The use of ‘off-the-shelf’ GPS technology to support people living with dementia and their care partners.

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Abbreviations

AD	Alzheimer’s disease
ADL	Activities of daily living
AL	Assistive Living
ALT	Assistive Living Technology
AT	Assistive Technology
BAME	Black, Asian and minority ethnic
CCG’s	Clinical Commissioning Groups
CP	Care Partner
GPS	Global Positioning System
IAT	Intelligent Assistive Technology
ICT	Information and Communication Technology
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
OTS	Off-the-shelf
PCT	Primary Care Trust
PlwD	Person living with dementia
SCIE	Social Care Institute for Excellence
TEC	Technology-enabled care
UK	The United Kingdom
UN	United Nations
WHO	World Health Organisation

DEDICATION

In memory of my Granddad, who taught me the value of hard work and that ‘if a job's worth doing, it's worth doing well’. He forever strived to make the world a more equal place. He is the person I will always aspire to be.

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ABSTRACT

This doctoral thesis explores the perceptions and experiences of people living with dementia and their care partners on off-the-shelf Global Positioning System (GPS) technology. ‘Off-the-shelf’ GPS devices are readily available, without a specific use attached and are often more economical than products labelled for use within dementia care.

This study was designed to guarantee that people living with dementia were an essential part of the study. This was not research ‘about them’, or through the use of a proxy to explore what people with dementia might do instead, this research sought to ensure that their voice was heard, understood, and had an impact. This was done through a two-phased approach. The first phase acted as a consultation session, employing a focus group to explore the views, opinions, and experiences of participants living with dementia and care partners on a range of off-the-shelf GPS devices. Findings indicated that the wearability, usability, and cost of products were integral to their success and adoption. Phase two utilised these findings with eighteen new participants using the off-the-shelf device chosen by participants of phase one, alongside training and technical support, for a period of three months. In-depth interviews with participants took place before and after this period of use.

Findings resonate with existing research, but also build upon the evidence base, to show the benefits and challenges of using this technology. This study demonstrates the benefits of GPS in relation to a person’s psycho-social needs, with barriers found relating to a person’s relationship with technology. The approach taken provided new insights into conducting research with people living with dementia as well as during times of crisis. Conclusions reached argue that off-the-shelf GPS devices are a viable, inclusive alternative to ‘dementia branded’ products, that could reduce healthcare inequalities and increase access to potentially vital technology.

IMPACT STATEMENT

In March 2020, the World Health Organization (WHO) declared SARS-CoV-2 a pandemic. As a result, the United Kingdom was forced into a national lockdown with restrictions placed on social contact. Individuals living with dementia and their care partners were encouraged to shield, with initially little access to support groups and limited contact with family and friends.

In relation to this study, the pandemic had a detrimental impact on the planned design of the research. Ultimately, in order for my study to go ahead and not face severe delays, all face-to-face elements of the project were removed. My initial recruitment and training strategies (for phase two of this study) involved presenting aspects of my research in person to individuals at local dementia support groups. As a result of government guidance and COVID-19 related restrictions, such presentations could not take place and alternative methods of recruitment and training were required. Recruitment and training were instead facilitated through the use a custom-built website, where I applied my skills in web design to create a platform that would advertise my study and promote my research. The website also acted as a training tool, where participants could receive step-by-step guidance and learn how to use the technology featured in this study. Data collection methods were also revisited in light of the pandemic, with in-depth interviews instead taking place remotely.

The pandemic, together with advice issued by Public Health England in response to COVID-19, has impacted on the ways in which people living with dementia engage with going outdoors. For some, the outbreak of COVID-19 caused newfound fears that resulted in a reluctance to go outside, which in turn, will have impacted on their engagement with this study. The Government also issued guidance for people considered to be “clinically vulnerable from COVID-19” to remain indoors. Many participants of this study would likely have fallen into this category and that, alongside general stress and anxiety surrounding the pandemic, could have impacted upon their engagement.

The aforementioned closure of support groups for people living with dementia and their care partners also impacted on the level of support this project received from external organisations. Prior to the pandemic, several dementia support groups reached out to me to express an interest in being part of the study, not only to help facilitate recruitment, but also assist in face-to-face training initiatives. Such training may have resulted in greater technological confidence for participants when using GPS devices, which in turn may have resulted in more positive experiences.

Despite these challenges, the study was adapted, and I have gained skills in being flexible, while being able to continue to undertake this research. Whilst I acknowledge the negative impact COVID-19 had on this study, this thesis will document how challenges were overcome and news ways of working presented.

CHAPTER ONE

INTRODUCTION

CHAPTER ONE: INTRODUCTION

1.1 Introducing the research

This thesis explores the experiences of using off-the-shelf Global Positioning System (GPS) devices for people living with dementia and their care partners. There is evidence in the literature, which is examined in chapter 2, that reports upon the crucial role that GPS can play in facilitating freedom, independence, and peace of mind for community dwelling individuals living with dementia. However, as the use of GPS has gained popularity in this area, an industry has formed around selling ‘dementia branded’ GPS devices; products that advertise their suitability for use within dementia care. Such products have a price tag often exceeding £150. Whilst for some this cost is immaterial given the safety and security such devices can provide, for others this amount only adds to existing inequalities. For many people, this cost may be considered excessive and beyond their reach, resulting in an access barrier, excluding them from the potential benefits such devices offer.

This research explores a more economical and inclusive alternative in ‘off-the-shelf’ technology. ‘Off-the-shelf’ products are readily available, for immediate purchase, and do not carry a specific use. The use of ‘off-the-shelf’ GPS devices as a piece of assistive technology for people living with dementia is understudied, with such devices retailing for as little as £10. Additionally, existing research that has investigated the use of GPS in supporting people living with dementia has, to date, failed to include them in the research design, in particular in the selection of the technology that is examined. From the outset, this study involved people living with dementia and their care partners. Phase 1 consulted them on the selection of an ‘off-the-shelf’ GPS device. Phase 2 was shaped by these findings and explored the experiences of using this ‘off-the-shelf’ GPS device over a period of 3 months.

1.1.1 Research Question, Aims and Objectives

This research aims to explore the views, opinions and lived experiences of individuals living with dementia on the use of off-the-shelf GPS technology. The aims and objectives of this study are:

1. To evaluate the user experience and acceptability of a range of GPS tracking devices, analysing factors that care partners and individuals living with dementia find the most important and characteristics that may be missing from certain products.
2. To explore the benefits that may be gained through using GPS technology, particularly in relation to freedom, independence, and safety.
3. Identify concerns that individuals living with dementia and their care partners may have in relation to the reliability and usability of GPS technology and how this could impact use.
4. To ensure that the views of people living with dementia and their care partners are taken on board and used to shape the project, utilising their wealth of knowledge and exploring the lived experiences of dementia.
5. To explore how the views and perceptions of the technology may change through the use of participant interviews before and after a period of use.
6. To explore how GPS can impact upon the wellbeing of a person living with dementia and their care partner
7. To explore the ethical concerns that Care Dyads may have regarding the use of GPS technology.

Following a declaration by the World Health Organisation in March 2020 of a global pandemic that would go on to disrupt much of society in unprecedented ways, an additional aim was added to the project.

8. To explore the lived experiences of the COVID-19 pandemic from the perspective of care dyads and consider if GPS could have assisted them during this time.

To achieve the above aims and objectives, the following research question was identified:

Research Question: ‘What are the perceptions and experiences of using ‘off-the-shelf’ GPS technology for people living with dementia and their care partners?’

1.1.2 Involvement of Individuals living with dementia

Throughout the research process, this study sought to ensure that the views of people living with dementia and their care partners were taken on board and used to shape the ongoing project. This aim reflects the growing urgency, reported within dementia research, to involve more people living with dementia and their care partners in research (Brooks et al., 2016; Miah et al., 2020; Morbey et al., 2019; McCabe and Innes, 2013). Individuals living with dementia, care partners and former care partners can provide vital personal experience and knowledge on research topics. Access to this wealth of knowledge and exploration of the lived experiences of dementia can help challenge and potentially change long-standing attitudes towards the involvement of individuals living with dementia in research (Dupuis et al., 2012; Murphy et al., 2015; Rivett, 2017; Wilkinson, 2002).

1.1.3 Two phased approach

This study was designed with two distinct phases, **Phase 1** sought to act as a consultation session, deploying the qualitative research method of a focus group to examine the views, opinions and experiences of a select group of participants who can be described as 'experts through experience', with all individuals having a direct relationship with the condition. The focus group was made up of individuals living with dementia, care partners and former care partners in a bid to gather diverse perspectives on a range of 'off-the-shelf' devices presented before them. Devices used in this phase were carefully selected using a rigorous process that involved inclusion criteria and product testing that narrowed down 157 results to the 7 that were shown to participants. During the focus group each 'off-the-shelf' device was discussed in turn, with attendees also presenting their own experiences of using technology as well as what they look for when selecting and adopting technology. Phase 1 concluded by asking participants to select the device they deemed most suitable. Thematic analysis of the focus group findings informed the questions asked in Phase two as well as the technology provided to participants.

Phase two began by inviting care dyads to attend a semi-structured interview to explore their initial views, opinions and experiences. Participants were then provided with the device selected by phase 1 participants and given appropriate training and support on how to use the technology, before being asked to use the device in their everyday lives over a period of three months. Throughout this period, technical support was provided by myself and available via a custom-built website. Data was collected after this period of use, again through a semi-structured interview, to explore their lived experiences of using the technology.

