'm suffering from very bad back pain"* (Participant 1, Wife, Living with person with dementia).

While some of these issues were long standing, a few physical health issues arose because of caring for the person with dementia.

> *"I mean, I have picked him up and ended up in hospital because I had done the disc in my back"* (Participant 17, Wife, Living with person with dementia).

Carers also made changes to their lifestyle, as a result of their caring role for the person with dementia.

> *"Even things like, you know, my diet is affected, because he has to be fed completely and his ability to chew and swallow is, is impaired. So, therefore I tend to think, "Oh, well, I'll eat just whatever he's eating [liquid diet]"* (Participant 9, Wife, Living with person with dementia).

In this context, AT did have a positive impact on the physical wellbeing of carers, especially for moving and handling of the person with dementia.

> *"It's certainly taken the strain off of my body, off my muscles and off my back. So it's been a great help, both the [electric] bed and the hoist"* (Participant 11, Wife, Living with person with dementia).

The reassurance provided by AT used for safety, especially for carers who lived away from the person with dementia, assisted carers in better sleep and maintaining an active and healthy lifestyle.

> *"So I can fall asleep better [carer using door alarm for wandering alerts]"* (Participant 22, Daughter, Visits daily).

7.5.3.2 Mental wellbeing of carers:

Caring for a person with dementia did cause a strain on the mental health of carers.

> *"So, it created a huge amount of stress, as Mum was deteriorating being on her own all the time"* (Participant 19, Daughter, Living with person with dementia).

Some of the issues were indeed compounded by carers having to look after their own families in addition to a parent.

> *"My son, he has Asperger's, so at home it can be quite stressful at home at times"* (Participant 21, Stepdaughter, Visits weekly).

The use of AT did offer relief to carers and provided reassurance to them.

> *"So, it means we know that she's taken her tablets. We know that there's music if she wants to. We know she can use the bed"* (Participant 10, Daughter, Visits daily).

Some of the AT also filled a need among carers for their own leisure and communication needs.

> *"I would be lost without my technology, socially, mentally I need it…I still run a [virtual] group but I also am able to join other groups"* (Participant 17, Wife, Living with person with dementia).

The AT also provided much needed time to carers for themselves and do tasks that they wanted to complete.

> *"Well, I think it's just that I can entertain Mum [using tablet computer] so that I can have some time to just catch up on paperwork or make a phone call"* (Participant 19, Daughter, Living with person with dementia).

7.5.3.3 Social wellbeing of carers:

In addition to physical and mental health impacts, AT also had an impact on the social wellbeing of carers and the person with dementia.

> *"So, having the Facetime or the WhatsApp [on smart phone] has been very good, so she can see them [family] and keep, keep in touch"* (Participant 14, Daughter, Visits daily).

It also provided an opportunity for carers to continue to engage in social activities that they enjoyed before the diagnosis and progression of illness for the person with dementia.

> *"We were still able to use assistive technology [GPS tracker, web camera] while mobile so that we could, we could still go out and about and be able to get the alarms or the, the contact if there was an issue"* (Participant 2, Son, Visits weekly).

During COVID-19, carers appreciated when their wider social networks adapted to the needs of the person with dementia, such as increased in-person visits (when restrictions were eased) to support the person with dementia and carer to compensate for them not being able to go out.

> *"But fortunately, my children were very supportive, and one or other of them would be here every weekend"* (Participant 13, Husband, Living with person with dementia).

Additionally, carers also reported that neighbours and social contacts were mindful of social distancing rules, even when the person with dementia could not remember to follow them.

> *"And so, if they see mum and she goes towards them, they will step back from her…They don't rely on her remembering that she's got to be six [sic] feet away…"* (Participant 14, Daughter, Visits daily).

7.5.4 Theme 4: AT use in daily life:

From the survey, carers revealed that the AT had not significantly changed the level of care they provided to the person with dementia. Carers also reported that AT helped in reducing the need for paid/formal care. The interviews helped explain that this was one of the reasons for carers recommending AT use to others.

7.5.4.1 Coping with caring:

AT is perceived by carers as supplementary to the care that they provide. As the abilities of the person with dementia deteriorate with progress of the illness, AT helped carers cope with the additional caring needs.

> *"We would look at the cameras if we were uncertain whether she had eaten fully"* (Participant 2, Son, Visits weekly).

AT was perceived as being integrated into the daily life and routines of the carers, especially when it concerned the safety and welfare of the person with dementia.

> *"Well, all of them [CCTV, movement sensor, door alarm] become integrated. I mean I've got the front, the exit monitors on all the time… because, you know, you can't be in the same room as them [person with dementia] all the time, can you?"* (Participant 6, Daughter, Living with person with dementia).

Some carers felt that the use of AT increased the frequency of checking-up on the person with dementia and added to their caring tasks.

> *"So, we've just resorted to checking her frequently [using CCTV], having the carer check her once a day … that's the best thing that we can do … Oh, it's, well, the monitoring of it has taken over our life"* (Participant 14, Daughter, Visits daily).

7.5.4.2 Person with dementia using AT:

Carers also reported that persons with dementia had varied ability in using the AT by themselves, which meant carers had to provide additional support to them in the use of the AT.

> *"Despite the fact it has the day and the date [dementia clock] she [Person with dementia] still sits and asks what day it is … so, we say, 'Well, have a look at the clock'… the radio, I thought it would be more useful than it is. It's all, it's quite easy*

to set up, but I think with all of these things, they all require lots of support from somebody else" (Participant 10, Daughter, Visits daily).

Sometimes, persons with dementia continued to struggle with using AT even with prompts from carers.

"When the alarm goes off, she goes, 'What's that, what's that noise?' 'It's your alarm watch, are you gonna switch it off?'… 'No, no' and she just wouldn't switch it off, she wouldn't do anything with it" (Participant 15, Friend, Visits daily).

7.5.4.3 Use of simple devices:

Even though carers used AT, they combined these with non-electronic or simple devices/solutions that worked in supporting and caring for the person with dementia. This combined use of simple devices and electronic AT proved more effective in caring for a person with dementia and supported reduction in the stress and anxiety associated with caring.

"I also write our shopping lists on there [white board] so, anything we've run out of I write on there, or [Person with dementia] writes on there. So, we, we write our shopping list out and then I'll wipe it all off afterwards. So, it is very, very handy" (Participant 1, Wife, Living with person with dementia).

Carers also adapted existing AT when the ATs' use as intended did not support the person with dementia.

"And I'd adapted a seven-day pill box to make, you know, to, to make sure there's, that each compartment is one particular time [adapting electronic pill dispenser]" (Participant 15, Friend, Visits daily).

7.5.5 Theme 5: Wider support systems in supporting caring:

In the survey, carers reported that AT is an adjunct to supporting a person with dementia. The costs, privacy concerns, support from wider care networks and support systems all played a role in how carers used AT.

7.5.5.1 Support from others:

Carers who used AT for moving and handling of a person with dementia needed ongoing additional support from formal carers. However, this did not always work as intended.

> *"I know Social Services do not allow the [electric] hoist to be used by a single person. Well, all the carers that I know we all did it on our own because there wasn't anybody else"* (Participant 13, Husband, Living with person with dementia).

Even when AT supported a carer in caring tasks, they continued to rely on formal/paid carers to provide much needed respite from constantly caring for a person with dementia.

> *"We managed to get a [paid] carer to come in two days a week for three hours so I had a little bit of relief…so it's had a dramatic effect on my life"* (Participant 4, Daughter, Living with person with dementia).

In some instances, AT provided easier access to healthcare professionals, however carers had to provide additional support and time for the person with dementia to access these services.

> *"…Zoom or WhatsApp or Skype have had a tremendous help [to stay in touch], otherwise the impact would have been significantly greater…but I have to help with all of those"* (Participant 20, Husband, Living with person with dementia).

For most carers, visits by the person with dementia to local day care centres and memory cafes was the time that they could have for themselves and was seen as a time for respite by the carers. Due to the changes in socialising rules and lack of support staff available to

operate these centres, they were closed during the two national lockdowns in 2020. This had a negative impact on carer wellbeing.

> *"…but the going out for my mum is a breather from my dad* [person with dementia] *and he couldn't go to his day centre because it's closed, and mum didn't get any time to herself*" (Participant 22, Daughter, Visits daily).

> *"I did have access to and used carer support groups but again that's all gone"* (Participant 9, Wife, Living with person with dementia).

Carers had to provide additional support and care due to the sudden lack of visits from formal carers.

> *"They withdrew all care and I was left looking after him. I couldn't even get [him] out of a chair, and so as far as what it's done is distanced myself from him"* (Participant 17, Wife, Living with person with dementia).

Carers felt there was a general lack of access to healthcare professionals during the COVID-19 pandemic. A significant amount of the consulting and advice services was moved to a digital format due to the COVID-19 restrictions, which did not always work as intended and carers found it difficult to access services and professionals and had to provide increased support to the person with dementia as a result.

> *"Although, most of it's done over the phone now. And of course, you know, there was one, there's been several calls where you had to log into a website … in order to have the face-to- face consultation, which has been really complicated. She would, there's no way she would have done that on her own"* (Participant 15, Friend, Visits daily).

> *"Yeah, so, in fact, the detrimental side of it is with the medical services, the fact that everything is by phone, nothing is by video, and they haven't a clue what's going on.*

> *They can't, there's no body language, they can't read body language, they're just listening to voices and the standard of care has been, is, is now abysmal"* (Participant 17, Wife, Living with person with dementia).

7.5.5.2 Ethical issues in using AT:

Carers clarified ethical issues associated with consent and continued use of AT when cognitive and behaviour issues associated with dementia worsened. Carers let persons with dementia assume AT were innocuous devices and this encouraged the continued use of the AT.

> *"At the moment she thinks that it [GPS tracker] controls her house-key. She doesn't realise it's a tracker. So, she never ever leaves it because she knows she can't get back in the house"* (Participant 14, Daughter, Visits daily).

Carers did set up what could be seen as intrusive AT with consent from a person with dementia, but continued to use the AT, even when ongoing consent might be an issue, due to the progressive cognitive decline in the person with dementia.

> *"So we've got, we set up internal cameras with her full knowledge and agreement but I don't think she remembered about those after a while"* (Participant 2, Son, Visits weekly).

Carers were aware of and keen to avoid privacy and data leaking issues, when sensitive information could go out externally.

> *"Those smart speakers are a brilliant idea in theory, but I feel very unhappy about the idea that every single sound that goes into that thing [smart home system] goes back in some form or another to whoever"* (Participant 20, Husband, Living with person with dementia).

Additional illustrative participant quotes for the themes and sub-themes are provided in Table 7-2.

Table 7-2 Explanatory interviews - themes and sub-themes with illustrative quotes:

Theme	Sub-theme	Example quote 1	Example quote 2	Example quote 3
Use of AT	Staggered purchase and use of AT	We got things as, as she worsened (Participant 2, Son, Visits weekly)	Well as we got problems, we found these technological solutions to enable us to continue to care for him at home (Participant 23, Daughter, Visits daily)	Yeah. I, I got them, I think, gradually as Mum's condition progressed ... I was trying to maintain her independence as long as possible (Participant 6, Daughter, Living with person with dementia).
	Ease of using AT	I think it's [electric bed], it's much more help than, than anything else...As I say, because she still can cooperate with using it (Participant 12, Daughter, Visits every three weeks)	I mean, I am very, I'm, I'm not au fait, au fait with it all but what I do know I'm, I'm able to use quite efficiently (Participant 4, Daughter, Living with person with dementia)	His own phone, he's okay answering it and doing the odd text with one word. I, I've got to admit, though, his iPad has been beneficial to him (Participant 5, Wife, Living with person with dementia)
	Problems using AT	She would take it [pendant alarm] off from her neck and just throw it onto the settee which activated the alarm (Participant 14, Daughter, Visits daily)	But there was, there was at one point the, the hoist that, it hadn't charged and so he got stuck half-way (Participant 18, Wife, Living with person with dementia)	[There is a] GPS tracker on her phone but after a while she forgot to, to take her phone with her, so when she went walkabout, we had no idea where she was, and that really problematic (Participant 2, Son, Visits weekly)
	Ability of the person with dementia	She's got rheumatoid arthritis (Participant 15, Friend, Visits daily)	She's got quite severe depression... She won't come downstairs, she refuses, she won't go out in the garden. She's in that room and that is it (Participant 4, Daughter, Living with person with dementia)	She can't remedy any mistakes that she makes. She gets very frustrated, she panics and then she presses all sorts of buttons and then calls us (Participant 14, Daughter, Visits daily)

Theme	Sub-theme	Example quote 1	Example quote 2	Example quote 3
Satisfaction with AT	Ability of the carer to problem solve	I've got a little key finder, which I call my mum finder, and I…slip it in her pocket or something, or it's on a lanyard so she will play with it, and it's just more if we get separated (Participant 19, Daughter, Living with person with dementia)	What we did instead was use these pressure pads that you put under the cushion. So, as he started to get up out of the chair, …the beep would go off and I could go and make sure he was okay. (Participant 23, Daughter, Visits daily)	Well, I can, I can use it, but I don't find any technology particularly easy. I've always got to sit and think through it, you know? (Participant 10, Daughter, Visits daily)
	Supporting strengthened relationships	That [CCTV camera] has helped because, and obviously being able to see him, helps him because he thinks, yes, there's people out there that care about him (Participant 23, Daughter, Visits daily)	I think it's [AT], it's maintained a very close and stable relationship that was always there. It's, it's just experienced in a different way (Participant 7, Husband, Living with person with dementia)	It [Youtube on tablet computer] has helped me and mum because instead of just sitting there keeping her occupied, and doing puzzles and, and chatting and watching, we've been able to do the tai chi (Participant 10, Daughter, Visits daily)
Impact of AT on carers	Physical wellbeing of carers	It affected me physically because I ended up having to either lift him up or help him into bed, or get him into a wheelchair, get him into the car (Participant 18, Wife, Living with person with dementia)	I do a little workout routine with Mum in the morning to YouTube (Participant 19, Daughter, Living with person with dementia)	Physically, without that [electric bed and hoist] assistance, I could not have managed (Participant 13, Husband, Living with person with dementia)
	Mental wellbeing of carers	'…Zoom or WhatsApp or Skype have had a tremendous help, otherwise the impact would have been significantly greater' (Participant 10, Daughter, Visits daily)	I can't begin to tell you, how much, how much, how helpful they [GPS tracker, movement sensor] were and how much anxiety they took away. (Participant 6, Daughter, Living with person with dementia)	I tend to use the technology for my own amusement at times (Participant 20, Husband, Living with person with dementia)

Theme	Sub-theme	Example quote 1	Example quote 2	Example quote 3
	Social wellbeing of carers	It [Smart phone and tablet computer], it's absolutely helped to sustain my social life (Participant 17, Wife, Living with person with dementia)	Yes, it's [AT] helped there [socialising] definitely…it does mean that one person can look after my dad at a time, rather than two people being there if you need to do lots of things (Participant 23, Daughter, Visits daily)	We can communicate with our daughter and grandson in [city] via WhatsApp or anything and actually see them while we're talking to them which has obviously made a difference if she does that (Participant 7, Husband, Living with person with dementia)
AT use in daily life	Coping with caring	Yes, we wouldn't be able to function at all without those [Electric bed; memory clock; pendant alarm] (Participant 11, Wife, Living with person with dementia)	You know, when you have worked out routes for him to take, the length of time it takes him to walk [using the GPS tracker] and basically if he's not back within that time then I, then I would have to go and see what's happening (Participant 16, Wife, Living with person with dementia)	I could go out more often, and maybe not going more than a quarter of an hour from home or something like that, so I could get back if a problem arose [find out using the CCTV camera, smartphone] or, or I could ring the next door neighbours and say, 'Please go and sort her out' (Participant 20, Husband, Living with person with dementia)
	Person with dementia using AT	He watches television which is good for stimulating him but he can't use the remote control, so he relies on me to sort of get it all set up for him (Participant 11, Wife, Living with person with dementia)	When she comes over to us in the evening then we will, do a Zoom or we'll do a, a Facetime or, a WhatsApp with our children so that she can see them, but left to her own devices she couldn't do it (Participant 14, Daughter, Visits daily)	An internet device which calls my phone if she has a fall or if she wants to get in touch and she can talk to me over it. It's [community alarm] becoming less and less useful, because she can't do anything … she can't go anywhere on her own (Participant 7, Husband, Living with person with dementia)

Theme	Sub-theme	Example quote 1	Example quote 2	Example quote 3
	Use of simple devices	We have a visual calendar in his, in his kitchen that we write things on that are happening and he really likes that (Participant 21, Daughter, Visits weekly)	So my idea is to keep regular photos of the family where possible so that she's aware of how they are changing and who they are (Participant 8, Daughter, Living with person with dementia)	The key safe outside, it means if at all necessary, if she forgot. Well, she wouldn't know how to use it, but we would always have a key if, if we had to run up in an emergency or something, there would be a key there (Participant 10, Daughter, Visits daily)
Wider support systems in supporting caring	Support from others	It's [formal carer visits] a, it's a safety net and it also enables mum to see somebody else (Participant 14, Daughter, Visits daily)	I now have a private carer who comes to help me one hour in the morning Mondays to Fridays and one hour in the evening Tuesday, Wednesday, Thursday just to give me a hand (Participant 9, Wife, Living with person with dementia)	Even though there is a carer there as well moving her and doing a lot of things needs two people now (Participant 12, Daughter, Visits every three weeks)
	Ethical issues in using AT	The [GPS] tracker, she doesn't know what it is. I sneak it on her with her sunflower lanyard when we have to go in shops (Participant 19, Daughter, Living with person with dementia)	We didn't tell him what it was for, we just said that there was a button on it that he could press if he needed us and it would ring on the phone here. But we didn't actually tell him that we knew where he was going or that we could see where he was because he wouldn't have accepted it (Participant 22, Daughter, Visits daily)	I think personal security, personal secrecy worries me a little bit on that front (Participant 20, Husband, Living with person with dementia)

7.6 Discussion:

The attention on person-centred care has enabled people with dementia to live longer lives in the community. Without adequate support for their progressive physical and cognitive needs, most persons with dementia may end up in long-term care institutions. There are predictions that the availability and ability of carers to continue to support persons with dementia in the community will not match demand [255]. Using AT is seen as a solution in supporting persons with dementia and their carers and facilitating home based care and support for persons with dementia.

This study explains the impact of using AT on carers who look after persons with dementia living at home. Carers viewed AT as an adjunct to providing care for the person with dementia and in addition use AT themselves for leisure, improved social contacts and mental wellbeing. Carers modify existing 'off the shelf' AT to meet their unique needs [26] and requirements and in most instances, carers were satisfied with the use of AT. This study also explained how AT use in dementia care may not solely rely on the dementia related needs of the person with dementia; it is also dependent on the co-morbidities of persons with dementia and the carers themselves.

Carers with existing physical and psychological challenges exacerbated by their own age and health experience additional burden while caring for a person with dementia. AT use in these instances helped reduce their burden and improved their perceived quality of life. Similar to earlier studies [38], older carers are less likely to access and use new AT, as they may be unaware of these devices and are less likely to request support in the acquisition and continued use of these AT. This study also explained how carers expressed better

satisfaction with AT when it is integrated into daily life and how they adapted their role and routines to better use the AT in supporting the person with dementia at home.

Dementia changes the dynamics of the relationships between the person with dementia and their carer [265]. While caring and supporting a person with dementia may be perceived as stressful, AT could strengthen the caregiving relationship, as the AT itself became a socially connective device [155] and facilitated additional time spent using the AT together, especially for leisure and communication.

Sophisticated AT and smart homes exist, but carers use this alongside simpler devices and non-electronic AT. This enhanced satisfaction and met carers' needs in these interviews, as has been reiterated in the recently concluded largest AT Trial involving persons with dementia [60]. This study highlights that AT augments the amount of time carers provide care for a person with dementia. However there is a need for respite care for carers [266, 267], and social communication with wider family members (who could look after the person with dementia and substitute for the main carer); this social aspect of care cannot be replaced with AT only solutions.

Carers (in the survey) did not consider or were not overly concerned with data sharing and privacy issues connected to AT use. Some carers in the interviews were specifically concerned about privacy issues and limited the type of AT being used. This is an emerging area for concern and is likely to require further research and policy intervention as AT devices become sophisticated and ubiquitous in use.

This mixed-method study reinforces earlier findings [79, 209] of a mixed picture of use and usefulness of AT and adds to the literature on the impact of AT use on carers. AT by itself or in combination with other simple devices, support from formal carers and wider support

networks has the potential to be an important addition to efforts to improve the safety and welfare of people with dementia, who wish to continue to live at home and it will consequently support their carers.

7.7 Strength and limitations of this study:

The interviews provided an opportunity to explain and delve deeper into the findings of the survey that explored the experiences and impact of AT use in dementia care amongst carers. Selecting participants from across the UK ensured that geographical limitations of procuring and using AT did not limit the transferability of our findings. The interviews were conducted over telephone due to restrictions from the COVID-19 pandemic and this might have missed out on some non-verbal cues and interactions from carers. Despite repeated efforts, only one participant in the interview was from an ethnic minority group. It remains important to further investigate how carers from Black, Asian or other Minority Ethnic communities in the UK are using AT and if there are differences in the impact experienced by this group of carers when using AT.

7.8 Conclusions:

This study demonstrates that carers have positive and negative experiences with using AT, but there is generally a beneficial impact on carers who look after persons with dementia. AT devices with the right functionality and when used at those times when needs arose are regarded as useful and satisfactory and are integrated into daily life and routines of the person with dementia and their carer. Carers should be consulted and involved in the development and trial of AT solutions. Policy, funding and clinical pathways of care need to

facilitate prevention and risk reduction for persons with dementia as well as encouraging education and accessibility of AT to all carers.

7.9 Summary:

This chapter describes how AT is currently used in dementia care in the UK and the impact it has on carer wellbeing. The chapter highlights that to prevent a future carer crisis, carers need better support systems including formal carer services, digital solutions that work for them and additional support for respite care. AT supplements, the care provided to a person with dementia in the community and appropriate use, access to AT and abilities of the carer can enhance the support provided through AT to both carers and the person with dementia.

Chapter 8 : Discussion

8.1 Introduction:

This thesis so far has detailed the steps involved in exploring carers' experiences with AT and the impact of the AT on them. In summary, the objectives of this research study were to:

- Review what types of AT carers use and prefer
- Understand how carers use AT
- Understand what support carers need to use AT
- Explore the benefits and disadvantages of AT use
- Explore the facilitators and barriers to using AT
- Investigate the impact of AT use on carer wellbeing

Findings from each stage of this research have been discussed in the preceding chapters in comparison to existing literature. This chapter provides an overview of the discussion of these findings in the context of health and care policy, and current literature.

Modern healthcare has played an important role in enabling people to live longer and provide more choice in where they want to live and be cared for. Persons with dementia and their carers want to live at home for as long as possible [39]. Families and communities play a vital role in supporting persons with dementia when they live at home and they may require support and help in the ongoing care of a person with dementia [20].

Most carers are spouses or children of the person with dementia, with extended family members, close friends and neighbours also taking on responsibilities for caring. Carers are involved in providing "hands-on" care and support for a person with dementia. Where needed, carers play a significant role in coordinating and managing the care delivered by formal/paid carers and health and social care professionals. The Johns Hopkins Translational

Aging Services panel convened to develop proposals on future directions for home-based dementia care [268], recommended home-based care for people with dementia as the nexus of economically efficient long-term care models and highlighted that "new technologies to promote best practices must be tested, integrated, and deployed" in dementia care.

Carers often know the person with dementia well. Carers' involvement is crucial for developing effective, personalised, needs-based care plans for persons with dementia. AT can support people with dementia to live independently and lead to greater efficiencies in care [126]. Carers make, and continue to make, decisions on the purchase and maintenance of AT. Thus, involving and including carers and taking account of their views and experiences with AT should form an integral part of providing good care for a person with dementia within their own home.

To discuss the findings from this research study, it is important to understand the process of including carers and supporting them in the care of the person with dementia in the context of how AT is typically provided in the UK.

8.2 The 2014 Care Act:

The Care Act of 2014 [64] created a legal duty for local authorities to provide assessment and support for carer needs in England, with some provisions of the Act applicable in Wales and Northern Ireland. Similar provisions are provided in Scotland under integrated care through the Public Bodies (Joint Working) (Scotland) Act 2014 [269]. The carer assessment mandated under the 2014 Care Act includes - whether the carer is able (and is likely to continue to be able) to provide care for an adult needing care, the outcomes that the carer wishes to achieve in day-to-day life, and whether, and if so to what extent, the impact of

provision of support could contribute to the achievement of those outcomes. The Care Act strengthens the rights and recognition of carers in the social care system and gives carers a right to receive services, even when not providing substantial care on a regular basis.

Despite the general understanding that carers would benefit from the provision of assessment and support, in most instances of providing care for their spouse or parent, in reality, there are concerns those carers may not get a choice of how much care they provide and how involved they need to be. The support offered through the local authority or through the healthcare services can be sparse [270] and it is unclear to what extent a carer assessment may ease the demands, anxiety and stress associated with looking after a person with dementia.

8.3 Assistive technology pathway in the UK:

Typically, AT is purchased by carers or extended family members of persons with dementia [271]. AT could also be prescribed, loaned or provided by the NHS and adult social care services. Usually, publicly funded AT services are commissioned by local clinical commissioning groups of NHS England, Health boards in Wales and Northern Ireland or NHS Scotland. Funding is connected to a person's General Practitioner or through the local authority, where people with dementia are normally resident. This invariably leads to a variance in the amount, type and sophistication of the AT provided across the country. Referrals for AT could be made to the NHS or adult social care services from health or care professionals. The person with dementia or a carer could also self-refer themselves for an assessment of AT needs.

Once a referral is received, the typical pathway [48, 272] that is followed is:

- the person with dementia is assessed at home by a member of the AT service (usually an Occupational Therapist);
- equipment is carefully tailored to each individual taking into account their functional abilities and goals;
- training is provided for the person with dementia and/or to the carer in the use of the AT;
- maintenance, on-going support and regular servicing (when needed) is provided and agreed with the person with dementia and/or their carer.

Reviews should be completed annually or if the person with dementia is referred again to the AT service. The annual review does not routinely assess AT needs based on carer preferences or use, nor does it consider ongoing consent from the person with dementia for the use of AT.

Personal health budgets (for healthcare needs) and personal budgets (for social care needs) [273] allow persons with dementia or their carers, after a means-tested financial assessment [274], to purchase AT equipment that may not be readily available through the publicly funded system. Some AT can be provided after an assessment through community equipment stores for persons with dementia or their carer to try (on loan) or purchase. Most of these AT are stand-alone devices and when connected to a monitoring centre involve a subscription cost paid for by the person with dementia and/or their carer.

8.4 Discussion:

This research has shown that the use of AT involves:

1) The person with dementia
2) The carers who support and interact with the person with dementia

3) The commissioners, policy makers and prescribers of AT and
4) The developers and designers of AT

The findings show that the experiences and impact of using AT in dementia care, from the perspective of carers, can be summarised into the interconnected stages of design, selection, use, and integration of AT into their own lives and the daily lives of the person with dementia they care for.

8.4.1 Stage 1: Development of AT:

The systematic review (Chapter 3) highlights the wide variety of AT currently in use for persons with dementia and their carers. Some AT devices are available as commercial products and others are still under development. Much of the AT used in dementia care was not specifically developed for use by persons with dementia or to support them.

Dementia is a progressive illness with a varying trajectory of cognitive decline and physical problems. For many of the products that are commercially available, developers have paid only limited attention to the needs of persons with dementia or their carers from conceptualisation of the product through to testing and commercialisation. This research highlighted that the environment and space available at home for using AT impacts on carers' abilities to use the AT (e.g., hospital beds, hoists) and the consequent effectiveness and usefulness of the AT. Designers and developers of AT must therefore understand and take into account the physical and cognitive abilities associated with dementia, as well as understanding and taking into account the settings in which the AT will be used.

Currently, the 'need' for AT is defined by those providing the AT (developers or health and social care professionals) [57]. Developers and health and social care professionals generally adopt a "one-size-fits-all" approach, with persons with dementia and their carers

seen as passive recipients and users of AT. The development of AT that will be useful in dementia care requires the engagement of persons with dementia and their carers at every level of design and not just a short trial once the AT has been created. This inclusion will ensure that the needs of persons with dementia and their carers are sufficiently addressed. Examples of this would be development of 'passive' AT devices that do not require input from the person with dementia, development of AT equipment that can anticipate and offer support for behavioural changes in a person with dementia, AT that can alert carers regarding falls even if the person with dementia is unable to call for help, and AT that can support the person with dementia with their activities of daily living tasks and thus reduce burden for the carer.

8.4.2 Stage 2: Selection of AT:

This study (Chapters 3 and 4) reveals that the main uses of AT were for safety, memory and social interaction. Carers chose and used multiple AT devices based on the changing functional abilities of the person with dementia and for reassurance to themselves, where the welfare and safety of the person with dementia was concerned.

Selection and choice of the AT depends on knowledge of AT. Carers generally had access to few formal resources which could support them to identify technologies which may be appropriate to the person they cared for. There is a mixed economy of AT acquisition (Chapter 6), including purchase predominantly by carers, local authorities, healthcare providers and private care companies [49]. Carers generally find information on AT from multiple sources including general internet searches, but the most usual route appears to be through charity and voluntary sector organisations for persons with dementia.

Health and social care professionals follow a 'crisis' model of AT use [124], in which AT is typically put in place as a response to an individual crisis (e.g., a fall) of the person with dementia. This complicates the use of AT, simply because a person with dementia may no longer be able to learn how to use a device and consequently the role of facilitating AT use falls on the carer, who may also struggle to learn to use the AT, whilst needing to cope with caring for the person with dementia. Carers are thus left to select AT anticipating potential problems that the AT could resolve based on current functional abilities of the person with dementia, rather than awaiting a crisis situation to unfold.

With the ubiquitous nature of availability of technology and its use, it can be assumed that carers would naturally turn to AT to support caring for a person with dementia. AT is perceived as an adjunct to providing care for the person with dementia, but carers need to be better informed about AT use, where to find devices and how to purchase the AT. It should not be only those carers who are adept at adapting to using the AT or finding information about AT, who derive benefit from using the AT. Some of this information regarding AT could be provided by health and social care professionals, at the point of diagnosis or review of care plans for the person with dementia. This may lower carer burden as they would not need to find out all this information themselves and may even prevent the person with dementia from coming to harm.

Selection and subsequent use of the AT is not a 'one-off' event, carers need to continue to provide support, assist with maintenance and respond to AT alerts. Depending on the AT used, carers purchased AT and tried it with the person with dementia and then found some of it not to be of use to the person. The lack of usefulness and the progressive nature of dementia meant that AT was frequently abandoned within a short period of time.

Larger AT items such as electric beds, stair lifts and hoists are usually provided by the health or adult social care services but smaller AT devices such as smart phones, dementia clocks and GPS trackers are normally purchased by the carers themselves at considerable cost to them [126]. Carers would benefit from trying AT, selecting those that work for them and the person with dementia and returning AT devices when they are no longer of use. Setting up an AT store that includes AT devices such as smart phones, tablet computers, environment control systems and voice assistant devices such as *Alexa* and *Google* would benefit carers who would otherwise be unable to afford to try these devices. State/publicly funded purchasing power of some of these items could benefit more individuals even if they were paying for them, either in whole or in part.

8.4.3 Stage 3: Use of AT:

The success of AT use in dementia care is affected by the background in which it is used. This context of use comprises the social and cultural context in the society as well as the carer and person with dementia's individual preferences and abilities. When carers, especially elderly carers, lacked familiarity or confidence with technology, this limited the choice and use of AT, even when AT was suggested to help, support and improve caring for the person with dementia.

Being a carer for someone with dementia may affect the carer's physical and mental health and social wellbeing [275]. As the results from this research reveal (Chapters 6 and 7), even when carers are physically and psychologically well, there could be some age-related functional limitations among elderly carers, which impact on their ability to care and consequent dependence on AT. Use of remote monitoring technology, location finding GPS trackers, motion sensors and door alarms support and alert carers or emergency services if

they detect any problems. Such AT helps to support individuals who would be otherwise at risk of social isolation or of wandering and associated harm. Use of AT in this way, in addition to enabling people with dementia to stay in the community for longer, reduces the anxiety and stress of carers, especially when they live away from the person with dementia.

Persons with dementia and their carers may have multiple morbidities. AT use in these instances, for example, using a hoist or electric bed to physically assist a carer when looking after a person with dementia, helps reduce their burden and improves their quality of life [117]. This research also found that AT helps to strengthen the caring relationship. Some of the AT such as large button remote controls, dementia clocks and memory alarms are useful for the carers themselves, when they use it alongside the person with dementia. AT facilitates spare time that carers can spend with the person with dementia, using the AT together, especially when the AT is used for leisure and communication.

Even after carers started using and benefitting from AT, carers often had to modify and customise AT for effective use with the person with dementia (e.g., modifying pendant alarms to stop them being accidentally activated or modifying an electronic medication dispenser for daily instead of weekly use). Carers provide these adaptations or changes to the AT itself or to the environment and spatial arrangements where the AT is in use. For this 'bricolage' (objects that have been used before are modified/reorganised with a new perspective) [26, 57] to happen, AT itself must be simple to set-up and easy to use, in addition to being aesthetically pleasing. Carers ended up using everyday technologies, such as smart phones, for video communication and location tracking of a person with dementia to fill the gap in available and affordable technologies.

Carers attempt and find solutions to modify and use AT yet, despite this, the AT could eventually fail as the person with dementia's impairment worsened. In addition, the inherently improvisational nature of AT use, trial and error in finding the appropriate AT to use and constant modifications to everyday life, when combined with a lack of support from health and social care professionals means using AT in dementia care becomes a frustrating and sometimes wasteful process. This frequently led to carers abandoning or rejecting AT in dementia care.

Carers are concerned about privacy and intrusive surveillance (using remote cameras or motion detectors) of a person with dementia and do favour autonomy of the person with dementia and unobtrusive monitoring at the same time, giving rise to a conflict between safety of the person with dementia and their freedom [153]. Carers however took a pragmatic approach and prioritised safety and welfare concerns over that of ethical dilemmas around surveillance [276]. Carers generally prefer AT that is integrated and can interact with other devices and technologies. Privacy of data collected by AT and data transfer issues for some of the connected AT such as voice assistants and remote surveillance are only emerging now and may need further investigation. AT used within this vulnerable group must adhere to the highest privacy standards for the collection, use, storage and transmission of data [277].