1.1.4 Research Context

Dementia

Dementia is a progressive condition that, in recent years, has become a public health priority (WHO, 2017), with the worldwide prevalence of dementia set to increase from 46.8 million to around 132 million by 2050 (Prince et al., 2016; WHO, 2017). The latest studies have estimated that across the world, 9.9 million people are diagnosed with dementia annually, working out at one new case every three seconds (WHO, 2017; Prince et al., 2016; ADI, 2021). Dementia is an umbrella term for a variety of progressive conditions affecting the brain (Dementia UK, 2019). Such conditions include Alzheimer’s disease which accounts for 62% of cases of dementia, as well as Vascular dementia, Dementia with Lewy bodies, Frontotemporal dementia and Parkinson’s dementia (Prince et al., 2014). Dementia contributes to dependency among older adults; impacting their memory, their cognitive abilities and behaviour and ultimately their ability to perform activities of daily living unaided (WHO, 2017). Globally, the proportion of older people who live independently, either alone or with a spouse, varies dramatically. Figures range from as low as 2% in low-income countries, where extended families may be required to care for their elders, to 93.4% in the Netherlands (UN, 2017). In the UK, this figure stands at around 85% (UN, 2017). It is worth noting that social and cultural norms influence these statistics alongside factors such as the support systems that are available to older people residing in certain countries as well as their economic conditions (UN, 2017). As dementia is a condition with no available cure, solutions to help manage symptoms and aid individuals to live independently, for as long as possible, are being sought in the realm of technology.

Dementia in the UK

It is estimated that in the UK, 885,000 people live with a diagnosis of dementia (Alzheimer’s Society, 2019a). In 2009, Dementia was made a key priority by the

UK government and NHS England through the ‘Living Well with Dementia: a national dementia strategy’ policy paper (DoH, 2009). This marked a shift in the conceptualisation of dementia care, with policy focusing on the retained abilities of the person living with dementia and how people can live positively with the condition (DoH, 2009). Over the last decade, UK policy has explored improving diagnosis rates and post-diagnosis care and support, access to dementia services, as well as sustaining independence and improving quality of life (DoH, 2009; DoH, 2016). This thesis will examine the UK dementia strategy in greater detail during the review of the literature. Around 540,000 people in England care for an individual living with dementia, with it estimated that one in three people will care for an individual living with dementia in their lifetime (NHS, 2020). The financial cost of dementia is estimated at £26.3 billion annually, with a significant proportion of this cost covered by people living with dementia and their care partners (Prince et al., 2014). This economic cost is predicted to triple in the next 20 years (NHS, 2020). At present, it has been reported that £17.4 billion a year is paid by people living with dementia, their care partners and families, with £11.6 billion of this figure coming from unpaid care (Prince et al., 2014). Unpaid care is often necessary as people living with dementia wish to remain living independently in their own homes, and they may hold assets above the current upper capital limit. The upper capital limit in the UK (at the time of writing) is currently set at £23,250, meaning that if a person living with dementia has assets totalling more than this figure, they may be required to pay the full cost of charges for their care services (AgeUK, 2020).

Such increasing costs for people living with the condition and their care partners come at a time of economic struggle for older people generally, with reports detailing that a fifth of those aged 75 and over are currently living below the poverty line, including a quarter of this figure being single women of this age demographic (Independent Age, 2015; AgeUK, 2020). For many older people, surviving on a state pension can be a struggle, with difficulties affording basic necessities such as heating, transport, care and support, as well as impacting their ability to stay connected with friends, family and society (Independent Age, 2015). Difficulties in affording such basic human needs has been linked to the austerity measures in place across the UK. These measures are strict government economic policies that aim to achieve debt reduction through reduced government spending and have been found to hurt deprived groups the most (Stuckler et al., 2017). There is a growing body of literature that investigates the impact of such measures on health, in particular the effect of cuts to healthcare services, reductions in health coverage and restricting access to care (Stuckler et al., 2017; Taylor-Robinson et al., 2013). Findings show the link between austerity measures and the rise in old-age mortality across Europe, with the UK experiencing the largest rise in the yearly mortality rate for more than 50 years (Stuckler et al., 2017). This rise has been attributed to cuts in social care and financial support to older adults (Loopstra et al., 2016). In such times of austerity, solutions to reduce the costs facing individuals living with dementia, and the cost of support to retain independence, should be sought.

This research has been conducted amidst a global pandemic. The World Health Organization (WHO) first declared SARS-CoV-2, also referred to as the coronavirus disease, or COVID-19, a pandemic, in March 2020 (WHO, 2020). This global pandemic has caused grave disruption across all aspects of society, generating social, economic and cultural effects that will go on to have long-term effects worldwide (The British Academy, 2021). It has also been found that the impact of this global disease has not been felt uniformly across society, with COVID-19 intensifying social inequalities, disproportionately impacting vulnerable populations, and exposing disparities by income, age, race, sex and geographic location (WHO, 2021; The British Academy, 2021). The COVID-19 pandemic has also highlighted how essential access to information and communication technology is for all individuals in society (United Nations, 2021).

Since the start of the pandemic, there has been increasing interest placed upon COVID-19 within the dementia literature, exploring the profound impact of COVID-19 on people with dementia in terms of care and support (Alzheimer’s Society, 2020a; Canevelli et al., 2020; Wang et al., 2020). Social support services have been heavily impacted by the pandemic and some were unable to quickly adapt and continue providing support for people living with dementia and their care partners (Giebel et al., 2021). During lockdowns and due to social restrictions, people living with the condition expressed feelings of fear, frustration, boredom, and confinement (Goodman-Casanova et al., 2020). It was also found that a lack of social contact and change in routines led to excess mortality among people with a diagnosis of dementia during COVID-19 (The British Academy, 2020).

Dementia and Technology

The impact technology has on human life is perhaps most visible in the arena of healthcare, where it has changed the landscape of treatment and service provision (Thimbleby, 2013; Satariano et al., 2014; Trenfield et al., 2019). Promising technologies are frequently being developed that are designed to enhance aging in place and improving wellbeing for older populations (Satariano et al., 2014). Global Positioning System (GPS) technology is one such example of an emerging innovation being used within the healthcare sector in a bid to improve a person's quality of life, particularly in the context of dementia. GPS has the potential to provide individuals living with dementia the independence and autonomy they need, whilst simultaneously increasing safety and security (Bartlett and Brannelly, 2019).

However, as stated by Carroll et al. (2008, par.1), "Information and communications technology (ICT) does not transform every life and every facet of life equally", this refers to the digital divide that has surfaced following advancements in ICT. Factors that have been found to contribute to digital inequalities include income, education, geography, disability, language, and one of the strongest influences; age (Robinson et al., 2015; Cotten, McCullough, & Adams, 2011; Francis et al., 2019). This PhD thesis will draw influence from the literature available surrounding dementia, the digital divide, the causes of digital inequalities and the current situation in the UK in relation to accessing potentially vital AT.

'Dementia branded' technology

The cost of the technology that is available to individuals living with dementia and their care partners raised questions during the initial scoping exercise for this research. The price of GPS products aimed at, and recommended for people living with dementia, could be viewed as excessive and disproportionate particularly when comparing these to similar devices available. This drew me to investigate this issue further, utilising my knowledge in computing (detailed further in section 1.2 below) to investigate and examine the range of products available online. I found that 'off-the-shelf' devices (products that are available immediately and have not been specially made to suit a particular purpose) carried similar, if not identical, technical specifications to 'dementia branded' products.

The table below depicts one example, where a 'dementia branded' product (left) has been compared to an 'off-the-shelf' device (right), with the only major difference of these two products being the retail price.

Table 1: Comparison of dementia branded product vs off-the-shelf device

 **'Dementia Branded' Device**	 **Off-the-shelf device**
Weight: 46g	Weight: 20g
Size: 121mm x 121 mm x 50 mm	Size: 42.1mm x 42.1mm x 16.4mm
No geo-fencing options[1]	Geo-fencing
No Alert button	Alert Button
Positioning system[2]: GPS, Cellular, Bluetooth	Positioning system: GPS, Cellular, Wi-Fi and Bluetooth
Cost: £149.95	**Cost: £19.99**
Monthly cost: Dependent upon usage (100mb = £70)	**Monthly Cost: £2 (Unlimited use)**
Source: TechSilver (2021)[3]	*Source: Amazon (2021)*

Many 'off-the-shelf' products have comparable features to branded products. The example in figure 1 shows an 'off-the-shelf' GPS device which has been given 'dementia branding' and then remarketed at a considerably higher cost. In the figure below, the product on the left is an 'off-the-shelf' device, available to purchase from mainstream online marketplace, Amazon, at a cost of £26.75. The product on the right shows how the device has been 'rebranded' and now carries

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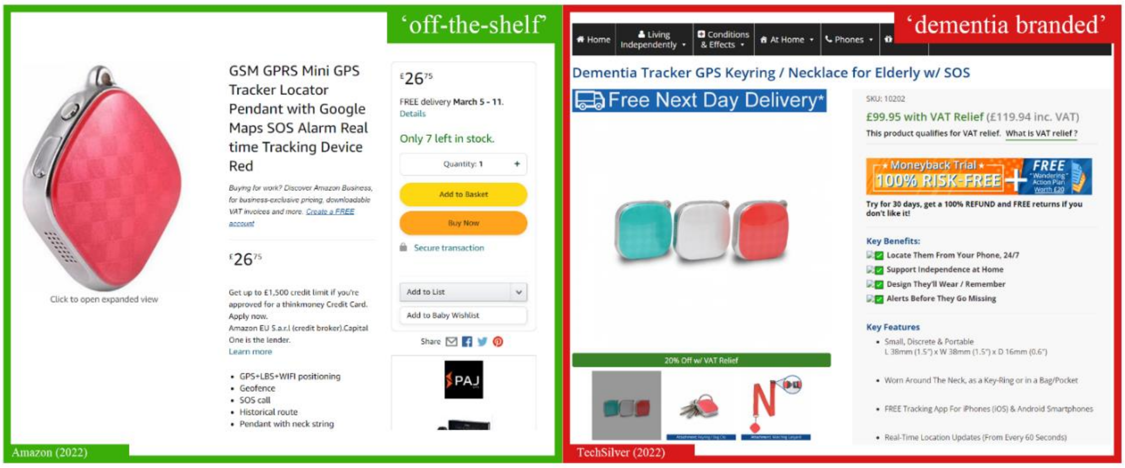
[1] A geo-fence is a virtual perimeter or boundary that triggers an alert upon entering or exiting, geo-fencing is covered in greater detail in section 2.5.3.

[2] Positioning systems determine geographical position and provide locational information, some are global (such as GPS), whilst others are local and have a limited range.