8.4.4 Stage 4: Integration of AT:

Dementia by its nature does not lend itself to a clear, sequential care pathway, as it affects people in very individual ways. Caring for someone with dementia is a highly individualised experience [35] and so is the experience of using AT in that care. This study (Chapters 6 and 7) reveals that using AT influences carers' emotional, social, financial and physical

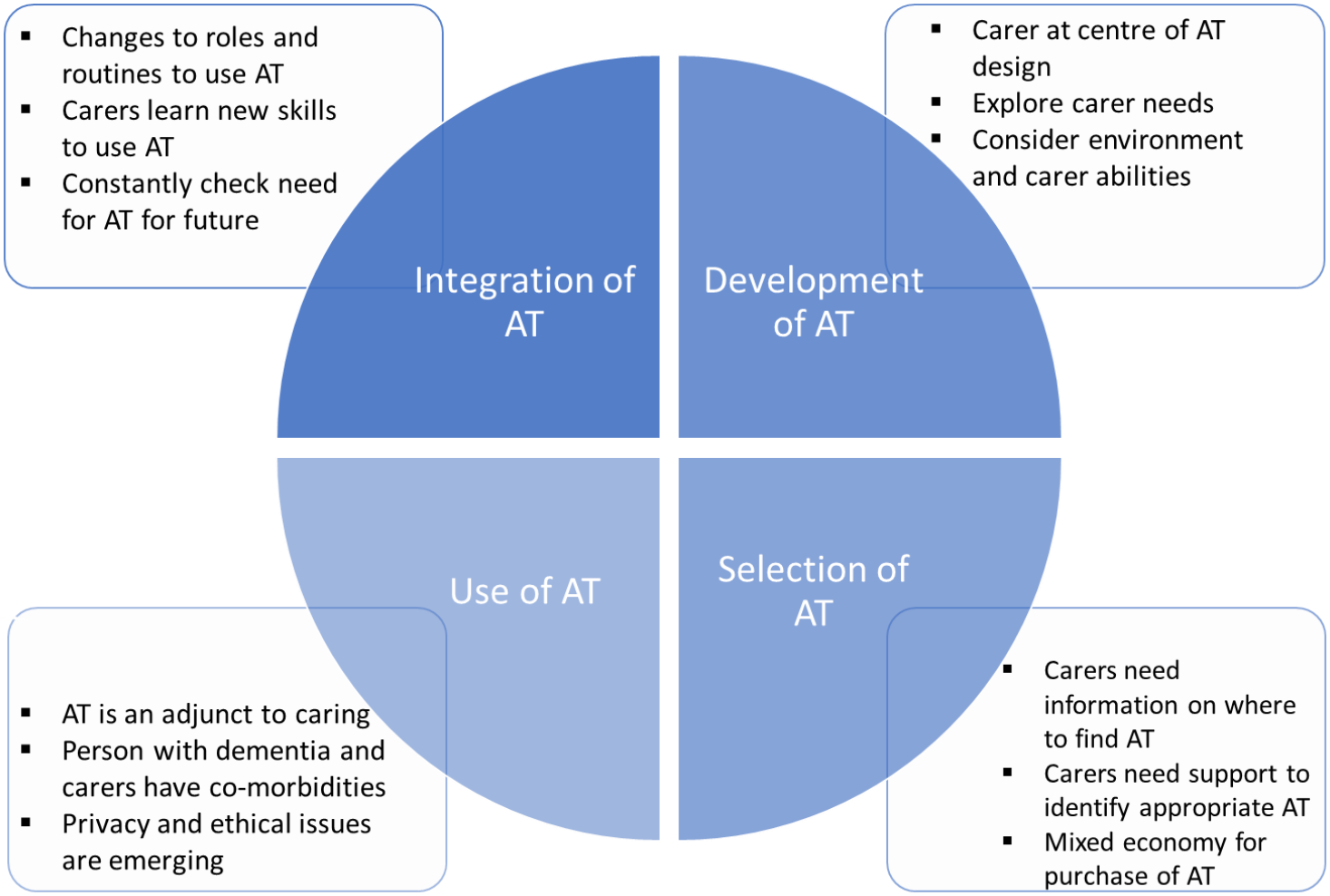
functioning. Carers play a significant role in whether or not, and in which ways, AT is integrated into the everyday life of persons with dementia and consequently into their daily life. Carers adapt their usual roles and routines to use AT, this in turn helps a person with dementia to incorporate them, which supports carers, with reassurance and decreased anxiety even when they are geographically distant.

Using AT in the care of a person with dementia requires the learning of new skills to use technologies (e.g., responding to motion sensor alerts, checking the movement of person with dementia on mobile devices) and the collaborative integration of the AT within the home setting. Even when carers and the person with dementia are proficient in AT use, external support (formal or from extended family) continues to be necessary, especially when AT breaks down.

Even relatively simple AT requires, from carers, a series of lifestyle changes to their routines if the AT is to work in practice. Carers for instance had to charge batteries, remind the person with dementia to wear their pendant alarm, install sensors and lights, carry out maintenance of the AT device, or updates on smart phones and computers. Carers had to continually assess whether these routines were working, at what point they needed changing, and when the AT needed to be abandoned [57]. Carers had to anticipate and plan for future AT needs for the person with dementia, which is a new role for them. Carers are best placed to identify practical solutions to the functional limitations of a person with dementia and introduce AT into their care, however carers also felt that they were 'on their own' in doing so. Information and education about AT and support in its ongoing use was scarce or unavailable from health and social care professionals.

Figure 8-1 gives a visual representation of these discussions as stages in the experience and impact of using AT.

Figure 8-1 Experience and impact of AT in dementia care:



8.5 Appraisal of the research:

This research study was conducted in multiple phases, and the value and processes of the different research methods are presented here.

8.5.1 Patient and carer involvement:

There is growing consensus about the importance of patient and public engagement and involvement in research [278]. One person with dementia and two carers of persons with dementia were involved in this research, as part of the research advisory group. Their involvement strengthened this research by shaping the research process and providing reassurance that the research investigated their concerns and answered questions for those in similar life circumstances. This group was involved throughout the research process and brought their unique knowledge and specific experiences relating to dementia to strengthen this research study. Their previous experiences of dementia care and AT use and ideas about relevant research questions, research procedures and design provide a perspective on the findings from this research, their interpretation and facilitated dissemination.

8.5.2 Using multiple methods research:

This study was conducted in stages, starting with a systematic review, followed by exploratory interviews and then a mixed-methods approach that involved a survey for the quantitative phase followed by explanatory interviews for the qualitative phase. This multiple method approach supported iteratively building up a clearer picture of what is important for carers, their experience of using AT and the impact of AT on them. For example, the questionnaire content for the CATEQ, used in the survey is derived “bottom-

up" from the experience of carers in the exploratory interviews, rather than from a professional/researcher driven plan.

Mixed-methods studies use procedures for collecting, analysing, and "mixing" or integrating quantitative and qualitative data at some stage of the research process within a single study for the purpose of gaining a better understanding of the research problem [170, 279]. The quantitative and qualitative elements of this research study complemented each other and provided a compelling analysis of the experiences and impact of using AT from the perspective of carers. The cross-sectional survey provided quantitative data, a sample of the participants of the survey then provided the qualitative data. The interview topic guide was informed by themes from the earlier phases in the study and the quantitative data from the survey. Interpretation of the results by integrating the findings from the quantitative and qualitative phases provided an in-depth understanding of carers use of AT in dementia care.

As this study involved multiple methods, including a sequential explanatory mixed-methods approach, attention was paid to issues of priority, implementation and integration of methods, discussed below [236].

8.5.2.1 Priority:

This research study examined aspects of carers' experiences with AT use in dementia. This is an area of emerging research, and the research focus was on the lived experiences of carers, so the priority was on qualitative data collection and analysis. This manifested itself in the inclusion of qualitative and mixed-methods studies in the systematic review, exploratory qualitative interviews, cognitive interviews in survey questionnaire development and the explanatory qualitative interviews. The data collection using quantitative methods was constrained to inclusion of quantitative studies in the systematic review and the cross-

sectional survey. The goal of the explanatory interviews was to explore and interpret the descriptive and bivariate statistical analysis of participant responses in the survey, using thematic analysis.

8.5.2.2 Implementation:

The stages in this study were conducted in sequence, with each stage building iteratively on the previous stage. This approach added to the richness of the data collected and the depth of understanding of carers' experiences and impact of using AT in caring for persons with dementia. Data from each stage of the research helped inform data collection, recruitment, analysis, and interpretation of the results. The research advisory group were consulted to strengthen the research process by tapping into their insights on living with and caring for a person with dementia.

8.5.2.3 Integration:

Multiple methods were integrated throughout this study. The research questions and objectives of this study could only be answered by using quantitative and qualitative methods and the results from each stage of the study were integrated into the next phase by informing the interview topic guide and questionnaire development. The data analysis of the survey informed the recruitment of participants for the explanatory interviews and the interview topic guide. The thematic analysis and interpretation of the explanatory interviews integrated the results from the quantitative and qualitative phases of the mixed-method study.

8.5.3 Integrity of the research process:

Using multiple methods could enhance confidence in the findings, in particular by increasing the ability to evaluate convergent and discriminant validity [280]. The use of multiple methods in this research study helped to:

- Identify overlapping aspects of carers' experience of selection, use and integration of AT in their daily life when caring for a person with dementia.
- Supplement and build iteratively the information gained from the initial systematic review to inform the exploratory qualitative interviews. Use the themes from these to design the survey questionnaire. Use the explanatory interviews to further understand and interpret the results from the survey.
- Identify, explore, and examine confirmatory and contradictory aspects of carers' experiences with AT obtained from multiple sources.
- Add scope, breadth and depth to the study.
- Guide the sampling, data collection and analysis techniques.

The integrity of the research process throughout this study was maintained by following established guidelines for systematic review, qualitative research, quantitative research, questionnaire development, survey methods and mixed-method research [211, 212, 280–283] and throughout the research process constantly focusing on and ensuring:

- The research conduct was systematic and rigorous
- The research was transparent and contextual
- The researcher was accountable for the research quality and claims
- The researcher engaged in critical scrutiny and active reflexivity
- The research produced convincing arguments and acknowledged limitations

8.6 Strengths and limitations:

The specific strengths and limitations of the different stages of this study have been previously described in Chapters 3 to 7.

The research advisory group was involved in the research study from the beginning and their insights, suggestions, and ability to 'sense-check' the findings at each stage of the research ensured that the research was acceptable and useful to carers of persons with dementia.

Including quantitative, qualitative, and mixed-methods studies as part of the systematic review gave a broad understanding of existing literature describing carer involvement in using AT in dementia care. The themes from the exploratory qualitative interviews and the systematic review were used to construct the CATEQ. The cognitive interviews used in the questionnaire development had participants from varying backgrounds and ethnic minorities. These cognitive interviews helped to ensure the questionnaire items were understood by carers and confirmed the design of the electronic and paper version of the questionnaire were appropriate. The participants' input during these cognitive interviews ensured that important issues that mattered to carers who use AT had not been left out of the questionnaire.

Research that is able to explore the nuances and issues of people and provide insights for services can contribute to improving the lives of persons with dementia, their carers, and also the wider community and society [170]. The use of hermeneutic phenomenology helped to gain an in-depth understanding of carers' experiences of using AT, allowed the researcher to investigate changes involved in using AT over time, and iteratively manage the interview topic guide to focus on issues that developed during the interviews, to clarify with

participants in subsequent interviews. The use of thematic analysis provided a highly flexible approach providing a rich and detailed, yet complex account of carers' experiences [284]. Thematic analysis was a useful method for examining the perspectives of different carers and highlighted similarities and differences, and generated unanticipated insights [285] into the impact of AT use by carers in dementia care.

The survey and interview participants were from a wide range of backgrounds, however similar to other findings [7, 20], women as carers were over-represented in this study. In the survey, there were more participants who had a university degree, which could have been as a result of carers who had higher educational attainment registering as a volunteer on the *Join Dementia Research* and *OxDARE* databases being more likely to complete the online survey. The choice of a paper version of the survey, delivered through the postal system, helped to improve participation from carers who would otherwise have chosen not to complete the survey online.

This research study was designed to explore the experiences and impact of AT use among carers who look after a person with dementia and so, for the survey, it was not possible to undertake a formal sample size calculation. The number of participants who completed the survey was similar to other studies investigating health related quality of life in carers of persons with dementia [286]. Some of the difficulty in recruiting larger number of participants for the survey could have been due to the lack of 'incentives' offered for participation. Due to financial constraints and the anonymous nature of the survey, incentives were not offered to survey participants. This may have meant potential participants finding it less enticing to give up their time to participate in this research. Carers who participated in the interviews were very motivated and generous with their time and

genuinely wanted to help, through their responses, and wanted to be kept informed on progress in the research and so participants were referred to the research website hosted on the Nuffield Department of Population Health, with a list of publications associated with this research study.

Even after repeated attempts, this research study could not recruit participants from sufficiently diverse ethnic minorities. This was disappointing, given the importance of understanding the perspectives of carers from all ethnic groups. This meant that this study could not directly compare carers' experiences of AT use in dementia care between different ethnic and cultural groups and understand what experiences, if any, are unique to any ethnic group. In addition, this study did not recruit large numbers of friends or neighbours who provided care to understand their experiences of using AT in caring for a person with dementia. Although less common than family carers, understanding their experiences would have been a valuable addition to this research, and is a possible avenue for future research.

The COVID-19 restrictions, including enforced social distancing practices, meant the explanatory interviews that were originally planned as face-to-face interviews had to be conducted as telephone interviews in 2020. This potentially meant some non-verbal cues were being missed and the researcher could not react appropriately to pauses and reflections from the participants. However, the surge in the use of digital technologies during the pandemic could have focused participants' thoughts on the practical uses of AT and provided a richer source of conversation and insight into the digital divide among participants, concerning issues around privacy and aspects of data transfer in the use of AT in dementia care.

8.7 Conclusions:

Dementia is an illness which changes an individual's personal, emotional and social capacity over time. Carers are invariably affected by these changes and AT solutions offer support for carers and the person with dementia. AT offers great promise for assisting with the physical and cognitive challenges for people with dementia and in helping to reduce the burden on carers. This research study offers an insight into the experience of carers who use AT in dementia care, the impact of the AT on their health and wellbeing and how AT is perceived as an adjunct to care for persons with dementia and enables them to stay at home for longer.

8.7 Summary:

This chapter provides an overview of the themes described in the research study on carers' experiences of AT use in dementia and an appraisal of the research in various stages of the study. In addition to the results learnt from using multiple methods a discussion on the strengths and limitations of various stages of this study was also presented. The next chapter draws conclusions from this research study as well as highlighting recommendations to various stakeholders and identifying directions for future research on this topic.

Chapter 9 : Conclusions

9.1 Introduction:

Carers continue to face physical, emotional, social and economic pressures, while caring for persons with dementia who live at home [249, 287]. Carers are central drivers who support and enable persons with dementia to live for longer at home. Currently there is no cure for dementia, and it is progressive with an uncertain trajectory of progress. AT could help carers to support the needs of a person with dementia and ease their caregiving tasks [79]. AT can only be effective in dementia care when it is combined with good support from carers and health and social care professionals, as well as it being person-centred, not just for the person with dementia but also the carer. This research study aimed to fill a gap in the literature, that so far had predominantly looked at AT from the perspective of persons with dementia and its use within institutional settings.

9.2 Summary of findings from this research:

This research explored and described the experiences of carers using AT in the care of a person with dementia and the impact of the use of AT on them. The main findings from this study have been described in Chapters 3 to 7 and a discussion on the research methods and findings have been described in Chapter 8. In brief, the findings are:

AT used by carers in the care for persons with dementia consists of many types and a mixture of simple devices and large items. AT included wearable alarms for summoning help or alerting others about falls and wandering out of the home, smart phones and tablet computers for leisure and two-way communication with others, GPS trackers and object locators to inform the position and confirm safety of the person with dementia, electronic medication dispensers to remind persons with dementia to take their medication on time,

dementia clocks to orient persons with dementia to the date, day and time, smoke, carbon-di-oxide alarms and home gas and electricity meters and environmental control systems. AT was variously used only by persons with dementia, jointly with carers and exclusively by carers in supporting persons with dementia. AT was predominantly used by carers for reassurance regarding safety and welfare of the person with dementia. AT was also used for communication, reminders and social activities. Use of AT supported carers who lived away from the person with dementia to "look in" on the person with dementia, which provided them with reassurance and contributed to decreased anxiety and stress.

Carers sought and obtained information and knowledge regarding AT from personal experience, recommendations from wider support networks such as other carers or family, trial and error and from charities rather than from health and social care professionals. Carers purchased AT by themselves. AT or the environment in which it was used often had to be modified by carers for successful use of the AT. As the functional abilities of the person with dementia diminished (when the illness progressed), AT was frequently abandoned. Due to concerns around cognitive decline, carers preferred AT devices that were 'passive' and did not need active interaction from the person with dementia. Existing AT needed to be 'personalised' and new AT devices were purchased to add to the support provided to the person with dementia.

Carers identified ease of using AT, changes to their roles and routines to use AT and ability to problem solve as important when using AT. AT supported physical and mental wellbeing for carers and had an impact on their social wellbeing. Choice and use of AT did not merely rely on the dementia related needs of a person with dementia, it dependent on the co-morbidities of persons with dementia and the carers themselves. AT were integrated into

the daily life of the person with dementia and their carers, when they met functional needs, supported physical co-morbidities and when carers did not experience problems during the use of AT. Ethical issues in the use of AT were also raised by carers and new emerging AT prompted discussions around privacy and data sharing when using AT.

9.3 Personal reflections:

The initial ideas for this research study were conceived based on my experiences with the use of AT in care of persons with dementia. I am an Occupational Therapist and have for the predominant part of my clinical career worked with persons with dementia and their carers. As part of my professional work, I have recommended and tried different forms of AT to support persons with dementia to remain at home for longer. The importance of involving carers in decision making and use of AT were reinforced by my clinical experience. I highlight an incident involving a person with dementia and AT use from my previous clinical experience.

Mr J was an 89-year-old gentleman who was admitted into a community intermediate care rehabilitation facility in London, following a fall and short hospital admission. He had a diagnosis of Alzheimer's disease and lived alone at home and walked using a wheeled walker frame. He had a history of falls, which appeared to happen mainly at night. The reason for the falls was identified as Mr J walking to the toilet in the early hours of the morning, his room was still dark as the lights were turned off. Mr J would walk back to his bed after using the toilet, the light switch for the toilet was turned off by him after he used it, and he would walk back to his bed in the dark.

To support Mr J's night-time toileting activity, the multi-disciplinary team, of which I was a part, agreed to try a movement triggered automatic light in his room. The idea was for the

light to be turned on by using sensors that activated when movement was detected close to Mr J's bed, as he got out of the bed. This would provide sufficient light for him to make his way to the toilet, he could then use the toilet and make his way back to the bed. A sensor that detected movement from near the toilet would keep the automatic light on until he got back into bed. This seemed a reasonable, less intrusive and more cost-effective way of managing Mr J's night-time needs than having a live-in carer, and the automatic light was installed at his home with his consent. Mr J had a trial discharge to his home, to assess his ability to manage to use the newly installed AT. However, Mr J, still had a fall at home. On investigation it was found that Mr J did not remember the concept of automatic lights, even when he was consulted on its use and installation. He would walk to the toilet, use the toilet and on returning to his bed, was troubled that the light was still on. He would then attempt to turn this light off and was searching for the light switch to turn the light off, without realising that his movements were triggering the sensors and keeping the light on. This led him to get agitated and unable to get back into bed and his search for the light switch to turn off the lights resulted in the fall.

I then consulted and involved the family, who lived away from London. This helped identify that Mr J had never used automatic lights before and was used to turning switches off near his bedside. In consultation with the family carers and Mr J, a light switch resembling one that Mr J had used before was installed next to his bed, this switch turned off the automatic light. This simple arrangement meant Mr J had the light that came on automatically when he got out of bed, but it could still be turned off by him, when he returned to bed, allowing him to stay safe at home and for the carers to be reassured that he was less likely to walk in the dark, stumble and fall. Mr J, continued to live at home, with support from the community health and social care team for another 3 years without further incidents of falls

and the family always attributed his ability to live at home for that period of time to the availability and use of AT.

During the COVID-19 pandemic, I was re-deployed to clinical duties on COVID wards between January-March 2021. Patients who were admitted to these wards in the acute hospital could not have visitors, as they would otherwise be able to, due to the strict rules in place. As part my clinical work during this time, I saw how AT devices such as smart phones and tablet computers provided a link for very ill patients, including persons with dementia, with their family. Even when patients themselves could not talk, hearing a family member or carer's voice and being able to see them via a video phone call, made a huge difference to their mental wellbeing. The use of this AT also provided support for ethnic minority patients. Carers could translate for the multi-disciplinary team and provide additional information on preferences for care and assist with discharge plans. This experience while mostly positive also highlighted to me the digital divide among some patients, especially the elderly, who did not have or could not use a smart phone device, which meant they could not communicate with their family directly and could only convey messages through the healthcare team or could only speak to their family, when the team supported them in doing so.

These experiences have allowed me to continue to reflect on how AT could be used in the care and support of vulnerable persons to facilitate and improve their independence, as well as the importance of involving carers and supporting them in the use of these AT. These reflections and practical experiences have been reinforced by the findings from this research study.

9.4 Recommendations to stakeholders:

Based on the findings from this research study. The following recommendations are made to stakeholders.

9.4.1 Recommendations to carers of persons with dementia:

- Carers should actively seek support from health and social care professionals to assist them with the choice, education and use of AT in dementia care.
- Carers should talk with the person with dementia about proxy decision making for ongoing AT use, privacy issues, data sharing and data donation from the use of AT, while the person with dementia, still has mental capacity to make those decisions.
- Carers should share their experiences of using AT with others who may be in similar situations, to help other carers make informed decisions about the use of AT.

9.4.2 Recommendations to health and social care professionals:

- Health and social care professionals when carrying out assessments and recommending the use of AT by carers should consider dementia as a long-term condition and move away from applying the existing 'acute care' model of brief interventions and rigid protocols.
- Annual reviews should include reviewing AT use in relation to the ongoing needs of the person with dementia as well as their carer and ensure consent issues are adequately addressed.
- Health and social care professionals should consider the ability of a carer to 'problem solve' when they suggest/recommend/provide AT; and if necessary, provide support with AT.

- Health and social care professionals should especially think about how AT matches the needs of the person requiring the use of AT, rather than the person being 'moulded' to match what AT is available for them.
- AT providers and professionals could use a survey tool such as the CATEQ periodically to sense check the types, uses and impact of AT and modify the development of new AT and provision of AT to people with dementia based on the findings.

9.4.3 Recommendations to commissioners and policy makers:

- Currently AT is named by the technology developer. There should be a shift towards person-centred naming of AT to ensure that AT devices are appropriately identified and used.
- From a policy perspective, consideration should be given to the establishment of a community based AT store/bank for use by persons with dementia or other long-term conditions. This AT store could recycle and reuse AT devices in the community to help reduce the burden of cost and trial and error of purchasing AT for persons with dementia, as their condition progresses.
- Active policy and legal interventions should look to address emerging data protection concerns of carers when using AT, especially when 'cloud-based' storage of data is becoming prevalent.

9.4.4 Recommendations to AT developers:

- Designs for AT should focus on solutions which are co-designed with those with lived experience of the challenges of dementia at home and should include carers, who live with and away from a person with dementia.

- AT developers should foster the development of technological innovations that, in terms of design and evaluation, respond to the physical, psychological, social and environmental needs of people with dementia and their carers.

9.4.5 Recommendations for future research:

- Further research should be carried out on how multiple AT devices could work together or be combined to better support persons with dementia and their carers.
- Additional research is needed on how AT such as pendant alarms are being used by persons with dementia, as their condition progresses. This is especially important in light of additional demands (such as increased monitoring and responding to alerts), that may be placed on carers with the use of such devices and as these devices continue to be the most commonly abandoned AT devices.
- Research should be carried out to consider how carers of persons with young onset dementia use AT, and cost-benefit analyses undertaken of AT use as a means of reducing the need for formal/paid care or longer community living.
- Research should also be directed at AT use in lower- and middle-income countries and how emerging AT devices that are not marketed as healthcare devices (such as smart phones, smart watches and tablet computers) are useful in supporting persons with dementia and their carers.
- Research should also be focused on understanding health and social care professionals' attitude, understanding, knowledge and skill in supporting carers in the use of AT in dementia care.

9.5 Conclusion:

Constant progress and technological advances mean better and more efficient AT solutions can be found. Suitable and appropriate AT would be one way of assuring people with dementia can continue to live at home, which is typically a welcome outcome for persons with dementia and their carers. This study demonstrates that AT has a beneficial impact on carers of persons with dementia. AT development, deployment and continued use requires active involvement of carers and health and social care professionals, policy makers and AT developers should actively include and consider carers' experience of AT use in dementia care.

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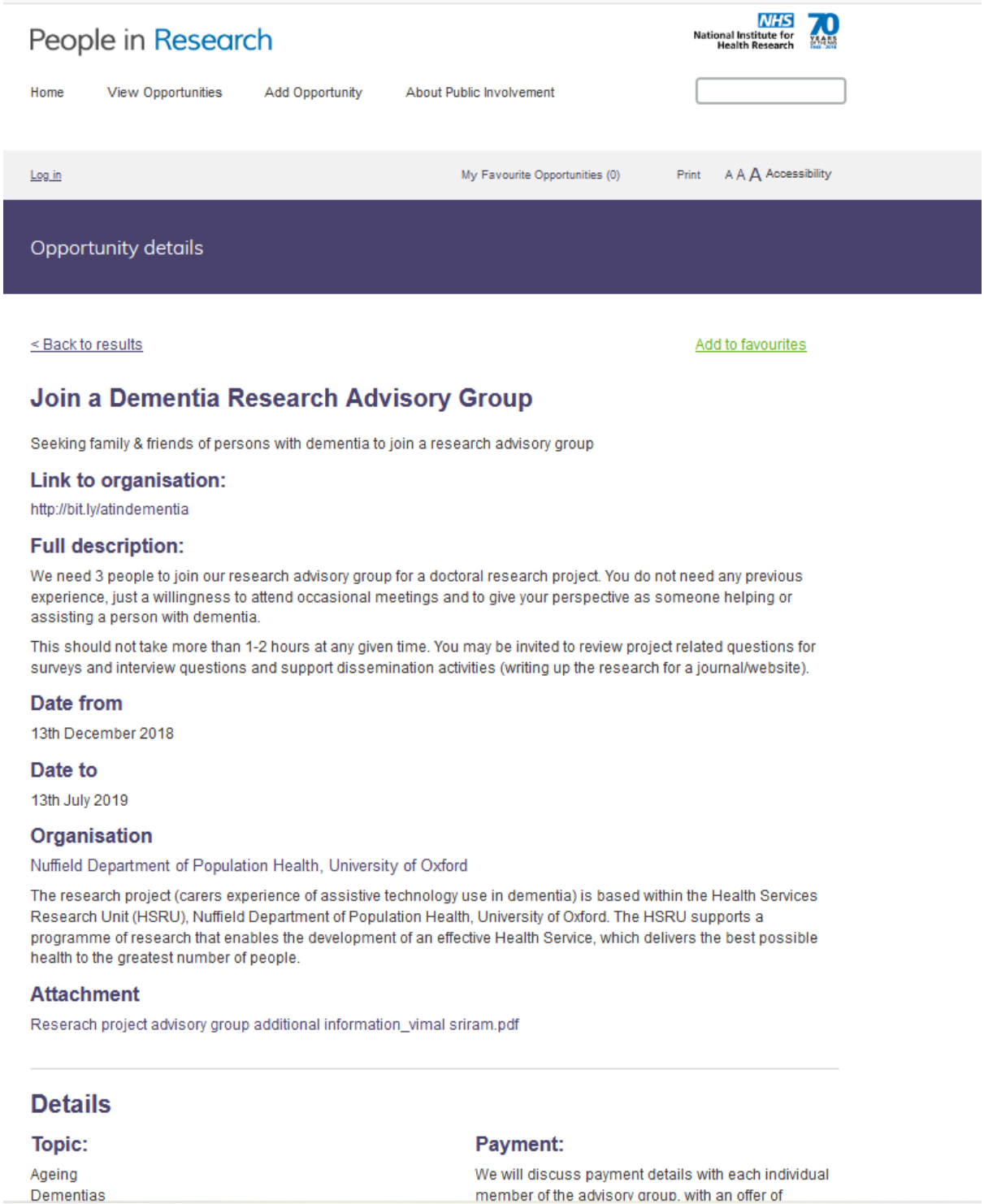
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Appendices

Appendix 1: Patient and public engagement and involvement advertisement:



People in Research

NHS National Institute for Health Research

Home View Opportunities Add Opportunity About Public Involvement

Log in My Favourite Opportunities (0) Print A A A Accessibility

Opportunity details

< Back to results Add to favourites

Join a Dementia Research Advisory Group

Seeking family & friends of persons with dementia to join a research advisory group

Link to organisation:

http://bit.ly/atindementia

Full description:

We need 3 people to join our research advisory group for a doctoral research project. You do not need any previous experience, just a willingness to attend occasional meetings and to give your perspective as someone helping or assisting a person with dementia.

This should not take more than 1-2 hours at any given time. You may be invited to review project related questions for surveys and interview questions and support dissemination activities (writing up the research for a journal/website).

Date from

13th December 2018

Date to

13th July 2019

Organisation

Nuffield Department of Population Health, University of Oxford

The research project (carers experience of assistive technology use in dementia) is based within the Health Services Research Unit (HSRU), Nuffield Department of Population Health, University of Oxford. The HSRU supports a programme of research that enables the development of an effective Health Service, which delivers the best possible health to the greatest number of people.

Attachment

Reserach project advisory group additional information_vimal sriram.pdf

Details

Topic:

Ageing
Dementias

Payment:

We will discuss payment details with each individual member of the advisory group, with an offer of

Appendix 2: Ethics approval:

MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE

Research Services, University of Oxford, Wellington Square, Oxford, OX1 2JD
Tel: +44(0)1865 616577 Fax: +44(0)1865 280467
ethics@medsci.ox.ac.uk

CONFIDENTIAL

Ref: R57703/RE001

20th June 2018

Mr Vimal Sriram
Health Services Research Unit
Nuffield Department of Population Health
University of Oxford
Richard Doll Building
Old Road Campus
Oxford

Dear Vimal

Research Ethics Approval - CUREC 1

Study title: Carers' Experience of Assistive Technology use in Dementia

The above application has been considered on behalf of the Medical Sciences Interdivisional Research Ethics Committee (IDREC) in accordance with the procedures laid down by the University for Ethical Approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and approval has been granted for a period of 34 months, commencing on 1st August 2018. The reference number for this study is R57703/RE001.

This is subject to:

a) your following the BPS guidelines for online research

b) it is your responsibility to comply with the requirements for administering any tests or questionnaires and, if in doubt, to contact the publisher of those tests or questionnaires.

c) if new research staff are engaged, the PI is responsible for ensuring they are suitably qualified by training and/or experience.

I would like to remind you that your study may be selected for review by the MS IDREC during an annual audit.

Amendments

Should there be any subsequent changes to the study, you should submit details to the MS IDREC for consideration and approval. Details of changes must be listed on an amendment form. If your study received University Sponsorship through CTRG, then the amendment will first need to be submitted to CTRG for approval of continued Sponsorship.

Please do not hesitate to contact me if you have any queries.

Yours Sincerely

H. Barnby-Porritt

Dr. Helen Barnby-Porritt
Research Ethics Manager, Medical Sciences

26.02.2020

By Email:

Dear Vimal,

Thank you for submitting a request for an amendment to project R57703, which has been reviewed on behalf of the Medical Sciences Inter-Divisional Research Ethics Committee (IDREC).

I am pleased to inform you that your requests to:

- finalise the Carers' Assistive Technology Experience Questionnaire (CATEQ)
- revise the online and postal versions of the consent form (Version 3)

have been judged as meeting appropriate ethical standards, on the basis of the information provided to the IDREC, and approval has been granted, under reference R57703/RE002.

Please note that this email is your sole approval.

Best wishes
Leah

Leah Butts
Research Ethics Administrator – Medical Sciences | Research Services

Postal Address: University of Oxford, University Offices, Wellington Square, Oxford, OX1 2JD
T: +44 01865 616575 **E:** ethics@medsci.ox.ac.uk
http://researchsupport.web.ox.ac.uk/governance/ethics/apply/msidrec

Appendix 3: Procedure for managing those who become distressed:

This project involves interviews with family and friends of persons with dementia. The interviews will be conducted by the Researcher ('interviewer') of the project and recorded on a digital audio recorder.

It is possible that during an interview participant may become upset or distressed due to the nature of the interview topics, the question they are answering, the experiences they are remembering and describing and the overall situation. Where this occurs, the interviewer will ask the participant if they would like to halt the interview and will pause the digital recording. The participant will be given as much time as they need to compose themselves. The interviewer and participant may or may not continue a discussion about the situation, as the participant wishes.

At an appropriate time, the interviewer will reiterate the following options to the participant:

a) They may return to the interview (the semi-structured nature of the topics will enable them to talk about why they are upset on recording if they so wish);

b) They can stop the interview and the data already collected can be used as part of the study or

c) They can stop the interview and withdraw the data they have provided so far.

Where a) or b) occur, participants will be reminded that they will be able to withdraw their data any time until their interview has been transcribed and anonymised.

To inform potential interview participants of this procedure the following statement is provided on the Information Sheet:

'The questions that you may be asked during the interview about you as a caregiver may be personal and occasionally some people may feel distressed when they are asked to think about how they are feeling and their experiences in looking after a person with dementia. You do not have to answer any question that you feel uncomfortable with or do not want to. If you are distressed you may wish to pause or stop the interview. You could then: terminate and withdraw your data (the interview recording would be deleted), terminate the interview and allow the interview recording until that point to be used in the research, or carry on with the interview when you are ready.

The researcher can also provide you with an information sheet which contains a list of organisations who you can get in touch with if you are feeling distressed in any way, who can offer support'.

Potential interview participants will receive the Information Sheet at least 24 hours before the scheduled interview time and once more before the interview begins. They will then freely sign a Consent Form that confirms they understand the information they have been given.

Supervisors of the researcher will be informed to notify that a participant will now not be contributing to the research, if the participant decides to withdraw their information.

Appendix 4: List of useful organisations:

If participating in this study has caused you distress, you may wish to contact one of the following organisations who can offer you information and support, in addition to contacting your own GP.