[3] TechSilver.co.uk is an online store that specialises in marketing technologies for older people.

a specific use/function, advertising it as a ‘dementia tracker’ suitable for the elderly at a cost of £119.94, representing a markup of 348%.

Figure 1: Off-the-shelf vs dementia branded product (Sources: Amazon, 2022; TechSilver, 2022)



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- FREE Tracking App For iPhones (iOS) & Android Smartphones
- Real-Time Location Updates (From Every 60 Seconds)

Definition of off-the-shelf technology

This project utilises ‘off-the-shelf’ (OTS) GPS technology in a bid to explore how such products could impact the lives of those living with dementia and their care partners. Definitions found within relevant literature are often broad, and due to the nature of off-the-shelf goods and services, a definition attempts to cover a large variety of products (Morisio and Torchiano, 2002). Drawing upon the works of Morisio and Torchiano (2002) and Oberndorf, (1998) within this study, the phrase ‘off-the-shelf’ is adopted to mean the following: An off-the-shelf product is one that is (1) exists a priori, without modification, and is thus readily available to the (2) general public at a (3) reasonable cost. The devices are not tailor-made for a specific use or function but carry with them a similar or identical specification to those with a defined use, OTS provide a sense to the consumer of getting “something that already does the job” (Oberndorf, 1998: p.143). The findings of this study have the potential to contribute to and address the concerns surrounding healthcare inequalities due to the economical and accessible nature of ‘off-the-shelf’ products.

1.2 Introducing the researcher

This study draws upon personal experience and builds upon the knowledge I have gained during prior research and education in the fields of computer science and management studies. My understanding of dementia and my desire to help people live well with the condition was influenced by my knowledge of technology and my personal connection to dementia. Dementia does not discriminate across class, race or background, with most people having a connection with someone who has a diagnosis of dementia; my biography is no different and has been shaped by experience of the condition, both in work and family life. Following my graduation from undergraduate studies, I sought out a role that could combine my aspects of interest as well as my desire to continue research and help people living with dementia. I was aware of the negative stereotypes associated with dementia, where people living with the condition were often ruled out and excluded from fully participating in society, due to having a diagnosis, despite the abilities they had retained and the contributions they could make.

Following discussion with a family friend, whose husband was living with dementia, I found that care partner fear was the underlying reason behind restricting what the person living with dementia could do. They were a married couple, and the wife was an informal care partner to her husband who was living with dementia. The husband, a keen long-distance walker, who always lived a very active lifestyle wished to remain as independent as possible following his diagnosis of Alzheimer’s disease. On a daily basis, the husband would walk the same 10-minute route to the local post office to collect his morning paper before returning home. Whilst for many years, post-diagnosis, this was a safe and replicated journey, in recent times he began to get lost along the route, perhaps after being interrupted by a friend or stopping for a moment. His wife wanted him to remain living in their home and in the community, and to be able to retain his independence. However, she became concerned and anxious from the threat of him getting lost when out walking on his own, and ultimately, she could no longer allow him to go out unescorted.

Following conversations with him, I began to understand the importance that this short, 10-minute, daily walk held for him. Whilst some may see this activity as insignificant, for him this was his routine, what he did and had done for 30 years.

I discussed with them the possibility of using technology to help facilitate his independence, something they were not aware of. Listening to people living with dementia over the course of this research study, I have realised similarities in peoples accounts and the importance and meaning that can be gained from seemingly insignificant daily activities. I have also recognised the value that can be gained through including the real experts, those living with dementia, in the discussion, and the importance of acknowledging the wealth of knowledge and experience that they can provide to research.

Prior to writing my PhD research proposal for this study, I investigated existing technology on the market and questioned why GPS technology was not recommended to our family friends. It appeared to me that GPS was an ideal solution as it could be utilised to support individuals living with dementia and their care partners. However, I also realised that the devices aimed at people with dementia were expensive, although they shared similar specifications with devices not aimed at dementia care. My first option was to consider creating my own device, however, upon further inspection I found that many of the off-the shelf devices currently available on online marketplaces presented a more economically viable opportunity, with attached software included.

Experience in the fields of computer science and management

Before undertaking this PhD, I gained a first-class undergraduate degree in Computer Science with Management studies BSc (hons) at The University of Leicester. This degree afforded me opportunities to develop my skills in Software engineering, program design and systems development, whilst equipping me with basic skills in research. For my final year dissertation project, I developed an online tool to assist people in financial management, in particular, improving their credit score. During this time, I became acutely aware of the challenges facing individuals with low computer literacy and how the digital divide had created a gap between those who were able to benefit from technology and those who could not. This gap could be caused by disparities in education, demographic differences, or economic inequality. I found that elements of software design could assist people who experience gaps related to learning how to use technology. Through research, I discovered that existing financial management tools often contained jargon, with useful content or advice situated behind a paywall, the tool I developed sought to change that.

My undergraduate degree combined computing and business topics, affording me expertise in programming, web technologies and information systems as well as providing me with valuable knowledge in areas of management, marketing, and accounting. This project draws upon many principles within marketing, with the 'dementia branded' products referred to in this study adopting strategic marketing techniques to facilitate greater appeal to intended audiences. This is something that concerned me from the outset of this project, and I felt that this was exploiting a potentially vulnerable group who may not be aware of 'off-the-shelf' alternatives that carry identical specifications.

Throughout my undergraduate degree, I also completed numerous software development projects that utilised agile methodologies. The agile philosophy is made up of software development methods that are based on iterative and incremental development (Kumar and Bhatia, 2012). This methodology recognises the need for close stakeholder collaboration and communication in processes in order to create a product fit for purpose. I have attempted to apply many of these skills and understandings throughout this thesis, incorporating concepts of an agile methodology into research design, such as close stakeholder involvement. Following the completion of my studies, I found I had a drive for further research and wanted to take the skills that I had gained into a new subject area. I found the field of digital health was one that enabled me to harness my skill set and utilise the knowledge that I had gained in computing, in an attempt to help address health-related challenges.

1.3 Thesis outline

This thesis is organised into seven chapters.

Chapter One provides an introduction to the study and contextualises it within the needs of those living with dementia and care partners.

Chapter Two presents the review of the literature available to date, designated into two parts. The first considers a broad review of the literature pertaining to assistive technology within dementia. This provides the reader with contextual information, including a background into dementia, assistive technology, GPS and the existing uses of GPS as a form of assistive technology is given, before exploring societal and political drivers, including current UK dementia policy. This section of the literature review seeks to allow the reader an appreciation of the challenges faced by individuals living with dementia and their care-partners. The second part of this chapter discusses the systematic review that took place for this study, investigating the benefits of using GPS technology for those living with dementia. The key benefits reported in the included studies were perceived increases in freedom and independence for individuals living with dementia. Gaining such benefits was dependent upon factors such as user trust, confidence in the technology and the ability to use features such as geo-fencing. Control, autonomy, peace of mind and usefulness were identified in the studies. This section of the literature review also draws on recommendations for future research to include examining how the value of GPS devices to support independent living may change over the course of an individual's dementia journey. Additionally, this review highlights the importance of enabling greater representation of individuals living with dementia in future research. The chapter concludes with a brief section that seeks to bridge findings from the literature review and the projects research design, focusing on the concept of person-centred care.

Chapter Three draws together a detailed account of the design of this research, and the research methodologies that underpin this study. I discuss why I utilised the qualitative data collection methods of focus groups and interviews, as well as how this study responded to change in light of the COVID-19 pandemic. The chapter concludes by detailing the ethical considerations that were made when designing this research, focusing on the ethical challenges that were considered when involving individuals living with dementia in the study.

The final 3 chapters of this thesis set out my findings and situate them within relevant literature.

Chapter Four reports upon data analysis from the first phase of data collection; the consultation focus group. This consultation phase was imperative to the design of this study and maximised the involvement of people living with dementia. The chapter presents the 5 themes that emerged from the focus group data and how findings were used to shape phase two.

Chapter Five introduces the 18 participants that took part in the main research study; a 3-month period of using the device deemed most suitable by those who took part in phase 1. The chapter discusses data analysis from initial interviews with participants, that identified 4 themes of: ‘Motivations for using GPS’, ‘Social participation’, ‘Previous experience of using GPS’ and ‘experiences of care dyads during the COVID-19 pandemic’. The chapter then considers the follow-up interviews undertaken after the 3-month period of use. Data analysis of the second set of interview data revealed 2 themes: ‘Relationship with technology’ and ‘the outcomes of using GPS’.

Chapter Six discusses my findings and situates them within the broader literature. The chapter discusses findings against each of the projects aims as well as the overarching research question. Key findings contribute to understandings that dementia impacts everyone differently, technology needs to flexible, adaptable and tailored to suit individual contexts and needs. Findings also consider non-adoption and discontinuance of GPS, whilst providing unique insights into the usage of GPS technology and how technology underutilization can occur. This chapter goes on to discusses the role of GPS in enhancing social inclusion, participation and engagement. Findings are also discussed alongside Kitwood’s (1997) model of Psycho-Social needs and how GPS can help support the fulfilment of the 5 fundamental psychological and social human needs.

Chapter Seven, the final chapter of this thesis, provides a summary of the research, before highlighting the novel contributions this research makes to the field. Contributions to knowledge, including how research can be co-produced with people living with dementia, as well as insights around conducting research during a pandemic. This chapter also shows how this research project has contributed to conceptual literature, policy and the technology focused world. The culmination of this thesis explores the strengths and limitations of the study, before offering recommendations for future research.

CHAPTER TWO

LITERATURE REVIEW

CHAPTER TWO: LITERATURE REVIEW

This chapter will present the findings of a review of the literature surrounding the use of Global Positioning System (GPS) technology within dementia care. This literature review chapter has been split into two parts: -

The first part of this chapter will present a review of the available literature pertaining to assistive technology within the dementia care arena and will include contextual information to allow the reader an appreciation of the challenges faced by individuals living with dementia, and their care-partners.

The second part of this literature review offers a systematic review of the evidence base and investigates the benefits of using GPS technology for those living with dementia. It will also identify opportunities to support individuals to live independently for as long as possible. The chapter concludes by presenting a summary of the findings of the literature review and identifies the implications from this review for my study.