- Age UK

Tavis House, 1-6 Tavistock Square, London, WC1H 9NA

Telephone: 0800 055 6112. Website: www.ageuk.org.uk

- Alzheimer's Society

43-44 Crutched Friars, London, EC3N 2AE

Telephone: 0300 222 11 22. Website: www.alzheimers.org.uk

- Mind

15-19 Broadway, Stratford, London E15 4BQ

Telephone: 020 8519 2122

Email: supporterservices@mind.org.uk. Website: www.mind.org.uk

- Samaritans

The Upper Mill, Kingston Road, Ewell, Surrey KT17 2AF

Telephone: 020 8394 8300. Website: www.samaritans.org

- Sane

St. Mark's Studios, 14 Chillingworth Road, Islington, London, N7 8QJ

Telephone: 0300 304 7000. Website: www.sane.org.uk

Appendix 5: Systematic review - search strategy and records identified:

Database: Embase <1974 to 2017 December 15>

Search Strategy:

1 exp Dementia/ or dement*.mp. (327618)

2 (lewy bodies or alzheimer*).mp. (207698)

3 exp Wernicke Encephalopathy/ or wernicke encephalopath*.mp. (2641)

4 exp Korsakoff Syndrome/ or korsakoff.mp. (2461)

5 1 or 2 or 3 or 4 (359221)

6 Technology/ or technolo*.mp. (576145)

7 (informat* adj2 communicat*).mp. (8326)

8 ict.mp. (6519)

9 Information Systems/ or Telemedicine/ or Monitoring, Ambulatory/ (62971)

10 (telemedicine or tele medicine or telehealth or tele health or telemonitor* or tele monitor* or ehealth or e-health or mhealth or m-health).mp. (31229)

11 telephone*.mp. or exp Telemedicine/ or exp Online Therapy/ (102636)

12 "Activities of Daily Living"/ or Self-Help Devices/ or assistive.mp. (61648)

13 device*.mp. (618224)

14 self care.mp. or Self Care/ (51841)

15 self help.mp. (16621)

16 (gero* adj2 tech*).mp. (33)

17 robo*.mp. or Robotics/ (59589)

18 (assist* adj2 (aid? or device?)).mp. (31835)

19 "Equipment and Supplies"/ or Equipment Design/ or equipm*.mp. (402108)

20 Signal Processing, Computer-Assisted/ or Clothing/ or wearable*.mp. (51185)

21 assistive technology.mp. or exp Assistive Technology/ (3349)

22 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (1714806)

23 Caregivers/ or caregiv*.mp. (90598)

24 (relatives or family or families).mp. or exp Family/ (1426264)

25 friend*.mp. or Friends/ (86423)

26 (neighbour? or neighbor?).mp. (26420)

27 Spouses/ or spous*.mp. (26242)

28 (wife or wives).mp. (11096)

29 husband?.mp. (12779)

30 (couple? or partner?).mp. (498454)

31 son?.mp. (147451)

32 daughter?.mp. (29845)

33 Home Nursing/ or carer*.mp. (70884)

34 Home Care Services/ or home.mp. (321048)

35 exp Home Care/ or exp Family Members/ or informal carer.mp. (65774)

36 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 (2392642)

37 5 and 22 and 36 (5646)

Database: PsycINFO <1806 to December Week 2 2017>

Search Strategy:

1 exp Dementia/ or dement*.mp. (86717)

2 (lewy bodies or alzheimer*).mp. (56910)

3 exp Wernicke Encephalopathy/ or wernicke encephalopath*.mp. (68)

4 exp Korsakoff Syndrome/ or korsakoff.mp. (715)

5 1 or 2 or 3 or 4 (94803)

6 Technology/ or technolo*.mp. (102473)

7 (informat* adj2 communicat*).mp. (7270)

8 ict.mp. (3106)

9 Information Systems/ or Telemedicine/ or Monitoring, Ambulatory/ (9321)

10 (telemedicine or tele medicine or telehealth or tele health or telemonitor* or tele monitor* or ehealth or e-health or mhealth or m-health).mp. (5946)

11 telephone*.mp. or exp Telemedicine/ or exp Online Therapy/ (29363)

12 "Activities of Daily Living"/ or Self-Help Devices/ or assistive.mp. (8598)

13 device*.mp. (36483)

14 self care.mp. or Self Care/ (10675)

15 self help.mp. (9405)

16 (gero* adj2 tech*).mp. (24)

17 robo*.mp. or Robotics/ (7381)

18 (assist* adj2 (aid? or device?)).mp. (1214)

19 "Equipment and Supplies"/ or Equipment Design/ or equipm*.mp. (10071)

20 Signal Processing, Computer-Assisted/ or Clothing/ or wearable*.mp. (2639)

21 assistive technology.mp. or exp Assistive Technology/ (2236)

22 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (203973)

23 Caregivers/ or caregiv*.mp. (52683)

24 (relatives or family or families).mp. or exp Family/ (367818)

25 friend*.mp. or Friends/ (62690)

26 (neighbour? or neighbor?).mp. (6767)

27 Spouses/ or spous*.mp. (26060)

28 (wife or wives).mp. (14604)

29 husband?.mp. (12939)

30 (couple? or partner?).mp. (121683)

31 son?.mp. (23554)

32 daughter?.mp. (12756)

33 Home Nursing/ or carer*.mp. (8884)

34 Home Care Services/ or home.mp. (107148)

35 exp Home Care/ or exp Family Members/ or informal carer.mp. (140630)

36 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 (679293)

37 5 and 22 and 36 (1653)

Database – CINAHL, Interface - EBSCOhost Research Databases
Search Strategy:

S1 (MH "Frontotemporal Dementia+") OR (MH "Dementia, Vascular+") OR (MH "Delirium, Dementia, Amnestic, Cognitive Disorders+") OR (MH "Dementia, Multi-Infarct") OR (MH "AIDS Dementia Complex") OR (MH "Lewy Body Disease") OR (MH "Dementia, Senile+") OR (MH "Dementia, Presenile+") OR (MH "Kohlschutter-Tonz Syndrome") OR (MH "Dementia") OR "Dementia/ or dement*.mp." (58,106)

S2 (MM "Wernicke's Encephalopathy") OR (MM "Korsakoff Syndrome") (145)

S3 (S1 OR S2) (58,204)

S4 (MM "Assistive Technology Services") OR (MM "Technology+") OR (MM "Assistive Technology") OR "Technology/ or technolo*.mp." (17,508)

S5 "ict.mp." (0)

S6 (MM "Home Health Care Information Systems") OR "Information Systems/ or Telemedicine/ or Monitoring, Ambulatory/" (82)

S7 (MH "Telehealth+") OR "(telemedicine or tele medicine or telehealth or tele health or telemonitor* or tele monitor* or ehealth or e-health or mhealth or m-health).mp." (10,199)

S8 "telecare" (257)

S9 (MM "Remote Consultation") OR (MM "Telephone Consultation (Iowa NIC)") OR (MM "Telephone+") (3,485)

S10 (MH "Self-Care: Instrumental Activities of Daily Living (Iowa NOC)") OR (MH "Self Care: Activities of Daily Living (Iowa NOC)") OR (MH "Activities of Daily Living+") OR (MH "Assistive Technology Devices+") OR (MH "Instrumental Activities of Daily Living Alteration (Saba CCC)") OR (MH "Instrumental Activities of Daily Living (Saba CCC)") OR (MH "Activities of Daily Living Alteration (Saba CCC)") OR (MH "Activities of Daily Living (Saba CCC)") OR (MH "Altered Activities of Daily Living (NANDA)+") OR ""Activities of Daily Living"/ or Self-Help Devices/ or assistive.mp." (57,900)

S11 (MM "Assistive Technology") OR "assistive technology" OR (MM "Assistive Technology Services") OR (MM "Assistive Technology Devices+") (18,632)

S12 (MH "Toileting Self Care Deficit (NANDA)") OR (MH "Self-Care Deficit (Saba CCC)") OR (MH "Self-Care Component (Saba CCC)") OR (MH "Self-Care Assistance: Dressing-Grooming (Iowa NIC)") OR (MH "Self-Care Assistance: Bathing-Hygiene (Iowa NIC)") OR (MH "Feeding Self Care Deficit (NANDA)") OR (MH "Dressing-Grooming Self Care Deficit (NANDA)") OR (MM "Self Care+") OR (MH "Bathing-Hygiene Self Care Deficit (NANDA)") OR (MH "Self-Care: Toileting (Iowa NOC)") OR (MH "Self-Care: Oral Hygiene (Iowa NOC)") OR "self care.mp. or Self Care/" (16,363)

S13 (MM "Robotics+") OR "robo*.mp. or Robotics/" (2,287)

S14 (MH "Equipment and Supplies") OR (MH "Equipment Design") OR (MH "Home Care Equipment and Supplies") OR ""Equipment and Supplies"/ or Equipment Design/ or equipm*.mp." (32,718)

S15 (MM "Signal Processing, Computer Assisted") OR (MH "Therapy, Computer Assisted+") OR (MH "Computers, Hand-Held+") OR (MH "Computer Aided Design+") OR "Signal Processing, Computer-Assisted/ or Clothing/ or wearable*.mp." (9,942)

S16 S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15) (139,248)

S17 (MH "Caregiver Burden") OR (MH "Risk for Caregiver Role Strain (NANDA)") OR (MM "Caregivers") OR (MM "Caregiver Support") OR (MH "Family Caregiver Status (Iowa NOC)+") OR (MH "Caregiver Well-Being (Iowa NOC)") OR (MH "Caregiving Endurance Potential (Iowa NOC)") OR (MH "Caregiver-Patient Relationship (Iowa NOC)") OR (MH "Caregiver Support (Iowa NIC)") OR (MH "Caregiver Stressors (Iowa NOC)") OR (MH "Caregiver Strain Index") OR (MH "Caregiver Role Strain (NANDA)") OR (MH "Caregiver Physical Health (Iowa NOC)") OR (MH "Caregiver Performance: Direct Care (Iowa NOC)") OR "Caregivers/ or caregiv*.mp." OR (MH "Caregiver Role Strain (Saba CCC)") (18,827)

S18 (MH "Extended Family") OR (MH "Family Relations") OR (MH "Dependent Families") OR (MH "Patient-Family Relations") OR "(relatives or family or families).mp. or Family/" (12,213)

S19 (MH "Support System Enhancement (Iowa NIC)") OR (MH "Social Networks") OR (MH "Home Nursing") OR "friend*.mp. or Friends/" (12,236)

S20 "(neighbour? or neighbor?).mp." (1)

S21 (MH "Spouses") OR (MH "Significant Other") OR (MH "Caregivers") OR "Spouses/ or spous*.mp." (26,686)

S22 (MH "Spouses") OR "(wife or wives).mp." (6,262)

S23 "husband*.mp." (0)

S24 "husband*.mp." (2)

S25 "(couple* or partner*).mp." (0)

S26 "(couple* or partner*).mp." (531)

S27 "son*.mp." (0)

S28 "son*.mp." (1)

S29 (MH "Daughters") OR "daughter*.mp." (985)

S30 (MH "Home Nursing") OR "Home Nursing/ or carer*.mp." (2,836)

S31 (MH "Home Health Care") OR (MH "Home Care Equipment and Supplies") OR (MH "Home Health Care Information Systems") OR "Home Care Services/ or home.mp." (16,568)

S32 (S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31) (66,762)

S33 S3 AND S16 AND S32 (810)

Appendix 6: Systematic review - data extraction form:

Quantitative studies:

Data to be extracted	Study Data
Publication Characteristics	
Title	
Publication type [Peer reviewed journal article, Trial, SR]	
Year of Publication	
Geographical location of study	
Author (s)	
Author contact details	
Study characteristics	
RCT, Case Control, Feasibility etc.	
Study duration (longitudinal, survey, pilot etc.)	
Participant characteristics (for informal carers)	
Age [in years]	
Gender [M/F]	
Relationship with person with dementia	
Ethnicity	
Type/severity of dementia (of person being cared for)	
Co-morbidities recorded	
Living arrangements (with patient with dementia or away)	
Other sub-groups reported	
Intervention characteristics	
Duration of participation [hours or days]	
Number of participants in each group	
AT description	
Suggested use of AT	
Number of hours AT used [hours]	
Mobile/Fixed device	
Stand-alone/system based AT	
Off- the shelf/bespoke AT	
Cost reported [Yes/No]	
Who paid for AT? [Self, Trial, Healthcare provider]	
Adherence to protocol [Yes, No]	
Comparator [If listed]	
Loss to follow-up/withdrawals	
Outcome characteristics	
Primary outcomes reported	
Secondary outcomes reported	

Measures used for Burden, QoL, wellbeing	
Are the measures used validated/peer-reviewed?	
Other Measures used	
Are the measures validated/peer-reviewed?	
Missing data reported	
How was missing data handled?	
Time points of data collection	
Other characteristics	
Conflicts of interests	

Qualitative studies:

Data to be extracted	Study Data
Publication Characteristics	
Title	
Publication type	
Year of Publication	
Geographical location of study	
Author (s)	
Author contact details	
Study characteristics	
Study Aim	
Theoretical perspective of the research	
Data collection approach - Interview, Focus group, Observation etc.?	
Study duration (longitudinal, pilot etc.)	
Participant characteristics (for informal carers)	
Appropriate sample included?	
Age [in years]	
Gender [M/F]	
Relationship with person with dementia	
Ethnicity	
Type/severity of dementia (of person being cared for)	
Co-morbidities recorded	
Living arrangements (with patient with dementia or away)	
Other sub-groups reported	
Intervention characteristics	
Duration of participation [hours or days]	
Number of participants	
AT description	
Suggested use of AT	

Number of hours AT used [hours]	
Mobile/Fixed device	
Stand-alone/system-based AT	
Off- the shelf/bespoke AT	
Cost reported [Yes/No]	
Who paid for AT? [Self, Trial, Healthcare provider]	
Loss to follow-up/withdrawals	
Outcome characteristics	
Data analysis (clear, systematic, rigorous etc.)	
Key themes reported: **First Order (Participant quotes):** **Second order (Author statements):** **Third order (summary):**	
Time points of data collection	
Relevance of findings	
Author's Key conclusions	
Generalisability	
Other characteristics	
Conflicts of interests	

Appendix 7: Systematic review - list of included studies:

- Altus DE, Mathews RM, Xaverius PK, Engelman KK, Nolan BAD. Evaluating an electronic monitoring system for people who wander. Am J Alzheimer's Dis. 2000;15(2):121-125. doi:10.1177/153331750001500201
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- Rosenberg L, Nygård L. Persons with dementia become users of assistive technology: A study of the process. Dement. 2012;11(2):135-154. doi:10.1177/1471301211421257
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- Nijhof N, van Gemert-Pijnen LJ, Woolrych R, Sixsmith A. An evaluation of preventive sensor technology for dementia care. J Telemed Telecare. 2013;19(2):95-100. doi:10.1258/jtt.2012.120605

- Olsson A, Engström M, Lampic C, Skovdahl K. A passive positioning alarm used by persons with dementia and their spouses - A qualitative intervention study. BMC Geriatr. 2013;13(1). doi:10.1186/1471-2318-13-11
- Riikonen M, Paavilainen E, Salo H. Factors supporting the use of technology in daily life of home-living people with dementia. Technol Disabil. 2013;25(4):233-243. doi:10.3233/TAD-130393
- Hastall MR, Eiermann ND, Ritterfeld U. Formal and informal carers' views on ICT in dementia care: Insights from two qualitative studies. Gerontechnology. 2014;13(1):53-58. doi:10.4017/gt.2014.13.1.003.00
- Jentoft R, Holthe T, Arntzen C. The use of assistive technology in the everyday lives of young people living with dementia and their caregivers. Can a simple remote control make a difference? Int Psychogeriatrics. 2014;26(12):2011-2021. doi:10.1017/S1041610214001069
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Appendix 8: Systematic review - sample quotes for themes and Sub-themes:

Theme	Sub theme	Example Quotation 1	Example Quotation 2	Example Quotation 3
Positive aspects	Relationships	'the use of the device generates longer instances of interaction' [129]	'Technology itself can become a 'member' of the social network, making it stronger' [101]	'I believe that my ability to have my mother continue to live with us would be dramatically reduced if we didn't have Night-time Monitoring System' [94]
	Freedom and autonomy	'As I say, *I couldn't have continued working as long as I did*, and I'm still, we're still benefitting from it [BUDDI device] you know. It, it's really, I think it's a wonderful device, wonderful' [126]	'In this way, the picture phone helped the person with dementia maintain independence, something the relatives described as important' [118]	'Informal caregivers, in contrast [to formal carers], request ICT solutions that enhance their personal freedom' [122]
	Safety	`I would like to keep it [the passive positioning alarm] because it really provides security´ [121]	'simple movement sensors or alarm systems that are networked to allow remote alerts were the most enthusiastically received' [95]	'Family caregivers expressed the belief that electronic tracking enables the patients' independent outdoor mobility and at the same time improves their safety' [115]

Theme	Sub theme	Example Quotation 1	Example Quotation 2	Example Quotation 3
	Quality of life (stress, burden, wellbeing)	'speaking watches" that read the time of day aloud at the push of a button. With this device, the caregivers experienced fewer questions and less stress and misunderstandings about the time' [103]	'The family caregivers were satisfied because the SRC [Simple Remote Control] removed both worries and burden of interruptions at work' [73]	'Informal caregivers reported that use of the system [preventative sensor technology] provided benefits to their mental well-being' [47]
	Competence	'it [GPS tracking device] was used to enable the person to continue to go out alone' [116]	'enabled them to better balance their needs for personal space with their desires to remain connected to the PWD during the night' [94]	'For the caregiver, data shows that the picture-button telephone was also most useful, with five out of six caregivers claiming they themselves were still using the product three months after its installation, and each reporting they considered it useful' [100]

Theme	Sub theme	Example Quotation 1	Example Quotation 2	Example Quotation 3
	Freedom and autonomy	'Some participants feared that technology which simplified tasks too much might weaken a person's own abilities such as in remembering numerical series and codes' [119]	'You can trust another person, but I think technology would be a bit … well, what if the technology went wrong? You can't be 100 per cent sure that the person would be cared for when you walk out of the door, can you? If somebody else is there, then you know' [95]	'Mrs B. pointed out the obligation to subscribe to an assistance platform. Mrs B. would like to have the possibility to buy the device and manage by herself her husband's wandering' [114]
	Relationships	'I think people need people – not just gadgets, you know? That's the worrying thing really, with the elderly in particular. The gadgets replace people, and there isn't any comparison' [95]	'The simple remote control used to be a great advantage for my wife, but now, after being at the hospital for some weeks, she doesn't know how to operate it any longer. I have to tell her how to use it, all the time, and she is no longer able to use it when she's alone' [103]	'We don't want technology – we want people' [95]
	Competence	'Future willingness to use a technology generally	'As she was not competent in informatics, Mrs B. had to rely on the personal care	'…..equipment may need some adjustments for use by elderly caregivers' [112]

Theme	Sub theme	Example Quotation 1	Example Quotation 2	Example Quotation 3
Negative aspects		outstripped their current willingness to use it' [125]	attendant: ''She logs very easily and communicates information to me''. Thus, the situation was not under Mrs B.'s control' [114]	
	Quality of life (Stress, burden, wellbeing)	'Adding activities into the [electronic] calendar was extremely time-consuming and complicated compared to an ordinary calendar: "I cannot sit here evening after evening and struggle with this computer!' [103]	'One of the caregivers reported that in some circumstances the system might increase the burden of care, if the sensors detected certain situations where additional care was required' [47]	'…family members were not sure how to raise the issue of using an electronic tracking device: "How do you explain [to] your relatives that they will be monitored in all their outdoor activities?' [115]
	Ethical issues	'The persons with dementia and their spouses saw the value of being locatable and saw no problem with the persons with dementia being monitored; they had not even considered that aspect' [121]	'Among the most central worries were fears of a dehumanized care' [122]	'…relatives shifted between their own needs for safety and security and what they perceived to be the need of the person with dementia when reflecting on the use of ICT' [118]
	Help and support from carers	'The engagement and interest of FC [Family Carers] was crucial in order to follow up the new AT	'Carers provide practical help that involves cognitive effort	'the use of assistive technology was in some cases influenced by the

Theme	Sub theme	Example Quotation 1	Example Quotation 2	Example Quotation 3
		device and support the person with YOD in using it' [103]	and is emotionally challenging' [102]	availability of a caregiver willing to remind the person about the product' [100]
Use of AT	Raising issues of using AT	'She said she felt, it (a pendant alarm) made her feel like a crock, you know (laughing). She says, "I don't need this, I'm perfectly alright." And the way that I persuaded her to wear it was, I said, "It just makes me feel better to know that you can contact somebody if you have a fall in the house, or if you're not too well and you can't get to the phone." So, I said "You might not want to wear it, but wear it for me please because it, it stops me worrying about you." Erm, so that was why she wore it, really' [126]	'The carers' attitude, commitment and will to learn about and follow through with the testing of the technology were vital if the equipment was to be useful and functional' [71]	'One participant had adjusted their newly purchased washing machine by labelling each compartment of the machine so that his wife would know where to put the washing detergent and the rinsing agent, thus enabling her to "still be ruler of the laundry room," as he put it' [119]

Theme	Sub theme	Example Quotation 1	Example Quotation 2	Example Quotation 3
Acceptance and knowledge of AT	Costs and resources	'It was striking that no participant talked about any time or money savings through using networked technologies' [95]	'Several carers noted that AT was generally expensive. You know, some people can't afford it. I don't mind paying for it 'cause it's helping her (mother) but I think it, it is expensive. It is quite steep, but then again, if her attendance money is there for it and she needs it, you, you don't mind getting it if it's going to help her, you know' [126]	'…when the participants considered technology to be beneficial to their relative with dementia or to themselves in their roles as significant others, they were ready to try technological solutions for support' [119]
	Acceptance of AT	'The participants saw technological innovations as an intrinsic feature of societal change and inevitable. The expectation was that the use of technology would increase, particularly for the next generation of carers who would have the aptitude and skills to adopt them' [95]	'One prerequisite for incorporation of technology emphasized in all groups was that technology must not be perceived as stigmatizing by the prospective user' [119].	'..the use and usefulness of the five products tested was largely determined by their technical capacity' [100].

Theme	Sub theme	Example Quotation 1	Example Quotation 2	Example Quotation 3
	Knowledge of Technology	'Carers and GPs generally found the term AT unhelpful and open to interpretation…… "Well, I think the whole thing was introduced to me in a very nebulous way. Technology, what the hell does that mean?"' [128].	'Timely information is important for the FC, because the AT may become too complicated to handle for the person with YOD, as the dementia progresses' [103].	'Dementia caregivers' knowledge of new technologies lags behind current technology development' [125].

Appendix 9: Exploratory qualitative interviews - Participant Information Sheet:

NUFFIELD DEPARTMENT OF POPULATION HEALTH

Nuffield Department of
POPULATION HEALTH
Medical Sciences Division

UNIVERSITY OF
OXFORD

Professor Crispin Jenkinson
e-mail: crispin.jenkinson@dph.ox.ac.uk
Telephone number: 01865 289441
Dr Michele Peters
e-mail: michele.peters@dph.ox.ac.uk
Telephone number: 01865 289428
Vimal Sriram (Doctoral Student)
e-mail: vimal.sriram@dph.ox.ac.uk
Telephone number: 01865 743762
Health Services Research Unit, Nuffield Department of Population Health
Richard Doll Building, Old Road Campus, Oxford OX3 7LF

Carers' experience of Assistive Technology (AT) use in dementia
PARTICIPANT INFORMATION SHEET

Ethics Approval Reference: R57703/RE001

1. *What is the purpose of this study?*

Dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem solving or language. Caring for a person with dementia can be demanding for informal carers (family, friends and neighbours) and can affect their mental and physical health and their social lives. **Assistive Technology (AT)** devices are often electronic. They include talking clocks, electronic medication dispensers, smart gas meters, falls and motion detectors and door exit alarms. While Assistive Technology is usually aimed at helping the person with dementia, these may also have an impact on carers. Due to the thinking and problem-solving difficulties of the person with dementia, the carer may need to be an active user of the Assistive Technology. It is not yet clear what positive or negative effects such technology may have on carers and there is little information on their experience with its use.

Purpose of this research:
This research will explore the experiences of Assistive Technology from the perspective of those looking after and helping persons with dementia at home. It will investigate which types of Assistive Technology (AT) they use, how they use it, their preferences for use, the benefits and Dis-advantages of use, facilitators or barriers to use and the support needed. In addition, we will develop a Carers Assistive Technology Experience Questionnaire for use with informal carers who support and help persons with dementia at home.

2. *Why have I been invited to take part?*

You have been invited because you are over 18 years of age and a family member/friend/neighbour of a person with dementia living at home.
To participate in the study, you need to be

- Providing at least 10 hours care (e.g. shopping, leisure, personal care, finance) per week to a person with dementia who lives in their own home (you can be living together with them or in your own home)
- Looking after or supporting a person with dementia who has used at least one electronic AT device (such as those described above) at home within the past year.

3. Do I have to take part?

No, your participation is voluntary. You can ask questions about the study before deciding whether to take part. If you agree to take part, you may withdraw from the study at any time, without any penalty and without giving a reason. If you choose to withdraw after the interview, the research team will delete any data including personal information and interview recordings and transcripts, and it will not be used in the analysis.

4. What will happen if I take part in the study?

If you are happy to take part, you will be asked to answer questions in an informal interview, like a conversation. The interview questions will ask you about your experiences of using Assistive Technology in helping your relative/friend/neighbour. The interview will be audio recorded to allow for us to type up your answers. You will never be identified by any of your personal information. The interview will take approximately 60-90 minutes and will take place at your home, your place of work, by telephone or at the University of Oxford. The interview location and time will be arranged in discussion with you, to suit your convenience and preference. The interviews will be conducted by Mr Vimal Sriram, a doctoral student at the University of Oxford.

5. ***Are there any potential risks in taking part?***

The questions asked during the interview may be personal and occasionally some people feel upset when asked to think about their experiences of looking after a person with dementia. You do not have to answer any question that you would prefer not to answer. If you become upset at any point, the researcher will ask you if you wish to pause or stop the interview. You could then: stop and withdraw your data (the interview recording would be deleted), end the interview and allow the interview recording until that point to be used in the research, or carry on with the interview when you are ready.

The researcher can also provide you with an information sheet which contains a list of organisations who you can get in touch with if you feel the need for further support.

6. ***Are there any benefits in taking part?***

You will not receive any direct benefit by taking part in this study. However, the information gained in this research study will provide a better understanding and insight of carers' experiences of using assistive technology. It will lead to a questionnaire that can be used by health professionals and researchers with other carers of persons with dementia who use AT.

7. ***What happens to my data?***

The **research data** will be stored and examined using University approved software.

Any information that you may have given in the interview that could identify you will be removed from the interview before it is analysed. Confidentiality will be maintained throughout this research study. If you consent to take part in this study, you will be required to sign an informed consent

form. To protect your identity, your name will be replaced by a pseudonym in any research reports. Any identifying information like your name, details or other personal information will not be used or disclosed to anyone outside, to any third party or appear on any transcripts, thesis, publications or on any academic paper.

However, there might be certain circumstances in which it may be necessary to breach this confidentiality and disclose information to a third party. This includes situations when someone provides information during the study that raises serious concern about:

- Intention to harm themselves or other people
- Risk to the health, welfare or safety of vulnerable adults such as someone with dementia
- Disclosure of a criminal offence

The researcher will discuss this issue with you before telling anyone else. The researcher will be obliged to share this evidence with his supervisors, who may advise that further action is taken.

Personal / sensitive information such as your name, age, gender, marital status, employment status, telephone number or address details in case of face-face interviews will be stored confidentially using computer software that does not allow anyone else except the researcher and his supervisors access to your data. All paper forms will be stored in a locked cupboard within the Department of Population Health, University of Oxford. Your personal/sensitive data, including your signed consent forms will be kept separately from audio recordings and transcripts from your interviews. Your answers may be quoted directly in the research publication with information suitably anonymised. All audio recordings will be erased permanently once they have been transcribed.
All research data and records will be stored for a minimum retention period of 3 years after publication or public release of the work of the research.

8. Will the research be published?

The research will be written up as a doctoral thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research. The thesis will be published open access.

Additionally, the research may be published in academic journals and presented in national and international conferences. The University of Oxford is committed to the dissemination of its research for the benefit of society and the economy and, in support of this commitment, has established an online archive of research materials. This archive includes digital copies of student theses successfully submitted as part of a University of Oxford postgraduate degree programme. Holding the archive online gives easy access for researchers to the full text of freely available theses, thereby increasing the likely impact and use of that research.

9. *Who is organising and funding the research?*

This study is being carried out as part of the DPhil (PhD) Programme in Population Health at the Nuffield Department of Population Health, University of Oxford.

10. *Who has reviewed this study?*

This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee (Reference number: R57703/RE001).

11. Data Protection:

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study. The University will process your personal data for the purpose of the research outlined above. Research is a task that we perform in the public interest. Further information about your rights with respect to your personal data is available from http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/."

12. *Who do I contact if I have a concern about the study or I wish to complain?*

If you have a concern about any aspect of this study, you can contact me through an email at vimal.sriram@dph.ox.ac.uk or by telephone on 01865 743762 or my supervisors Dr Michele Peters (michele.peters@dph.ox.ac.uk) or by telephone on 01865 289428 or Professor Crispin Jenkinson (crispin.jenkinson@dph.ox.ac.uk) or by telephone on 01865 289441, who will do their best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how we intend to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter in a reasonably expeditious manner:
Chair, **Medical Sciences Inter-Divisional Research Ethics Committee**; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

13. Further Information and Contact Details

The interviews for this researcher study will be carried out by Mr. Vimal Sriram (Doctoral student) from the Nuffield Department of Population Health, University of Oxford. The researcher will identify himself to you using a University of Oxford student card.



If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Mr. Vimal Sriram
Nuffield Department of Population Health
Health Services Research Unit
Richard Doll Building, Old Road Campus, Oxford OX3 7LF
Telephone number: 01865 743762
E-mail: vimal.sriram@dph.ox.ac.uk

Thank you for taking the time to read this information sheet.

Appendix 10: Exploratory qualitative interviews - Participant consent form:

NUFFIELD DEPARTMENT OF POPULATION HEALTH

Nuffield Department of
POPULATION HEALTH
Medical Sciences Division

UNIVERSITY OF OXFORD

Professor Crispin Jenkinson
e-mail: crispin.jenkinson@dph.ox.ac.uk
Telephone number: 01865 289441
Dr Michele Peters
e-mail: michele.peters@dph.ox.ac.uk
Telephone number: 01865 289428
Vimal Sriram (Doctoral Student)
e-mail: vimal.sriram@dph.ox.ac.uk
Telephone number: 01865 743762
Health Services Research Unit, Nuffield Department of Population Health
Richard Doll Building, Old Road Campus, Oxford OX3 7LF

PARTICIPANT CONSENT FORM

CUREC Approval Reference: R57703/RE001

Carers' Experience of Assistive Technology (AT) use in dementia

Purpose of Study:
This research explores the experiences of Assistive Technology use from the perspective of those looking after or helping persons with dementia. The research will look at types of Assistive Technology used and its benefits and disadvantages and explore facilitators or barriers to using Assistive Technology. In addition, we will develop a Carers Assistive Technology Experience Questionnaire.

		Please initial/tick each box
1	I confirm that I have read and understand the information sheet version____dated _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any adverse consequences or academic penalty.	☐
3	I am over 18 years of age.	☐
4	I understand that research data collected during the study may be looked at by designated individuals from the University of Oxford where it is relevant to my taking part in this study. I give permission for these individuals to access my data.	☐

5	I understand that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee.	☐
6	I understand only the researchers directly involved in this study will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.	☐
7	I Understand there might be certain circumstances (as outlined in section 7 of the participant information sheet) in which it may be necessary to breach this confidentiality and disclose information to a third party.	☐
8	I understand how this research will be written up and published.	☐
9	I understand how to raise a concern or make a complaint.	☐
10	I consent to the interview being audio recorded.	☐
11	I understand the audio recordings will only be used to transcribe the interview accurately and will be anonymised in research outputs.	☐
12	I give permission to be quoted directly in the research publication suitably anonymised.	☐
13	I agree to take part in the study.	☐

Name of Participant	Date	Signature
Name of person taking consent	Date	Signature

Appendix 11: Cognitive interviews - Participant Information Sheet:

NUFFIELD DEPARTMENT OF POPULATION HEALTH



Nuffield Department of
POPULATION HEALTH
Medical Sciences Division

Professor Crispin Jenkinson
e-mail: crispin.jenkinson@dph.ox.ac.uk
Telephone number: 01865 289441
Dr Michele Peters
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Telephone number: 01865 289428
Vimal Sriram (Doctoral Student)
e-mail: vimal.sriram@dph.ox.ac.uk
Telephone number: 01865 743762
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Developing the Carers Assistive Technology Experience Questionnaire

PARTICIPANT INFORMATION SHEET

Ethics Approval Reference: R57703/RE001

1. What is the purpose of this study?

Dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem solving or language. Caring for a person with dementia can be demanding for informal carers (family, friends and neighbours) and can affect their mental and physical health and their social lives. **Assistive Technology (AT)** devices are often electronic. They include talking clocks, electronic medication dispensers, smart gas meters, falls and motion detectors and door exit alarms. While Assistive Technology is usually aimed at helping the person with dementia, these may also have an impact on carers. Due to the thinking and problem-solving difficulties of the person with dementia, the carer may need to be an active user of the Assistive Technology. It is not yet clear what positive or negative effects such technology may have on carers and there is little information on their experience with its use.

Purpose of this research:

Using themes from existing research studies and interviews with carers, researchers from the Nuffield Department of Population Health, University of Oxford, have developed a Carers' Assistive Technology Experience Questionnaire for use with informal carers (family, friends and neighbours) who support and help persons with dementia at home.

To refine and understand, if the questions in this questionnaire measure what it is intended for and if carers understand and correctly interpret the questions, we want to carry out *cognitive interviews* with a sample of cares of persons with dementia who have used assistive technology.

The cognitive interviews will explore your interpretation and understanding of the survey questions within this questionnaire to identify errors and problems with the questionnaire before it is used in a survey.

2. Why have I been invited to take part?

You have been invited because you are over 18 years of age and a family member/friend/neighbour of a person with dementia.

To participate in the study, you need to be

- Looking after or supporting a person with dementia who has used at least one electronic AT device (such as those described above) at home within the past year.

3. Do I have to take part?

No, your participation is voluntary. You can ask questions about the study before deciding whether to take part. If you agree to take part, you may withdraw from the study at any time, without any penalty and without giving a reason. If you choose to withdraw after the interview, the research team will delete any data including personal information and interview recordings and transcripts, and it will not be used in the analysis.

4. What will happen if I take part in the study?

By taking part in this interview, you are helping us evaluate how easy or difficult the questions in the Carers Assistive Technology Experience Questionnaire are to understand and answer. If you are happy to take part, you will be asked to answer questions in an informal interview, like a conversation. The interview questions will ask you about your understanding of the survey questions, your views on any missing information from the questionnaire and if the questionnaire is user-friendly and comments on the visual appearance and layout of the questionnaire.

The interview will be audio recorded to allow for us to type up your answers. You will never be identified by any of your personal information.
The interview will take approximately 60-90 minutes and will take place at your home, your place of work, by telephone or at the University of Oxford. The interview location and time will be arranged in discussion with you, to suit your convenience and preference. The interviews will be conducted by Mr Vimal Sriram, a doctoral student at the University of Oxford.

5. Are there any potential risks in taking part?

The questions asked during the interview may be personal and occasionally some people feel upset when asked to think about their experiences of looking after a person with dementia. You do not have to answer any question that you would prefer not to answer. If you become upset at any point, the researcher will ask you if you wish to pause or stop the interview. You could then: stop and withdraw your data (the interview recording would be deleted), end the interview and allow the interview recording until that point to be used in the research, or carry on with the interview when you are ready.
The researcher can also provide you with an information sheet which contains a list of organisations who you can get in touch with if you feel the need for further support.

6. Are there any benefits in taking part?

You will not receive any direct benefit by taking part in this study. However, the information gained in this research study will improve the survey questionnaire and subsequently provide a better understanding and insight of carers' experiences of using assistive technology.