Part 1: Literature review – GPS contextualised

This part of the literature review aims to contextualise the use of GPS technology within the field of dementia care. First, it will provide a background in relation to dementia, before exploring the societal challenges related to ageing and dementia and current UK dementia policy. Assistive technology within dementia care will then be reviewed, before focusing on the role of GPS as a form of assistive technology.

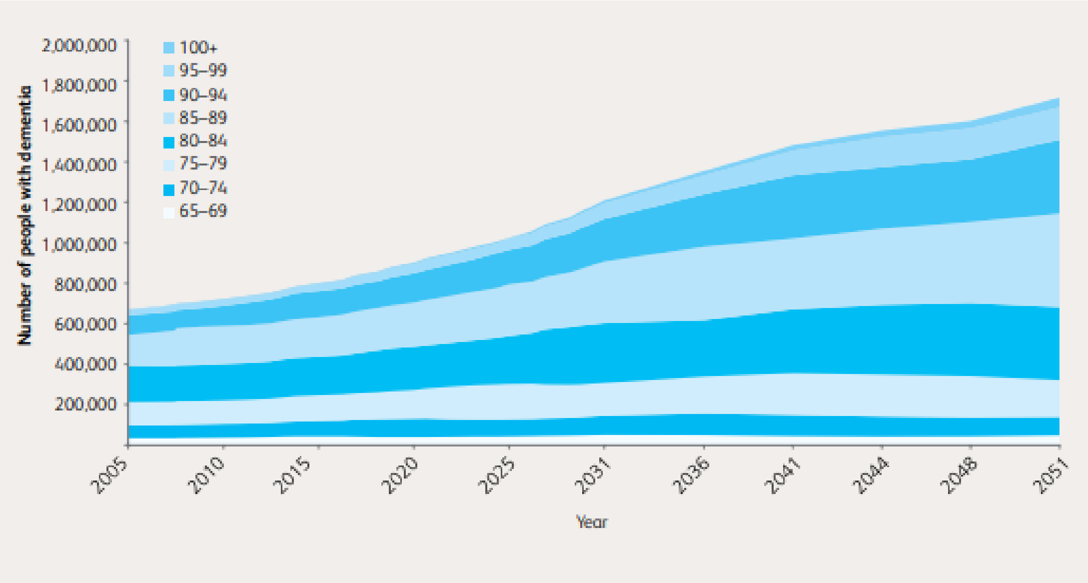
This review will evaluate the extent to which the individual living with dementia is involved in the research into the potential benefits and impact of GPS technology. As user involvement remains a key aspect in the development of emerging technologies globally, participation from individuals living with dementia should likewise be sought. However, it is often found that the views of this particular population are overlooked in lieu of proxy opinions (Robinson et al., 2009; Liu et al., 2018; Wilkinson, 2002), this is despite the vital information that can be gained through accounts of their personal opinions and experiences. This section of the review will conclude with the ethical considerations that must be taken into account when evaluating the use of this technology within dementia support.

2.1 Background into Dementia

2.1.1 Dementia

As life expectancy increases, the number of individuals who will go on to develop dementia subsequently rises and has serious implications for dementia care (Powell et al., 2010). It is estimated that 850,000 people in the UK live with a diagnosis of dementia with the financial cost estimated at £26 billion annually (Alzheimer's Society, 2018). Additionally, there are many people living in the UK without a formal diagnosis of dementia, with the dementia diagnosis rate for England currently standing at 67.9% (NHS, 2020a). Projections show that these figures are set to rise significantly over the next few decades, with the number of individuals living with dementia increasing to over 1 million by 2025 and surging to 2 million by 2051 (Alzheimer's Society, 2014); the graph in figure 2 below depicts such projections.

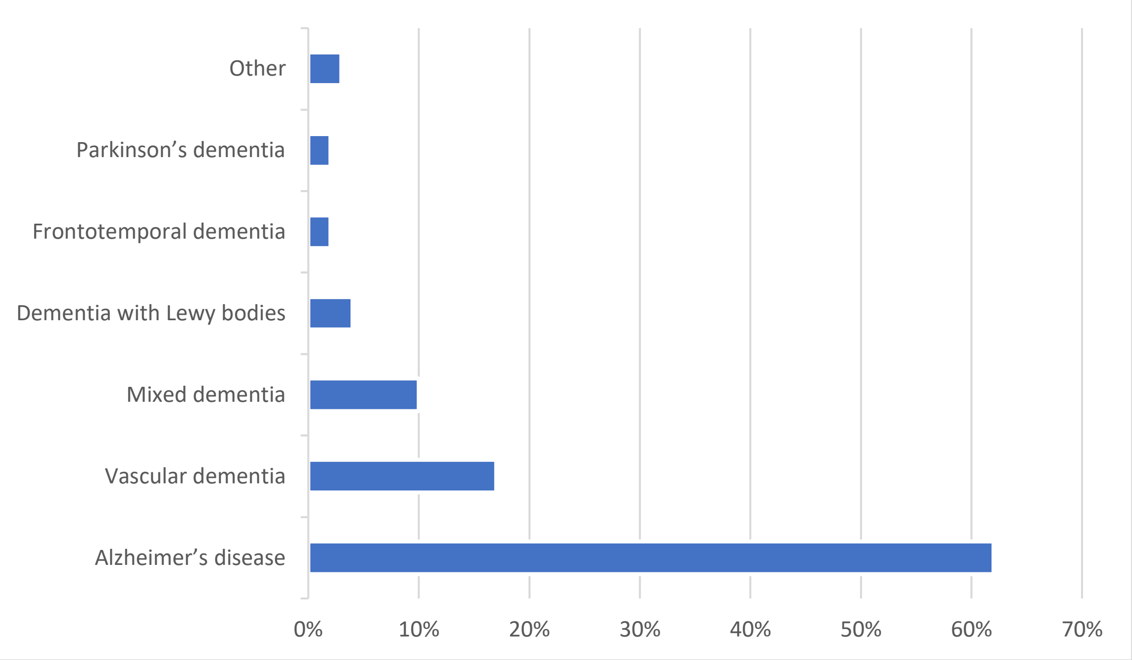
Figure 2: Projected increases in the number of people with dementia in the UK, by age group. (Prince et al., 2014)



Dementia is often used as umbrella term for a variety of progressive conditions affecting the brain (DementiaUK, 2019). Symptoms typically associated with dementia are those that affect memory, thinking, learning, orientation, language, and judgement (WHO, 2012). There are estimated to be more than 200 diagnosable types of dementia (DementiaUK, 2019), with subtypes of dementia being Alzheimer's disease, Vascular dementia, Lewy bodies dementia, frontotemporal dementia and mixed dementia. Most commonly diagnosed in individuals over the age of 65, young onset dementia is said to occur in individuals under the age of 65.

Alzheimer's disease (AD) is the most common form of dementia in the UK, estimated to make up between 60–70% of cases of dementia in the over 65 age group (WHO, 2017). Vascular dementia is considered to be the second most common form of dementia, making up around 17% of cases, affecting 150,000 people in the UK (NHS, 2017). The subtypes of dementia and the rates in which they occur can be seen in the figure below.

Figure 3: Dementia subtypes (Source: Prince et al., 2014)



Whilst the biggest risk factor for dementia is age, there is evidence to show that several other factors including ethnicity, gender, genetics, stroke history (Kuźma et al., 2018) and the diagnosis of other medical conditions and diseases all increase the chances of developing dementia. However, there are also less obvious influences such as depression (Karantzoulis and Galvin, 2011), smoking and excessive consumption of alcohol that all enhance a person's risk of developing the condition (Alzheimer's Society, 2016). Measures that are believed to reduce the risk of developing dementia include regular exercise, eating a healthy and balanced diet, being socially and mentally active and maintaining a healthy weight (NHS, 2020b; Alzheimer's Society, 2016).

As dementia progresses, the condition can present a challenge for both the individual experiencing dementia and those close to them, especially for individuals who want to remain in their own home and retain a sense of independence. It is reported that 700,000 friends and family care for a person with the condition (Lewis et al., 2014). For care partners, these challenges may include providing suitable and stimulating activities and accessing appropriate help and support (Alzheimer's Society, 2012). Individuals living with dementia may experience mobility issues, changes in behaviour and problems with verbal communication (Alzheimer's Society, 2020d).

The phrase "dementia journey" is often used in the literature and guidance to describe how the condition may impact a person over time. The Alzheimer's Society have attempted to map what a person may expect to happen over the course of their dementia journey below, to provide advice (see figure 4). The Alzheimer's Society (2020d: p.3) reports that it can be helpful for people diagnosed with dementia and their care partners to view dementia progressing in three stages – early, middle, and late; often referred to in the literature as mild, moderate, and severe, with these stages describing how much the symptoms may affect a person. However, it must be stated that every person's dementia journey is different and will not necessarily follow the linear progression as shown below. Viewing the dementia journey in this way may be problematic, as it fails to acknowledge that a person's skills and abilities may fluctuate and change at different times. Symptoms will not be predictable and may vary each day. Whilst some people may experience a slow gradual decline over many years, for others, their experience may be completely different; they may progress at different speeds and may experience good days and bad days, with their abilities fluctuating. It is also interesting to note that the Alzheimer's Society use the term "sufferers" in this figure; a phrase which contradicts the literature surrounding living positively with dementia (Kitwood, 1997).

Figure 4: Mapping the Dementia Diagnosis Journey to Improve Self-Guided Support (Alzheimer's Society, 2022)

Whilst there is a growing desire for individuals living with dementia to remain at home and in the community, during the later phases of an individual's dementia journey, institutional care is often required (Innes, 2009). Around 39% of those living with dementia in the UK reside in care homes (Prince et al., 2014), a figure often viewed as too high due to the nature of care homes and the environment of diminished physical freedom and greater exclusion from the community (Innes, 2009).