7. What happens to my data?

The **research data** will be stored and examined using University approved software.
Any information that you may have given in the interview that could identify you will be removed from the interview before it is analysed. Confidentiality will be maintained throughout this research

study. If you consent to take part in this study, you will be required to sign an informed consent form. To protect your identity, your name will be replaced by a pseudonym in any research reports. Any identifying information like your name, details or other personal information will not be used or disclosed to anyone outside, to any third party or appear on any transcripts, thesis, publications or on any academic paper.

However, there might be certain circumstances in which it may be necessary to breach this confidentiality and disclose information to a third party. This includes situations when someone provides information during the study that raises serious concern about:

- Intention to harm themselves or other people
- Risk to the health, welfare or safety of vulnerable adults such as someone with dementia
- Disclosure of a criminal offence

The researcher will discuss this issue with you before telling anyone else. The researcher will be obliged to share this evidence with his supervisors, who may advise that further action is taken.

Personal / sensitive information such as your name, age, gender, marital status, employment status, telephone number or address details in case of face-face interviews will be stored confidentially using computer software that does not allow anyone else except the researcher and his supervisors access to your data. All paper forms will be stored in a locked cupboard within the Department of Population Health, University of Oxford. Your personal/sensitive data, including your signed consent forms will be kept separately from audio recordings and transcripts from your interviews. Your answers may be quoted directly in the research publication with information suitably anonymised. All audio recordings will be erased permanently once they have been transcribed.
All research data and records will be stored for a minimum retention period of 3 years after publication or public release of the work of the research.

8. Will the research be published?

The research will be written up as a doctoral thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research. The thesis will be published open access.

Additionally, the research may be published in academic journals and presented in national and international conferences. The University of Oxford is committed to the dissemination of its research for the benefit of society and the economy and, in support of this commitment, has established an online archive of research materials. This archive includes digital copies of student theses successfully submitted as part of a University of Oxford postgraduate degree programme. Holding the archive online gives easy access for researchers to the full text of freely available theses, thereby increasing the likely impact and use of that research.

9. Who is organising and funding the research?

This study is being carried out as part of the DPhil (PhD) Programme in Population Health at the Nuffield Department of Population Health, University of Oxford.

10. Who has reviewed this study?

This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee (Reference number: R57703/RE001).

***11*. Data Protection:**

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study. The University will process your personal data for the purpose of the research outlined above. Research is a task that we perform in the public interest. Further information about your rights with respect to your personal data is available from http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/."

12. Who do I contact if I have a concern about the study or I wish to complain?

If you have a concern about any aspect of this study, you can contact me through an email at vimal.sriram@dph.ox.ac.uk or by telephone on 01865 743762 or my supervisors Dr Michele Peters (michele.peters@dph.ox.ac.uk) or by telephone on 01865 289428 or Professor Crispin Jenkinson (crispin.jenkinson@dph.ox.ac.uk) or by telephone on 01865 289441, who will do their best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how we intend to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter in a reasonably expeditious manner:
Chair, **Medical Sciences Inter-Divisional Research Ethics Committee**; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

13. Further Information and Contact Details

The interviews for this researcher study will be carried out by Mr. Vimal Sriram (Doctoral student) from the Nuffield Department of Population Health, University of Oxford. The researcher will identify himself to you using a University of Oxford student card.



If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Mr. Vimal Sriram
Nuffield Department of Population Health
Health Services Research Unit
Richard Doll Building, Old Road Campus, Oxford OX3 7LF
Telephone number: 01865 743762
E-mail: vimal.sriram@dph.ox.ac.uk

Thank you for taking the time to read this information sheet.

Appendix 12: Cognitive interviews – Participant consent form:

NUFFIELD DEPARTMENT OF POPULATION HEALTH

Nuffield Department of
POPULATION HEALTH
Medical Sciences Division

UNIVERSITY OF
OXFORD

Professor Crispin Jenkinson
e-mail: crispin.jenkinson@dph.ox.ac.uk
Telephone number: 01865 289441
Dr Michele Peters
e-mail: michele.peters@dph.ox.ac.uk
Telephone number: 01865 289428
Vimal Sriram (Doctoral Student)
e-mail: vimal.sriram@dph.ox.ac.uk
Telephone number: 01865 743762
Health Services Research Unit, Nuffield Department of Population Health
Richard Doll Building, Old Road Campus, Oxford OX3 7LF

PARTICIPANT CONSENT FORM

CUREC Approval Reference: R57703/RE001

Developing the Carers Assistive Technology Experience Questionnaire

Purpose of Study:
Carers' Assistive Technology Experience Questionnaire has been developed for use with informal carers (family, friends and neighbours) who support and help persons with dementia at home. To refine and understand, if the questions in this questionnaire measure what it is intended for and if carers understand and correctly interpret the questions, we want to carry out interviews to explore your interpretation and understanding of the survey questions within this questionnaire to identify errors and problems with the questionnaire before it is used in a survey

		Please initial/tick each box
1	I confirm that I have read and understand the information sheet version dated _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any adverse consequences or academic penalty.	☐
3	I am over 18 years of age.	☐
4	I understand that research data collected during the study may be looked at by designated individuals from the University of Oxford where it is relevant to my taking part in this study. I give permission for these individuals to access my data.	☐

5	I understand that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee.	☐
6	I understand only the researchers directly involved in this study will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.	☐
7	I Understand there might be certain circumstances (as outlined in section 7 of the participant information sheet) in which it may be necessary to breach this confidentiality and disclose information to a third party.	☐
8	I understand how this research will be written up and published.	☐
9	I understand how to raise a concern or make a complaint.	☐
10	I consent to the interview being audio recorded.	☐
11	I understand the audio recordings will only be used to transcribe the interview accurately and will be anonymised in research outputs.	☐
12	I give permission to be quoted directly in the research publication suitably anonymised.	☐
13	I agree to take part in the study.	☐

Name of Participant	Date	Signature
Name of person taking consent	Date	Signature

Appendix 13: Cognitive interviews - Plan-Do-Study-Act cycles template:

Worksheet for Testing Change- PDSA Cycle

Aim: (overall goal)

Every goal will require multiple small tests of change

Plan:

Describe first (or next) test of change	Person Responsible	When to be done	Where to be done

List the task needed to set up this test of change	Person Responsible	When to be done	Where to be done
1. 2. 3. 4. 5.			

Predict what will happen when the next test is carried out	Measures to determine if predictions accurate
1. 2. 3.	

Do:

Describe what actually happened when you ran the test

Study:

Describe the measured results and how they compared to the predictions

Act:

Describe what modifications to the plan will be made for the next cycle

Appendix 14: Cross-sectional survey - CATEQ

UNIVERSITY OF OXFORD

Carers' Assistive Technology Experience Questionnaire



Please send back the completed questionnaire in the reply-paid envelope.

Return Address: Vimal Sriram, DPhil student, Health Services Research Unit, Nuffield Department of Population Health, Richard Doll Building, Old Road Campus, University of Oxford, Oxford – OX3 7LF

Carers Assistive Technology Experience Questionnaire

General Information:
You are being invited to take part in the research study 'Carers' experience of Assistive Technology (AT) use in dementia'.
Assistive Technology (AT) are products such as talking clocks, electronic medication dispensers, robotic vacuum cleaners, smart gas meters, communication books, GPS navigation systems, falls and motion detectors, smartphone apps and door exit alarms.

You can take part in this survey if you are:

- Aged 18 years or above
- A family member/friend/neighbour looking after a person with dementia
- Providing at least 10 hours care (such as supporting shopping, leisure, personal care, finance) to the person with dementia per week at home
- Using/used at least one AT device at home within the past year

It should take you about 30 minutes to finish this survey. The purpose of this research is to find out: the benefits and disadvantages of AT; the facilitators or barriers to using AT; and the impact of using AT on carer wellbeing.

Do I have to take part?
Please note that your participation is voluntary. If you do decide to take part, you may withdraw at any point during the survey for any reason and you can simply choose not to send the questionnaire back to us.

How will my data be used?
Your answers will be completely anonymous, unless you provide your email address at the end of the survey to be contacted for an interview. We will take all reasonable measures to ensure that data remain confidential.
Your answers will be entered, stored and examined using University of Oxford approved software. All data will be stored in a password-protected file and may be used in academic publications. All the questions in this survey are optional. Research data will be stored for a minimum of three years after publication or public release.

Your email address (if provided) will only be used to contact you with a view to taking part in an interview at a later date. It will be deleted once the interview has concluded or if you tell us you no longer wish to be interviewed.

The data that we collect from you may be transferred to, stored and/or processed at a destination outside the European Economic Area ("EEA"), including in the UK. By submitting your personal data, you agree to this transfer, storing or processing.

Who will have access to my data?
The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study. The University will process your personal data for the purpose of the research outlined above. Research is a task that

we perform in the public interest. Further information about your rights with respect to your personal data is available at https://compliance.admin.ox.ac.uk/individual-rights

We would also like your permission to use your anonymised data in future studies, and to share data with other researchers (e.g. in online databases). Any personal information that could identify you will be removed or changed before files are shared with other researchers or results are made public.

Responsible members of the University of Oxford and funders may be given access to data for monitoring and/or audit of the study to ensure we are complying with guidelines, or as otherwise required by law.

This survey is for a DPhil (doctoral) research project. The Principal Researcher is Vimal Sriram, who is attached to the Nuffield Department of Population Health at the University of Oxford. This project is being completed under the supervision of Professor Crispin Jenkinson and Associate Professor Michele Peters.

This project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee [R57703/RE002].

Who do I contact if I have a concern about the study or I wish to complain?
If you have a concern about any aspect of this study, please contact Vimal Sriram, Nuffield Department of Population Health, Richard Doll Building, Old Road Campus Oxford OX3 7LF, UK on 01865 743762 or vimal.sriram@dph.ox.ac.uk or the supervisors Dr Michele Peters (michele.peters@ndph.ox.ac.uk) or Professor Crispin Jenkinson (crispin.jenkinson@ndph.ox.ac.uk) and we will do our best to answer your query. I will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Medical Sciences Interdivisional Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:
Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD. The Chair will seek to resolve the matter in a reasonably expeditious manner.

CONSENT:
Please select your choice below and place a tick (√) in the appropriate box.

Ticking on the "agree" button below indicates that:
- You have read the above information
- You voluntarily agree to participate
- You are at least 18 years of age

If you do not wish to participate in the research study, please decline participation by ticking on the "disagree" box or you can simply choose not to send the questionnaire back to us.

○ Agree

○ Disagree

There are three sections to this questionnaire.

The first section will ask you about the Assistive Technology (AT) that you are currently using and what you are using it for. We will ask about AT devices that you may have used before and are no longer using, later in the questionnaire.

The second section will ask you questions about your experiences of using the AT and its impact on your daily life.

The last section will ask you questions about yourself.

Section 1: Assistive Technology

Q1 What assistive technology are you or the person with dementia who you support and care for currently using? (please select all that apply)

- ☐ Assistive Robots
- ☐ Audio books
- ☐ Automatic gas switch-off device
- ☐ Automatic night lamp
- ☐ Baby monitors
- ☐ Bed occupancy sensor
- ☐ CCTV
- ☐ Computer/Laptop
- ☐ Cooker alarm
- ☐ Door alarm
- ☐ Electric bed
- ☐ Electronic day, date and time clock (Dementia clock)
- ☐ Electronic medicine dispensers
- ☐ Electronic reminders
- ☐ Electronic tracking device
- ☐ Falls alarm
- ☐ Flood detector
- ☐ GPS tracking device
- ☐ Large button telephone
- ☐ Memory clock
- ☐ Movement detectors/sensors
- ☐ Object locator
- ☐ Pendant alarm
- ☐ Picture button telephone
- ☐ Robotic pet(s)
- ☐ Smart gas and electricity meter
- ☐ Smart lights
- ☐ Smartphone
- ☐ Smart plugs
- ☐ Smartwatch
- ☐ Stove timer
- ☐ Tablet computer
- ☐ Video communication systems such as Skype or FaceTime
- ☐ Voice-controlled personal assistant such as Alexa or Siri
- ☐ Web camera

Q2 If you use any other assistive technology not listed, can you provide a list here?

_____

_____

Q3 What do you use the assistive technology for? (please select all that apply)

☐ Everyday activities such as eating, washing, dressing, toileting

☐ Indoor mobility

☐ Outdoor mobility

☐ Communication

☐ Memory or reminders

☐ Leisure

☐ Safety

☐ Managing day to day spending

☐ Managing finances

☐ Reducing effort when you care for someone with dementia

☐ Other _____

Q4 Who was involved in choosing the assistive technology <u>currently</u> used? (please select all that apply)

☐ The person with dementia

☐ Myself

☐ Myself together with the person with dementia

☐ Another carer (family, friend, neighbor)

☐ Health or social care professionals (Doctor, Nurse, Occupational Therapist, Social worker etc.)

☐ Other _____

Q5 Who paid for the assistive technology currently used? (please select all that apply)

- ☐ The person with dementia
- ☐ Myself
- ☐ Another carer (family, friend, neighbor)
- ☐ The assistive technology was provided by social services without a charge
- ☐ The assistive technology was provided by a charity
- ☐ Other _____

Q6 Can you give the approximate cost (in pounds) of initial buying of the assistive technology currently used, paid for by the person with dementia or by you or another carer (family, friend or neighbour)?

_____

_____

_____

Q7 Can you give the approximate cost (in pounds) of monthly ongoing costs of the assistive technology currently used, paid for by the person with dementia or by you or another carer (family, friend or neighbour)?

_____

_____

_____

Section 2: Using Assistive Technology

Q8 Please list **up to three** assistive technology devices that you are currently using. If you currently use only one or two devices list those.

Assistive Technology 1 _____

Assistive Technology 2 _____

Assistive Technology 3 _____

Answer the next set of questions on how you felt in your caring role in the past month using your selected assistive technology devices.

There might have been good and bad days, but we want to capture a snapshot of how you have felt on a typical day during the past month.

For each question below, choose the most appropriate option for the assistive technology device(s) you have chosen above, that best describes how you felt and select that option.

Q9 How involved are you in the on-going use of assistive technology?

	The person with dementia uses the assistive technology independently	I assist the person with dementia to use the assistive technology	The person with dementia and I use the assistive technology together	I use the assistive technology by myself
Assistive Technology 1	○	○	○	○
Assistive Technology 2	○	○	○	○
Assistive Technology 3	○	○	○	○

Q10 How often do you have to help the person with dementia to use the assistive technology?

	Never	Rarely	Sometimes	Often	Always	Need never arose
Assistive Technology 1	○	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○	○

Q11 Are you concerned about the cost of the assistive technology?

	Never	Rarely	Sometimes	Often	Always	Not applicable
Assistive Technology 1	○	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○	○

Q12 How helpful is the assistive technology in maintaining dignity of the person with dementia?

	Not at all helpful	A little helpful	Quite helpful	Helpful	Very helpful	Does not apply
Assistive Technology 1	○	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○	○

Q13 How concerned are you about your privacy and confidentiality when using assistive technology?

	A great deal	A lot	A moderate amount	A little	Not at all	Does not apply
Assistive Technology 1	○	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○	○

Q14 How concerned are you about privacy and confidentiality of the person with dementia when using assistive technology?

	A great deal	A lot	A moderate amount	A little	Not at all	Does not apply
Assistive Technology 1	○	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○	○

Q15 How helpful is the assistive technology in better managing the space/living arrangements for the person with dementia?

	Not at all helpful	A little helpful	Quite helpful	Helpful	Very helpful	Does not apply
Assistive Technology 1	○	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○	○

Q16 To what extent does the assistive technology meet your needs?

	A great deal	A lot	A moderate amount	A little	Not at all
Assistive Technology 1	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○

Section 2: Impact of using Assistive Technology

Q17 What input is required from you to use the assistive technology (please select all that apply)?

	Physical assistance	Verbal encouragement	Reminders and teaching	Monitoring	Responding to alerts	Maintaining assistive technology when it is not working	Removing assistive technology when it is not working or dangerous
Assistive Technology 1	○	○	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○	○	○

Q18 How often are you able to solve problems with the assistive technology by yourself?

	Never	Rarely	Sometimes	Often	Always	Need never arose
Assistive Technology 1	○	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○	○

Q19 How helpful is the assistive technology in reducing your effort in caring for someone with dementia?

	Not at all helpful	A little helpful	Quite helpful	Helpful	Very helpful
Assistive Technology 1	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○

Q20 How helpful is the assistive technology in reducing your stress?

	Not at all helpful	A little helpful	Quite helpful	Helpful	Very helpful	Does not apply
Assistive Technology 1	○	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○	○

Q21 How helpful is the assistive technology in managing your anxiety?

	Not at all helpful	A little helpful	Quite helpful	Helpful	Very helpful	Does not apply
Assistive Technology 1	○	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○	○

Q22 How helpful is the assistive technology in making your caring role easier?

	Not at all helpful	A little helpful	Quite helpful	Helpful	Very helpful
Assistive Technology 1	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○

Q23 How helpful is the assistive technology in giving you additional time for tasks that you have to do?

	Not at all helpful	A little helpful	Quite helpful	Helpful	Very helpful	Does not apply
Assistive Technology 1	○	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○	○

Q24 How helpful is the assistive technology in giving you more time for yourself?

	Not at all helpful	A little helpful	Quite helpful	Helpful	Very helpful
Assistive Technology 1	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○

Q25 How helpful is the assistive technology in reducing harm/potential harm to the person with dementia?

	Not at all helpful	A little helpful	Quite helpful	Helpful	Very helpful
Assistive Technology 1	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○

Q26 How helpful is the assistive technology in reducing the need for additional paid care?