2.1.2 Cost of dementia

Dementia has a huge economic impact on individuals living with the condition, their family, care partners, and society (Wittenberg et al., 2019). Calculating and understanding this cost is vital to engage with the public and encourage policymakers to invest in appropriate treatments, care and support, preventions and research (Wittenberg et al., 2019). From a UK perspective, the average cost of dementia, per person, has been estimated to stand at £32,250 per year (Prince et al., 2014). Given that publicly funded social care in England is means tested and dependent upon the income and assets of the person, and unlike healthcare, is not free at the point of use, costs generally fall to the person living with dementia and their families, alongside unpaid care. Globally, the World Health Organisation [WHO] (2021) have estimated that the total societal cost of dementia stands at US$ 1.3 trillion and anticipate this figure surpassing US$ 2.8 trillion in the next 10 years. In a report commissioned by the Alzheimer's Society (Prince et al., 2014) it was found that unpaid care (often carried out by family members) accounted for three-quarters (74.9%) of the total cost for all individuals living in the community with dementia. Given this substantial contribution from unpaid care partners, studies (Prince et al., 2014; Wittenberg et al., 2019; DoH, 2015) have made recommendations to increase the support that is available to such care partners. Wittenberg et al. (2019: p.1102) suggests this support is essential "in order to promote [the care partners] health and well-being and enable them (if they wish) to combine caring with employment or other activities". It has also been reported that dementia also impacts women disproportionally, with women providing 70% of informal carer hours for people living with dementia (WHO, 2021).

In addition to estimating the personal costs associated with dementia, Wittenberg et al. (2019) examines the cost to the health and social care systems in the UK. Individuals living with dementia are the main users of social care, with 70% of those living in residential care holding a diagnosis of dementia and 60% of those receiving home care also having the condition (Alzheimer's Society, 2019a). Wittenberg et al. (2019) highlights the cost burden that is placed on an already underfunded social care sector, citing the impact of cuts in central government funding for local authorities and the resulting decline in publicly funded community-based and residential care. Findings by Wittenberg et al. (2019) conclude that there is a greater need to finance social care fairly and efficiently, sharing the economic impact of dementia evenly between health and social care systems and reducing the substantial proportion of costs that are met by people living with dementia and their families. This fair distribution of the costs associated with dementia is essential to ensure care services can be delivered in a timely fashion and be of high-quality (Wittenberg et al., 2019).

2.2 Societal and Political drivers

2.2.1 UK dementia policy

In 2009, the Government launched its first National Dementia Strategy, 'Living well with dementia'. This strategy aimed to increase dementia awareness, improve early diagnostics and improve the range and access to dementia care services to positively impact upon the quality of life for those living with dementia and their care partners. The Prime Ministers Challenge on Dementia (DoH, 2012) was the next government policy to focus on delivering strategic change. The key objectives centred on making societal changes by creating dementia friendly communities in order to raise awareness of dementia and the challenges that people with dementia face within local communities. Improvements in health and social care saw an integrated approach to improve diagnosis, raise standards in acute and secondary care in the community, as well as in care homes. The commitments contained within the 'Prime Ministers challenge on dementia 2020' outlined the need to increase technology adoption within dementia care, to *"monitor health, reduce social isolation and connect people" (Department of Health, 2015: p.15).* The PM's challenge also committed increased funding to allow more research into care, cause and cure. The dementia challenge was updated in 2015, and year on year, culminating in the 2020 challenge (DoH, 2016; DoH, 2018). In terms of this research funding, a large proportion is given to finding a cure for dementia rather than projects focusing on care (Wong and Knapp, 2020). US data found that less than 5% of research projects focus on dementia care and the impact of the condition, with such figures equating to less than 4% of the $10,800 million of dementia-related research funding that is available (IADRP, 2020, cited in Wong and Knapp, 2020).

In 2019, The NHS long term plan set out a strategy to improve the national care framework and to improve the local health system five-year plans. It sought to provide equitable, affordable and high-quality care for those living with dementia. The recommendations were informed by the Alzheimer's Society (2019) which highlighted the rising costs faced by those living with dementia and their care partners. In 2019, the All-Party Parliamentary Group (APPG) on Dementia published a report focussing upon the challenges faced by individuals living with dementia from a societal perspective. The report aligned its recommendations to disability legislation and aimed these at local and national policies, calling for changes in employment, social protection, social care, housing, transport, and community life.

Dementia care pathways are now an established part of the NHS in the UK and are guided by both national and local guidelines. The guiding principles of the pathway are around raising awareness and understanding of dementia, increasing the early diagnosis and access to support services, and assisting those diagnosed with dementia to live well. It also highlights the importance of supporting decision making and care provision for those in the later stages of dementia, facilitating care and dignity.

These societal and political drivers have all impacted the lives and wellbeing of individuals living with dementia. However, there are still gaps in service delivery and access to care, particularly with respect to minority ethnic groups (APPG, 2019). This study reflects many of the overarching aims of these policies, in seeking to improve individual's quality of life, as they live with dementia. It also intersects with the Alzheimer's Society (2019a) report, investigating the costs associated with accessing dementia care.

2.2.2 Community-based dementia care services

Assessing the provision of dementia services in the UK is problematic. This is due to the decentralised approach to dementia care that is taken, with support agencies being commissioned from local authority budgets. This situation has evolved from the National dementia strategy, launched in 2009 and described above, to improve diagnostic rates and post diagnostic support and sought to provide guidance and support for commissioning bodies, strategic health Authorities, Local Authorities, acute, primary care and mental health Trusts (DoH, 2009). The responsibility for implementing the National Dementia strategy was allocated to the devolved administrations of Primary Care Trusts (PCT's) across England, who largely set their own policies for dementia care (Powell and Baker, 2019), with clinical guidance being determined by the joint National Institute for Health and Clinical Excellence (NICE) and Social Care Institute for Excellence (SCIE). An additional £150 million in funding was provided over a two-year period to PCT’s to establish local frameworks for dementia care delivery (Cook et al., 2019).

Contextually, these devolution measures have seen the passing of power from national to local bodies through a succession of policy initiatives designed to increase the level of local autonomy in health (such as the introduction of Foundation Trusts and Clinical Commissioning Groups [CCGs]). CCGs were given the responsibility for the planning and commissioning of health care services for local areas. Alongside this, the development of integrated care saw parts of the NHS and health and social care sector being brought together to enable the NHS, local authorities and other local partners to prioritise local needs and achieve more joined-up working and streamlined service provision. The impact of this decentralisation approach allowed the potential for local authorities to respond more effectively to local need and engage local people to influence the local decision-making. However, it also created the possibility of inequalities developing between regions (Stubbs, 2015) and a fragmentation of services (Andre and Garcia, 2014). In terms of dementia care, the latter two consequences can be observed across England (Frost et al., 2020).

2.2.3 The digital divide

Technological advancements have presented society with rapid opportunities for improvements across many spectrums, most notably in the arena of healthcare, and specifically to the ageing population (European Union, 2010; Schulz et al., 2015). However, such developments also bring challenges, and disparities, by way of inequalities in being able to use and access digital health provision, computer literacy and ethical dilemmas (Borg et al., 2015; WHO, 2016). A digital divide occurs when there exists a gap between those able to benefit from information and communication technologies (ICT) and those who are not. The divide is not solely related to simple access, but rather the psychological and emotional impacts that result from a lack of ICT access and use (Ball et al., 2017). A study by Ball et al (2017) investigates the experiences and social ramifications of the digital divide among older adults, considering the 4 access gaps as proposed by Van Dijk and Hacker (2003). Access gaps differ in nature and can be (1) ‘Mental’ access gaps; related to the emotional and psychological gaps caused by the Digital Divide; (2) ‘Material’ access gaps; concerning a simple lack of access to ICT; (3) ‘Digital skills’ access gaps; referring to how levels of experience with ICTs can result in the development of different skills; and finally, (4) ‘usage gaps’ detailing how individuals with different ICT experiences develop different usage patterns as a result (Ball et al., 2017).

In terms of demographics, older adults are the most digitally divided group (Ball et al., 2017) and a societal digital divide only serves to increase the likelihood of inequalities in ageing. Social and economic inequalities in relation to income, social status, geographic location, ability and age can all play a role in factors ranging from the quality of care an individual receives to their life expectancy (Borg et al., 2015). In addition to this, the implications of digital exclusion and digital inequalities for older adults can be serious, leading to restricted access to resources, a reduction in social ties and support as well as loneliness, depression and a decline in general health (Francis et al., 2019; Ball et al., 2017; Delello and McWhorter, 2016). More must be done to help older adults overcome the digital divide (Francis et al., 2019). Whilst it is acknowledged that due to the constant evolving nature of technology, a digital divide in some form may always exist, an increase in support and research may narrow the gap (Francis et al., 2019). Access to technology, for older people, can also be caused by stereotyping and making assumptions regarding older people’s engagement with technology (Mannheim et al., 2019).

2.2.4 Technology adoption

Technology adoption is a term used to define the acceptance, integration, diffusion and use of technology in society. Theories of adoption and diffusion trace back to the work of Everett Rogers, who in 1962 published his highly influential book ‘The Diffusion of Innovations’ which put forward the process by which innovations infiltrate and spread through society. Rogers (1962) illustrated this process as a bell curve, as seen in figure 5 below. This bell curve segregates consumers based on their increasing sensitivity to risk and the speed at which they adopt emerging products. Consumers fall into one of 5 categories: innovators, early adopters, early majority, late majority or laggards (Rogers, 1962; Beal and Bohlen, 1957; Meade and Rabelo, 2004). The x-axis on the bell curve represents the percentage of the population who make up each category. Rogers' (1962) work has become the framework for other theories of adoption and diffusion and has been adapted and extended for use in specific areas of interest (Straub, 2009).

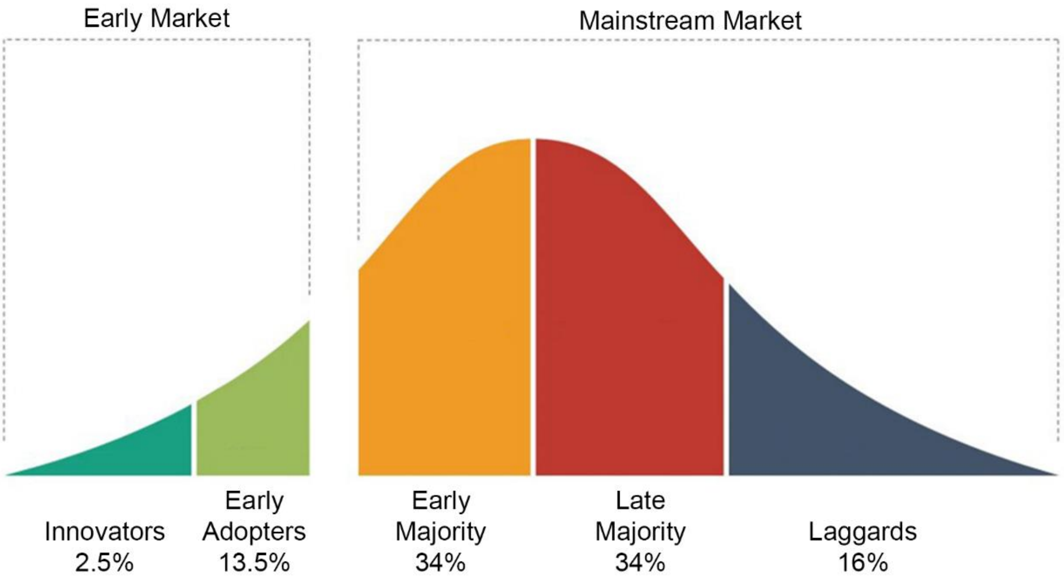
Rogers (2003) discussed that the timing of a person's decision to adopt technology (what he describes as their innovativeness) can be determined by how a set of product features (relative advantage, compatibility, complexity, trialability and observability) are perceived. These characteristics are defined by Rogers (2003) as the following:

- Relative advantage is *“the degree to which an innovation is perceived as being better than the idea it supersedes”* (Rogers, 2003: p.205)
- Compatibility is *“the degree to which an innovation is perceived as consistent with the existing values, past experiences, and needs of potential adopters”* (Rogers, 2003: p.213)
- Complexity is *“the degree to which an innovation is perceived as relatively difficult to understand and use”* (Rogers, 2003: p.225)
- Trialability is *“the degree to which an innovation may be experimented with on a limited basis”* (Rogers, 2003: p.226)
- Observability is *“the degree to which the results of an innovation are visible to others”* (Rogers, 2003: p.226)

Other studies (Frennert et al., 2013; Cho et al., 2008; Brooks et al., 2012) within the field of telehealth have used Rogers' (1962; 2003) theory of the diffusion of innovations, and the determinants described above to understand how telehealth initiatives are adopted (or not).

The technology adoption life cycle is an important tool for recognising the different needs, product requirements and reactions to new innovations that consumers of each category have (Meade and Rabelo, 2004). Whilst it is wrong to assume that older adult populations will automatically be defined as either part of the late majority or laggards (see Figure 5), studies show that older adults are more likely to be sceptical about technology in general, and this uncertainty forms a barrier to interacting with and adopting new technology (Hunsaker and Hargittai, 2018; Moore and Hancock, 2020; Vaportzis, et al., 2017; Berkowsky et al., 2017). Much of this scepticism is due to their perceived deficiencies in digital skills, some of which is caused by the digital divide as well as a lack of self-efficacy in their technical ability (Moore and Hancock, 2020). Issues are also caused as designers and developers of emerging technologies tend to avoid including these groups in processes, resulting in the limited involvement of older adults in the designing of technology (Padgett and Conceição-Runlee, 2000).

Figure 5: Rogers (1962) Bell Curve



Strategies to target consumers situated in the late majority bracket are different to those aimed at the early majority. For example, marketing strategies may be different, with late majority consumers being targeted with specific niche products, whilst those aimed at the early majority try to commodify the whole product for general-purpose use (Moore, 2001; Meade and Rabelo, 2004). Likewise, in terms of pricing strategies, a product is marketed differently depending on the category it is aimed at. The early majority see competition-based pricing with the aim to maximise market share, whilst the strategy for late majority consumers is to leverage how valuable a product might be to a consumer, to maximise profits. This is despite the fact that it is a clone of its low-cost alternative. Similarities can be drawn here between ‘off-the-shelf’ GPS devices and ‘dementia branded’ alternatives, where it can be seen, at times, that the only differences between such products relate to cost and marketing strategy. ‘Dementia branded’ devices are targeting a niche market, advertising its role as a “dementia tracker”, often exploiting a weak or vulnerable demographic, praying on a person’s concern for safety and their subsequent desire to retain independence. Safety is therefore used as a marketing feature for many ‘dementia branded’ products.

2.2.5 Assistive technology

Assistive technology (AT) is an umbrella term referring to a product or service that seeks to support and enhance independence (King’s Fund, 2001) with other, more generic definitions, referring to AT as *“any device or system that allows a person to accomplish a task they would otherwise be unable to do or increases the ease and safety with which the task can be performed*” (Cowan and Turner-Smith, 1999:325). Indeed, the concept of AT is closely aligned to the field of ‘gerontechnology’, a term coined in the 1990s (Östlund, 2004). ‘Gerontechnology’ represents one particular view of “successful aging”, whereby technologies can be used to compensate for human physical and cognitive decline with an aim to improving functioning and quality of life (Bronswijk et al., 2009).

Demand for AT is constantly growing, with the World Health Organisation (2018) recently reporting that more than one billion people now use one or more AT products, with this figure set to rise to two billion by 2030 as longevity increases around the world. Moreover, the global AT market is currently worth more than US$14 Billion and expected to surpass US$26 Billion by 2024 (McCue, 2017). Reflecting the demand for such products and services, the United Kingdom is keen to become a major contributor to the development of AT, with UK national policy driving forward the use of telecare and telehealth to promote safety, security and autonomous living (Brittain et al., 2010). Examples of such technologies range from clocks, calendars, and medication reminders to technological solutions for maintaining the safety of the individual, such as shut-off devices, automatic lights and fall sensors.

In recent years, newer forms of AT have emerged in the form of Intelligent Assistive Technologies (or IATs) (McMurray et al., 2017). IATs utilise artificial intelligence, giving them the ability to communicate information, and are considered ‘smart’ or ‘intelligent’ as they are able to “sense and respond to user needs and a changing environment” (Ienca et al., 2017; McMurray et al., 2017: p.2). The growth of IATs for individuals living with dementia and/or their care partners is exponential, with reviews into what IAT devices are available displaying a rise from 58 products in 2009 (Bharucha et al., 2009; Wangmo et al., 2019) to 539 products in a 2017 review (Ienca et al., 2017). As this growth in the number of IATs occurs, so does the variety and the choice that is available to the user, leading to technology that is not solely restricted to monitoring, but able to empower individuals (Ienca et al., 2017). IATs for dementia care have been developed to aid the user in several areas, from the completion of activities of daily living, to providing cognitive and emotional assistance (Wangmo et al., 2019). Many IATs focus on health and behavioural monitoring, tools to increase social interaction and engagement, facilitating remote communication or systems that provide an emergency alarm or mobility aids (Wangmo et al., 2019). Such technologies are able to promote the autonomous and successful completion of an array of daily activities as well as facilitating entertainment, engagement, and communication (Ienca et al., 2017).

As advancements in the arena of IATs continue, studies (Lindqvist et al., 2013; Williams et al., 2013; Czaja et al., 2013) highlight that benefits are primarily aimed at alleviating care partner burden as well as reducing the high costs associated with caring for an individual living with dementia (Wangmo et al., 2019; Ienca et al., 2017). Such technologies can also enable individuals living with dementia to remain at home as opposed to moving to alternative living arrangements within institutional care, perhaps prematurely (Dunk et al., 2010; Bartlett and Brannelly, 2019).

Individuals living with dementia often express a willingness and desire to be involved with studies seeking to explore new and emerging ideas within the field (Meiland et al., 2017). However, it is reported that only 40% of the IATs currently available are designed using a user-centred approach (Wangmo et al., 2019). Such user participation is a crucial factor in achieving a final product that is fit for use and central to technological acceptance from the intended user group. Holbø et al (2013) highlights the need for all ATs and IATs to accommodate the daily routines of a person living with dementia, an element that will go a long way in determining the acceptance, suitability as well as the efficacy of the technology.

More critical views within dementia studies may point to examples of ATs and IATs as merely offering a quick fix to certain problems without addressing issues directly (Hughes and Louw, 2002; Cahill, 2003; Alzheimer's Society, 2020e). The Alzheimer's Society (2020e) state AT should not be used as a replacement for human interaction and care but rather seen as a means of enhancing a person's quality of life. Cahill (2003: p.282) argues for a shift away from "quick fix practical solutions" such as GPS, towards understanding meanings behind behaviours and adopting person-centred approaches to solutions.

In the realm of healthcare, particularly concerning the use of AT and IAT, problems brought about through technological advancements are profuse, ranging from moral and ethical concerns to questions surrounding dependency and equality. The World Health Organisation (2017: p.11) have examined the growing need to develop '*robust, affordable but high-quality assistive products for which there is a much greater need'* to address the assistive technology divide in which the majority of the world is not benefiting from the new technologies that are available.

Furthermore, studies into the accessibility and availability of AT in developing countries (Borg et al., 2009; Rohwerder, 2018), and indeed in the developed world (de Witte et al., 2018), have highlighted the existence of the issues faced within society, with a lack of access to AT resulting in people experiencing exclusion, poverty, and increasing their support needs from their families and society (WHO, 2017; Marino et al., 2015; Rohwerder, 2018). The WHO (2018) reported that, worldwide, only 1 in 10 people have access to potentially vital assistive technology. Whilst there is focus on increasing accessibility to AT in the least economically developed countries, similar issues are found in high-income countries with this largely due to high costs of acquiring AT in addition to a lack of awareness of what is available, trained personnel, policy, and financing. McCabe et al (2021) reported that older people may be financially restricted when it comes to purchasing assistive technological devices, citing the cost of equipment and, how, due to the continual development of technology, devices quickly go out-of-date and require constant upgrading. McCabe et al (2021) also considered the associated costs with technology, in particular the cost of internet service provision that not everyone can afford. These points coincide with this literature reviews earlier focus on the digital divide, suggesting that the accessibility of AT and IATs may contribute to access gaps and may indeed exacerbate socio-economic inequalities (Ienca et al., 2017). To prevent a digital divide among individuals living with dementia who can afford such ATs or IATs and those who cannot, steps must be taken to promote low-cost and open-sourced technologies (Wangmo et al., 2019; Ienca et al., 2017).