	Not at all helpful	A little helpful	Quite helpful	Helpful	Very helpful	Does not apply
Assistive Technology 1	○	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○	○

Q27 Since you started using the assistive technology, how has the care you provide for the person with dementia changed?

	Improved a lot	Improved a little	Not changed	Deteriorated a little	Deteriorated a lot
Assistive Technology 1	○	○	○	○	○
Assistive Technology 2	○	○	○	○	○
Assistive Technology 3	○	○	○	○	○

Q28 How would you rate the value for money of assistive technology?

- ☐ Extremely good
- ☐ Somewhat good
- ☐ Neither good nor bad
- ☐ Somewhat bad
- ☐ Extremely bad

Q29 Would you recommend assistive technology to other carers?

- ☐ Definitely
- ☐ Probably
- ☐ Unsure
- ☐ Probably not
- ☐ Definitely not

Q30 Overall how would you say your satisfaction with assistive technology has been?

- ☐ Extremely satisfied
- ☐ Somewhat satisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Extremely dissatisfied

Section 2: Previously used Assistive Technology

Q31 Are there assistive technology devices that you have previously used and are no longer using?

- ☐ Yes
- ☐ No

Q32 If Yes, which assistive technology are you no longer using? (please select all that apply)

- ☐ Assistive Robots
- ☐ Audio books
- ☐ Automatic gas switch-off device
- ☐ Automatic night lamp
- ☐ Baby monitors
- ☐ Bed occupancy sensor
- ☐ CCTV
- ☐ Computer/Laptop
- ☐ Cooker alarm
- ☐ Door alarm
- ☐ Electric bed
- ☐ Electronic day, date and time clock (Dementia clock)
- ☐ Electronic medicine dispensers
- ☐ Electronic reminders
- ☐ Electronic tracking device
- ☐ Falls alarm
- ☐ Flood detector
- ☐ GPS tracking device
- ☐ Large button telephone
- ☐ Memory clock
- ☐ Movement detectors/sensors
- ☐ Object locator
- ☐ Pendant alarm
- ☐ Picture button telephone
- ☐ Robotic pet(s)
- ☐ Smart gas and electricity meter
- ☐ Smart lights
- ☐ Smartphone
- ☐ Smart plugs
- ☐ Smartwatch

- ☐ Stove timer
- ☐ Tablet computer
- ☐ Video communication systems such as Skype or Face time
- ☐ Voice-controlled personal assistant such as Alexa or Siri
- ☐ Web camera
- ☐ Other_____

Q33 When you were using the assistive technology, what did you use it for? (please select all that apply)

- ☐ Everyday activities such as eating, washing, dressing, toileting
- ☐ Indoor mobility
- ☐ Outdoor mobility
- ☐ Communication
- ☐ Memory or reminders
- ☐ Leisure
- ☐ Safety
- ☐ Managing day to day spending
- ☐ Managing finances
- ☐ Reducing effort when you care for someone with dementia

☐ Other _____

Q34 Why are you no longer using the assistive technology? (please select all that apply)

- ☐ The person with dementia is no longer able to use it
- ☐ The assistive technology is no longer working
- ☐ The assistive technology device has been replaced by a better device
- ☐ I, or a family member support the person with dementia
- ☐ Formal/paid carers support the person with dementia
- ☐ Removed assistive technology as it was dangerous
- ☐ Removed assistive technology as person with dementia no longer wanted it
- ☐ Ethical reasons
- ☐ Other

Q35 If you chose other, can you give some detail why you are no longer using the assistive technology?

_____

_____

_____

Section 3: About You

The following questions asks for some basic information about you and your health. This information will help us to see how the experience of using assistive technology varies between different people. All information will be treated in the strictest confidence.

Q36 In general would you say your health is:

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

Q37 On a typical day, does your health now limit you in moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf? If so, how much?

☐ Yes, limited a lot

☐ Yes, limited a little

☐ No, not limited at all

Q38 On a typical day, does your health now limit you in climbing several flights of stairs? If so, how much?

☐ Yes, limited a lot

☐ Yes, limited a little

☐ No, not limited at all

Q39 During the past four weeks, have you had any problems with your work or other regular daily activities as a result of your physical health and accomplished less than you would like?

☐ Yes

☐ No

Q40 During the past four weeks, have you had any problems with your work or other regular daily activities as a result of your physical health and were limited in the kind of work or other activities?

☐ Yes

☐ No

Q41 During the past four weeks, have you had any problems with your work or other daily activities as a result of any emotional problems (such as feeling depressed or anxious) and accomplished less than you would like?

☐ Yes

☐ No

Q42 During the past four weeks, have you had any problems with your work or other daily activities as a result of any emotional problems (such as feeling depressed or anxious) and did work or other activities less carefully than usual?

☐ Yes

☐ No

Q43 During the past four weeks, how much did pain interfere with your normal work (including work both outside the home and housework)?

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

Q44 How much of the time during the past four weeks have you felt calm and peaceful?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

Q45 How much of the time during the past four weeks did you have a lot of energy?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

Q46 How much of the time during the past four weeks have you felt downhearted and blue?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

Q47 During the last four weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A good bit of the time

☐ A little of the time

☐ None of the time

Q48 During the past four weeks, thinking of the physical and emotional demands of caring, do you feel that they have had…

☐ No impact on your health

☐ Little impact on your health

☐ Some impact on your health

☐ A significant impact on your health

☐ A very significant impact on your health

Q49 During the past four weeks, considering all the demands that caring places on you, do you feel overall that you have…

☐ Coped very well
☐ Coped quite well
☐ Coped OK
☐ Coped quite poorly
☐ Coped very poorly

Q50 Your relationship with the person with dementia over the last four weeks has been…

☐ Very good
☐ Quite good
☐ Fair
☐ Quite poor
☐ Very poor

Q51 How would you describe your gender?

☐ Male

☐ Female

☐ Prefer to self-describe as_____

Q52 What is your age in years?

_____

Q53 Which of these best describes what you are doing at present? (please tick all that apply)

- ☐ Full-time paid work (30 hours or more each week)
- ☐ Part-time paid work (under 30 hours each week)
- ☐ Full-time education at school, college or university
- ☐ Part-time education at school, college or university
- ☐ Self-employed
- ☐ Permanently sick or disabled
- ☐ Fully retired from work
- ☐ Looking after the home
- ☐ Voluntary/Charity work
- ☐ Unemployed
- ☐ Doing something else (please specify)

_____

Q54 What is your legal marital status or same-sex civil partnership status?

- ☐ Single (never married and never formed a civil partnership)
- ☐ Married / living as married / in a civil partnership
- ☐ Separated (but still legally married / in civil partnership)
- ☐ Divorced / legally dissolved civil partnership
- ☐ Widowed / surviving partner from civil partnership

Q55 What is your ethnic group?

- ☐ White
- ☐ Mixed/Multiple ethnic groups
- ☐ Indian/Indian British
- ☐ Pakistani/Bangladeshi/ Pakistani or Bangladeshi British
- ☐ Black/African/Black or African British
- ☐ Caribbean/Caribbean British
- ☐ Chinese/Chinese British
- ☐ Other Ethnic group (please specify)

_____

Q56 What is the highest level of education you have completed?

- ☐ Secondary school
- ☐ College (further education)
- ☐ Undergraduate university degree
- ☐ Postgraduate university degree
- ☐ Other (please specify)

_____

Q57 To help assess the financial impact of using assistive technology, it is necessary to ask you for details of your family income, if you wish to disclose it.

☐ Less than £10,000	☐ £10,000 - £20,000	☐ £20,001 - £30,000
☐ £30,001 - £ 40,000	☐ £40,001 - £50,000	☐ £50,001 - £60,000
☐ £60,001 - £70,000	☐ More than £70,000	☐ I do not wish to say

Q58 What are your living arrangements with the person with dementia you provide care for?

☐ I live with the person with dementia	☐ The person with dementia lives with me	☐ I live away from the person with dementia but visit at least daily
☐ I live away from the person with dementia but visit at least weekly	☐ I live away from the person with dementia and visit at least monthly	

☐ I have other arrangements (please specify)

_____

Q59 The person with dementia is my

- ☐ Parent
- ☐ Child
- ☐ Sibling
- ☐ Friend
- ☐ Neighbour
- ☐ Other (please specify) _____

Q60 We would like to interview some participants from this survey. If you are happy to be invited for an interview, please indicate that below and provide us with your contact details.

- ○ Yes, I am happy to be contacted about an interview
- ○ No, I do not want to be contacted about an interview

Q61 If Yes, please provide your email address and/or telephone number below. This information will only be used to contact you about your participation in an interview and will not be shared with anyone outside the research team.

_____

Thank you for your time in completing the survey. After analysis, a summary of the results from this survey will be available on the study website: http://bit.ly/atindementia

Appendix 15: Explanatory qualitative interviews - Participant Information Sheet:

NUFFIELD DEPARTMENT OF POPULATION HEALTH



Nuffield Department of
POPULATION HEALTH
Medical Sciences Division

Professor Crispin Jenkinson
e-mail: crispin.jenkinson@dph.ox.ac.uk
Telephone number: 01865 289441
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Vimal Sriram (Doctoral Student)
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Richard Doll Building, Old Road Campus, Oxford OX3 7LF

Carers' experience of Assistive Technology (AT) use in dementia
PARTICIPANT INFORMATION SHEET

Ethics Approval Reference: R57703/RE001

1. What is the purpose of this study?

Dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem solving or language. Caring for a person with dementia can be demanding for informal carers (family, friends and neighbours) and can affect their mental and physical health and their social lives. Assistive Technology (AT) devices are often electronic. They include talking clocks, electronic medication dispensers, smart gas meters, falls and motion detectors and door exit alarms. While AT is usually aimed at helping the person with dementia, these may also have an impact on carers. Due to the thinking and problem-solving difficulties the person with dementia may have, the carer may need to be an active user of the AT. It is not yet clear what positive or negative effects such technology may have on carers and there is little information on their experience with its use.

Purpose of this research:
This research will explore the experiences of Assistive Technology from the perspective of those looking after and helping persons with dementia at home. It will investigate the types of AT used and preferred, the purposes, benefits and disadvantages of the AT, and how the AT impacts on their burden and wellbeing.

2. Why have I been invited to take part?

You have been invited because you participated in a survey of the 'Carers' experiences of AT use in dementia project' and indicated, that we can invite you for an interview.
To participate in the interview, you need to be:

- Continuing to provide help or support to a person with dementia living at home (e.g. shopping, leisure, personal care, finance).

3. Do I have to take part?

No, your participation is voluntary. You can ask questions about the study before deciding whether to take part. If you agree to take part, you may withdraw from the study at any time, without any penalty and without giving a reason. If you choose to withdraw after the interview, the research team will delete any data including personal information and interview recordings and transcripts, and it will not be used in the analysis.

4. What will happen if I take part in the study?

If you are happy to take part, you will be asked to answer questions in an informal interview, like a conversation. The interview questions will ask you about the impact and effects of using Assistive Technology in helping care for your relative/friend/neighnour. The interview will be audio recorded to allow us to type up your answers. You will never be identified by any of your personal information.

The interview should take approximately 60-90 minutes and will take place at your home, your place of work, by telephone or at the University of Oxford. The interview location and time will be arranged in discussion with you, to suit your convenience and preference. The interviews will be conducted by Mr Vimal Sriram, a doctoral student at the University of Oxford.

5. Are there any potential risks in taking part?

The questions asked during the interview may be personal and occasionally some people feel upset when asked to think about their experiences of looking after a person with dementia. You do not have to answer any question that you would prefer not to answer. If you become upset at any point, the researcher will ask you if you wish to pause or stop the interview. You could then: stop and withdraw your data (the interview recording would be deleted), end the interview and allow the interview recording until that point to be used in the research, or carry on with the interview when you are ready.

The researcher can provide you with an information sheet which contains a list of organisations who you can get in touch with if you feel the need for further support.

6. Are there any benefits in taking part?

You will not receive any direct benefit by taking part in this study. However, the information gained in this research study will provide a better understanding and insight of carers' experiences of using AT and its impact on their well-being. This can be used by health professionals and researchers to support other carers of persons with dementia who use AT.

7. What happens to my data?

The **research data** will be stored and examined using University approved software.

Any information that you have given in the interview that could identify you will be removed from the interview before it is analysed. Confidentiality will be maintained throughout this research study. If you consent to take part, you will be required to sign an informed consent form. To protect your identity, your name will be replaced by a pseudonym in any research reports. Any identifying information like your name, details or other personal information will not be used or disclosed to anyone outside, to any third party or appear on any transcripts, thesis, publications or on any academic paper.

However, there might be certain circumstances in which it may be necessary to breach this confidentiality and disclose information to a third party. This includes situations when someone provides information during the study that raises serious concern about:

- Intention to harm themselves or other people
- Risk to the health, welfare or safety of vulnerable adults such as someone with dementia
- Disclosure of a criminal offence

The researcher will discuss this issue with you before telling anyone else. The researcher will be obliged to share this evidence with his supervisor, who may advise that further action is taken.

Personal / sensitive information such as your name, age, gender, marital status, employment status, telephone number or address details in case of face-face interviews will be stored confidentially using computer software that does not allow anyone else except the researcher and his supervisors access to your data. All paper forms will be stored in a locked cupboard within the Department of Population Health, University of Oxford. Your personal/sensitive data, including your signed consent forms will be kept separately from audio recordings and transcripts from your interviews. Your answers may be quoted directly in the research publication with information suitably anonymised. All audio recordings will be erased permanently once they have been transcribed. All research data and records will be stored for a minimum retention period of 3 years after publication or public release of the work of the research.

8. Will the research be published?

The research will be written up as a doctoral thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research. The thesis will be published open access.

Additionally, the research may be published in academic journals and presented in national and international conferences. The University of Oxford is committed to the dissemination of its research for the benefit of society and the economy and, in support of this commitment, has established an online archive of research materials. This archive includes digital copies of student theses successfully submitted as part of a University of Oxford postgraduate degree programme. Holding the archive online gives easy access for researchers to the full text of freely available theses, thereby increasing the likely impact and use of that research.

9. Who is organising and funding the research?

This study is carried out as part of the DPhil (PhD) Programme in Population Health at the Nuffield Department of Population Health, University of Oxford.

10. Who has reviewed this study?

This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee (Reference number: R57703/RE001).

11. ***Data Protection:***

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study. The University will process your personal data for the purpose of the research outlined above. Research is a task that we perform in the

public interest. Further information about your rights with respect to your personal data is available from http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/."

12. Who do I contact if I have a concern about the study or I wish to complain?

If you have a concern about any aspect of this study, you can contact the researcher through an email at vimal.sriram@dph.ox.ac.uk or by telephone on 01865 743762 or my supervisors Dr Michele Peters (michele.peters@dph.ox.ac.uk) or by telephone on 01865 289428 or Professor Crispin Jenkinson (crispin.jenkinson@dph.ox.ac.uk) or by telephone on 01865 289441, who will do their best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how we intend to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter in a reasonably expeditious manner:
Chair, **Medical Sciences Inter-Divisional Research Ethics Committee**; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

13. Further Information and Contact Details

The interviews for this researcher study will be carried out by Mr. Vimal Sriram (Doctoral student) from the Nuffield Department of Population Health, University of Oxford. The researcher will identify himself to you using a University of Oxford student card.



If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Mr. Vimal Sriram
Nuffield Department of Population Health
Health Services Research Unit
Richard Doll Building, Old Road Campus, Oxford OX3 7LF
Telephone number: 01865 743762
e-mail: vimal.sriram@dph.ox.ac.uk

Thank you for taking the time to read this information sheet.

Appendix 16: Explanatory qualitative interviews - Participant consent form:

NUFFIELD DEPARTMENT OF POPULATION HEALTH

Nuffield Department of POPULATION HEALTH Medical Sciences Division

UNIVERSITY OF OXFORD

Professor Crispin Jenkinson
e-mail: crispin.jenkinson@dph.ox.ac.uk
Telephone number: 01865 289441
Dr Michele Peters
e-mail: michele.peters@dph.ox.ac.uk
Telephone number: 01865 289428
Vimal Sriram (Doctoral Student)
e-mail: vimal.sriram@dph.ox.ac.uk
Telephone number: 01865 743762
Health Services Research Unit, Nuffield Department of Population Health
Richard Doll Building, Old Road Campus, Oxford OX3 7LF

PARTICIPANT CONSENT FORM

CUREC Approval Reference: R57703/RE001

Carers' Experience of Assistive Technology (AT) use in dementia

Purpose of Study:
This research explores the experiences of Assistive Technology use from the perspective of those looking after or helping persons with dementia. The research will look at types of Assistive Technology used and its benefits and dis-advantages. We will explore facilitators or barriers to using Assistive Technology and its impact on burden and well-being.

		Please initial/tick each box
1	I confirm that I have read and understand the information sheet version dated _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any adverse consequences or academic penalty.	☐
3	I am over 18 years of age.	☐
4	I understand that research data collected during the study may be looked at by designated individuals from the University of Oxford where it is	☐

	relevant to my taking part in this study. I give permission for these individuals to access my data.	
5	I understand that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee.	☐
6	I understand only the researchers directly involved in this study will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.	☐
7	I Understand there might be certain circumstances (as outlined in section 7 of the participant information sheet) in which it may be necessary to breach this confidentiality and disclose information to a third party.	☐
8	I understand how this research will be written up and published.	☐
9	I understand how to raise a concern or make a complaint.	☐
10	I consent to the interview being audio recorded.	☐
11	I understand the audio recordings will only be used to transcribe the interview accurately and will be anonymised in research outputs.	☐
12	I give permission to be quoted directly in the research publication suitably anonymised	☐
13	I agree to take part in the study	☐

Name of Participant	Date	Signature

Name of person taking consent	Date	Signature