2.2.6 GPS as a form of AT

As the development of assistive technologies continues, those responsible for the design and creation of such products or services are continually monitoring new and emerging technology in an attempt to see how they could be harnessed to support people with disabilities or the older population. The past decade has seen a rise in the use of Global Positioning System (GPS) technology within AT arenas. Examples include aiding those visually impaired to navigating more independently (Hersh and Johnson, 2010), helping individuals living with chronic disease by monitoring outdoor activity and providing activity and location-based data (Zheng et al., 2010), assisting those living with neurodevelopment disorders (Lancionia, 2018) and, perhaps more prominently, for dementia care.

2.3 GPS and dementia

The use of GPS devices, as a form of assistive technology, in the area of dementia care is not a new phenomenon, with GPS technology being used to support individuals living with dementia since the 1990s (McCabe and Innes, 2013). As the use of GPS has become more commonplace in society generally, Topfer et al (2016) notes that GPS technology is being more frequently used to facilitate autonomy and increase independence. Independence is promoted through tracking and monitoring, whereby GPS enables a care partner, or indeed the individual themselves, to view their location on demand (White and Montgomery, 2012). GPS tracking devices can be used in the form of a wearable device, perhaps as a wristwatch, carried on the person or even fitted into items of clothing, such as shoes (Wu et al., 2016; Yang and Kels, 2016; Auti and Hulle, 2015).

The main objective of GPS assistive technology in dementia care is being able to support people to live independently, for as long as possible, in the place of their choosing (Bartlett et al., 2019). However, it could be argued that GPS tracking devices could be used to enable surveillance (Plastow, 2006), acting as a method to increase intrusion on autonomy and privacy (Niemeijer et al., 2015). Niemeijer et al (2015) found that surveillance technologies such as GPS can leave an individual feeling like that are constantly being watched, leading to mixed feelings regarding its use. Issues surrounding privacy and autonomy as well as additional criticisms related to the cost and the industry formed around GPS technology within dementia care will be discussed later in this thesis.

GPS technology has the potential to enable an individual to participate more fully in society, without restricting them to the confines of their own home and could enable them to retain features that have been present in their lives up to the point of diagnosis (Bartlett and Brannelly, 2019). GPS technology helps to challenge misconceptions regarding dementia, including the belief that such individuals cannot continue to safely walk independently and the idea that those living with dementia move aimlessly or ‘wander’ with the term ‘wandering’ often viewed as misplaced by those in the field of dementia studies as well as the individuals living with dementia themselves (Alzheimer’s Society, 2019b). This term has been described as “deceptively simple” (Algase et al., 2007: p.686), with authors (Featherstone and Northcott, 2020: p.138) noting how it was rarely considered that a person living with dementia could be walking somewhere, instead, an assumption was made that these actions are purposeless ‘wandering’ and “inevitable features of a dementia diagnosis”. Studies have shown (McCabe and Innes, 2013; Bartlett and Brannelly, 2019; White-Bantry et al., 2010) that through the use of GPS technology, care partners, care professionals, researchers and the individual living with dementia can track their movements and actions and continue to walk unaided where it is safe to do so, completing activities of daily living.

The systematic review, in the second part of this literature review, describes the various uses of GPS technology within dementia care, ranging from how it can be used to support safe walking, to the concept of Geo-fencing, all of which are now proving to be vital devices in bids to keep individuals living with dementia as independent as possible for as long as possible.

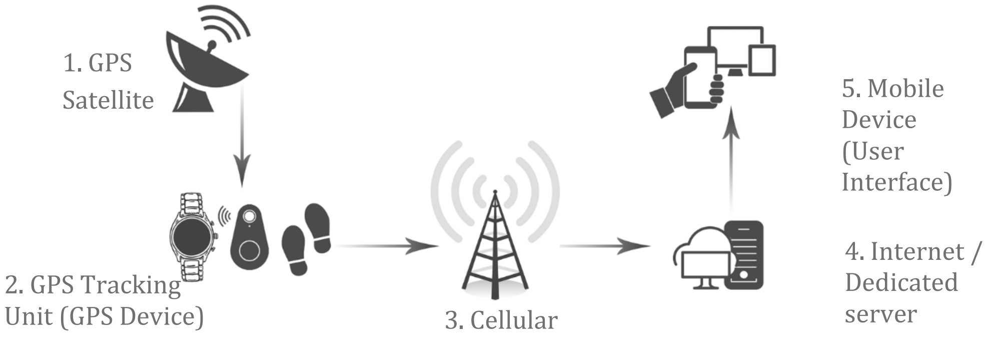
Whilst GPS tracking is not a novel concept within the field of dementia (McCabe and Innes, 2013; Bartlett and Brannelly, 2019; White-Bantry et al., 2010), it must be stressed that the literature to date has stopped short on addressing certain concerns and challenges. A concern that is yet to be raised or addressed within the body of literature is surrounding the cost of GPS products and the industry that has formed around GPS within dementia care. The gaps in the literature, as well as criticisms and limitations of the technology will be further discussed later in this section.

2.3.1 How GPS technology works

In terms of the technology itself, GPS is a network of satellites orbiting the Earth, broadcasting radio signals that provide geolocation and time information to any GPS receiver. Developed in the 1990s by the United States and managed by the United States Air Force, GPS services are free of charge and available for peaceful civil, commercial, and scientific uses worldwide (US Department of Defence, 2008; Ananda et al., 1990). In recent years, as technology advances, the hardware required to receive such signals have become cheaper, more accessible and increasingly more accurate, on average the location of a GPS Tracking Unit can be pinpointed to within 4.9m (gps.gov, 2017) with further plans to boost accuracy planned. Recent reports have claimed the next generation of mass-market GPS technology will boost this accuracy to around 30cm (Moore, 2017).

Figure 4 illustrates how GPS technology works. A group of 4 of the 24 GPS satellites positioned in orbit transmit precise signals enabling GPS receivers to calculate accurate location, speed, and time information (gps.gov, 2017). Such information can then be passed on via a cellular network and the internet to a mobile device which displays such information to the user (gps.gov, 2017). Within dementia care, the user interface is held by the care partner, however, a secondary mobile device can also be carried by the individual themselves.

Figure 6: Overview of GPS technology



2.3.2 The cost of GPS

The last decade has seen GPS technology become more affordable and reliable as accuracy and precision has increased, with GPS capabilities becoming built into most smartphones, smartwatches, tablet, Personal Computers and other handheld ‘off-the-shelf’ devices. The increasing availability of inexpensive GPS tracking units could enable individuals to purchase AT for use within dementia care even when the product isn’t solely marketed for such use.

The cost of the devices raises potential concerns, especially given the cost for similar GPS technology marketed for an alternative use, such as fitness, children or indeed pet tracking devices. First, GPS itself is a service that is freely available and as the price of the hardware, and software, plateaus at a very low cost, the price of devices intended for use by individuals living with dementia should justly fall. However, this review of the evidence to date suggests there is no sign of such events occurring. Second, as a higher accuracy becomes almost unachievable, the specification of devices may struggle to be improved upon, with research to date suggesting that more economical ‘off-the-shelf’ versions of GPS devices have similar, if not identical, product specifications. A GPS enabled smartwatch, for use in health and fitness can be procured for as little as £30 (Huawei, 2019), yet, alternately, a similar smartwatch, with comparable or indeed reduced specifications but carrying the dementia label can retail from £150 to £400 (TechSilver, 2019) with an additional monthly fee added. The pricing strategy for these devices is arguably a method for exploiting a user group, where tracking units that have been proven to help facilitate prolonged independence for an individual living with a condition, within the familiar environment of their own home, are sold for what could be considered an unjustifiable cost merely due to the ‘dementia branding’ written on the box.

Meiland et al (2017) observed that studies to date have not considered the cost-effectiveness of assistive and health care technologies in dementia, creating a gap in knowledge, also previously noted by Bowes et al (2013). Cost-effectiveness, in terms of GPS technology within the dementia field, may also boil down to its duration of usefulness. A publication by Topfer et al (2016) regarding the use of GPS locator devices for people living with dementia concluded that usefulness must be considered when developing and indeed purchasing GPS devices, noting that due to the progressive nature of dementia, usefulness can be dependent upon where an individual’s is within their dementia journey. Topfer et al (2016) found no evidence for the usefulness of technological interventions and devices for individuals living with, what the author describes as, ‘advanced dementia’. Where the subject of cost is raised, studies focused on how the use of GPS technology reduces the time required searching for missing individuals living with dementia (Milne et al., 2014; Nauta et al., 2013) as well as the number of personnel required to locate individuals (Topfer et al., 2016).

As it stands, only 1 in 10 people have access to potentially beneficial assistive technology (WHO, 2018), with accessibility often (Bennett et al., 2017; Rohwerder, 2018) cited as an unmet requirement for most assistive technological products. If studies prove GPS technology can improve the quality of life of individuals living with the condition, the cost and availability of such devices must be further scrutinised as moral questions arise from enabling some individuals who have the means of procuring such technology where others cannot.

2.3.3 Involving users in the design and evaluation of GPS devices

Barriers exist preventing individuals from accessing potentially beneficial technology. The most common barriers facing individuals relate to cost (Berry, 2011; McCabe et al., 2021), inappropriate design (Charness and Boot, 2009), user experience (Alvseike and Brønnick, 2012), learning (Fischer et al., 2020), awareness (Boot et al., 2018) and self-efficacy (Alvseike & Brønnick, 2012; Megges et al., 2017). To overcome many of these barriers, greater user involvement is required during the design and creation phases for products and services. User involvement is already an established practice in the design and testing processes for technological devices across the spectrum. Whilst involvement in research is increasing for people living with dementia, the same cannot be said with regards to participation from this user group in the design of this technology. It has been found that individuals living with dementia are often excluded from the design and evaluation phases of vital technology that can have a major impact on their lives (Gurley and Norcio, 2009). This review has already noted the need for user involvement in terms of fulfilling usability requirements and Liu et al (2017) discusses how, due to practical and ethical challenges, it is often difficult to obtain the opinions of individuals living with cognitive impairment. Therefore, the level of user involvement is often given by proxy from the perspective of the care partner (Liu et al., 2017; Miguel Cruz et al., 2021).

2.3.4 Alternative to GPS tracking systems

Whilst GPS technology is the main focus of this thesis, it must be noted that alternative technologies are also available to provide a similar service for use within dementia care. Bluetooth Low Energy (BLE) is one such location-based tracking service explored by Lin et al (2015) to determine its suitability in providing a similar role in caring for individuals living with dementia. A BLE tag is a small, inexpensive, waterproof device fitted with a battery that can be used for over a year, providing benefits not found in the evaluation of GPS devices, such as the ability for the unit to be worn all the time (Lin et al., 2015; Palumbo et al., 2015). This technology is limited, arguably more confusing and thus harder to use for care partners, BLE requires additional help when attempting to monitor the location of an individual wearing a BLE tag, as it is a short-range device, it is restricted by Bluetooth range of approximately 61m depending on the class of Bluetooth (Park et al., 2016). Additionally, BLE lacks the capability to track in real-time and is heavily dependent on the strength of the Bluetooth signal between the tracker and device. A user would be required to wait until positioning coordinates are refreshed and hope the signal strength is sufficient. Whilst the accuracy of a BLE device may be sufficient when an individual is indoors, one study (Kolakowski et al., 2020) evaluating the use of BLE for older adults living in the community found that increased accuracy outdoors is needed. The author additionally cited the environment in which the system is installed as having a significant impact on the accuracy and reliability of the positioning data, with the layout, building materials and items of furniture, all impacting the signal levels and delay (Kolakowski et al., 2020).

2.3.5 The design of GPS devices

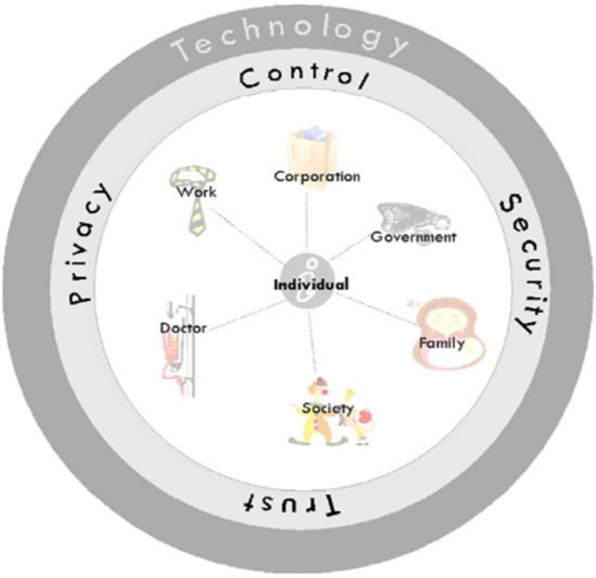
The wearability of forms of AT is a major factor to consider when evaluating the usefulness and acceptance of devices intended for use by individuals living with dementia (Mahoney and Mahoney, 2010). The variable of wearability may include the comfort of such devices as well as the aesthetics and design of tracking units. Williams et al (2011) states how, in practice, GPS tracking devices, those worn on the wrist, become an item of jewellery to the individual and they will want the tracking unit to suit their aesthetic and blend in with their clothing or colour preferences. Williamson et al (2017) discusses the prevention of technology that appears ‘childish’ or may suggest that the wearer has a disability. This point coincides with the idea of reducing the stigma individuals living with dementia face. GPS devices should be made as discrete as possible (Yang and Kels, 2017) and designed with the individual at the forefront of the process. McCabe and Innes (2013) discuss participants wanting a discrete device that avoids making an individual living with dementia vulnerable to stigma and prejudice.

Wearability will also consider how easily a device can be removed, with some tracking bracelets designed to only allow removal using a specialised tool (Williams et al., 2011). Respondents to a 2009 study by Landau et al into the perspectives of GPS tracking technology from family and professional care partners were in favour of using a device that could not be easily removed, to lower the risk of accidental removal.

2.3.6 Ethical considerations

The rapid adoption of GPS technologies within society has led to an influx of ethical concerns being raised (Mcnamee, 2005; Bantry-White and Montgomery, 2014). Certainly, the tension between GPS technology and healthcare is often viewed as a ‘double-edged sword’, due to the prominent value in its uses and potential solutions that it can provide, but also the ethical concerns accompanying it (Apte et al., 2019). When considering the use of GPS technology in the field of healthcare, there is a greater level of scrutiny than in other areas, which is largely due to the vulnerability of its potential user group (Fuller et al., 2017). The navigational side of using GPS devices itself poses no direct ethical threats, however, there is a serious concern surrounding the use of such technology as a means to track, monitor and, some would argue, control the population (Dobson and Fisher, 2005; Michael et al., 2008). Ethical concerns surrounding GPS technology often break down into 4 recurring themes, as seen in figure 7: privacy, control, trust, and security (Michael et al., 2008). This section will discuss these themes and the differing ethical aspects raised, as well as exploring how such risks could potentially be mitigated.

Figure 7: Socio-ethical framework of location-based services. Michael et al (2008)



Privacy

Privacy is defined as the “right or entitlement to solitude, autonomy and individuality such that with it we are able to go where we please … and live the kind of life we want” (Glasser et al., 2007:103) and tends to be the first point on the agenda for those arguing against the use of GPS tracking technology. As such, the ethical implications of using GPS technology have come to dominate relevant literature, appearing in studies ranging from tracking children (Gelman et al., 2018) to cars and vehicles (Li et al., 2018) and especially presented in literature surrounding the presence of GPS in the healthcare setting (Apte et al., 2019; Fuller et al., 2017).

Our intrinsic right to privacy is potentially threatened due to the way information is collected, retained, used, and disclosed by GPS technologies (Michael et al., 2008), thus suggesting this is the reason that privacy is the most important and challenging ethical issue faced by such technologies. Some individuals living with dementia have stated the continuous monitoring of their movements, even where consent is initially given, has led them to feel constantly “watched” (Dobson and Fisher, 2005; Niemeijer et al., 2015). Whilst on the opposite side of the ethical argument, individuals have felt that increased monitoring and surveillance of their movements has enabled them to lead a much more independent life, with greater freedom (Øderud et al., 2015).

In an attempt to counteract the ethical concerns, care partners may attempt to self-minimise the tensions between privacy and awareness. In a study by Wan et al (2014), a care partner describes how GPS can provide her with added reassurance, however she acknowledged the need to appropriate the system, to preserve privacy for her husband. By reducing the frequency of position reports, refusing to use geo-fencing functions and limiting the amount she used the system, the care partner was afforded peace of mind that her husband was safe, whilst feeling that she wasn’t being too intrusive (Wan et al., 2014).

Control

Control is a socio-ethical theme that can be viewed from differing aspects. Perusco and Michael (2007: p.11) explored the presence of control, within the use of location-based services (such as GPS), in terms of “control over one’s own situation (Vulnerability), caring control of a loved one (Liberty), or forced control, such as over parolees (Association, Policing, and Duplicity)”, citing care purposes as an area where control can be exhibited. Such examples of utilising GPS technologies to exert control coincide with the concept of ‘Geoslavery’, a term used by Dobson and Fisher (2005: p.2) to depict ‘‘the practice in which one entity, coercively or surreptitiously monitors and exerts control over the physical location of another individual”. Certainly, it is asserted by Bantry-White and Montgomery (2014) that the issue of control is largely responsible for the negative perception many hold towards GPS tracking technology. The activity of tracking or tagging individuals already comes with negative connotations, the stigma of using GPS technology may not resonate from the technology itself, rather from the social constructions of the meaning of its use, in the aforementioned instances, such as, law enforcement (Bantry-White and Montgomery, 2014).

Trust

Trust is closely associated with terms such as autonomy, independence and freedom (Michael et al., 2008). When analysing the ethical considerations of GPS technology. Trust can be viewed from two perspectives, the first being the faith or confidence one has in another individual, and the second being the ability to place reliance on the technology itself. The development of accurate and reliable GPS technological devices has resulted in a transferal of trust from in an individual to trust in technology (Michael et al., 2008).

When considering the ethical stance in relation to trust, academics (Abbas et al., 2011; Michael et al., 2008; Sloan and Warner, 2015) have highlighted the impact GPS technology has had on relationships within society, from trust within the workplace to the relationship between a husband and wife, GPS tracking technology has been shown to have the ability to erode relationships, being described as a dehumanizing tactic (Sloan and Warner, 2015). Trust and reliance are delicate issues within dementia care and due to the nature of the condition, care partners cannot always rely on an individual living with dementia returning home. An unobtrusive means of obtaining valuable location knowledge on the individual in their care could be paramount if they wish to continue to allow an individual living with dementia the freedom and independence they need (Fetherstonhaugh et al., 2013).

From the care partner's perspective, they cannot rely on trust or faith to know that the person they feel a responsibility for is safe, with reassurance playing a massive part in the use and value of GPS technology. Whilst in everyday relationships constant monitoring of a person's location may be viewed as unhealthy, controlling or 'dehumanizing', in a dementia context, this can provide a care partner with a necessary respite from care whist still retaining assurance of the individual's whereabouts. A study by Landau et al (2009) found that family care partners showed high support for the use of GPS technology for their own peace of mind, with the ability to track the whereabouts of an individual under their care, in real time on demand, a major incentive for using such technology. Additionally, a study by Landau and Werner (2012) stated that among individuals living with dementia, those earlier in their dementia journey often support GPS devices for the sake of the care partner's peace of mind.

Autonomy

Autonomy is a challenging ethical issue when providing support for independent living, with a range of different meanings often related to characteristics of self-rule, self-determination, freedom of will, dignity, integrity, individuality and independence (Smebye et al., 2015). A study by Fetherstonhaugh et al (2013) found that remaining involved in the decision-making process is critical for individuals living with dementia in terms of their self-determination and feelings of worth, with individuals themselves expressing a desire to remain central in decision making that affected them for as long as possible.

Conversely, potential threats to autonomy that surveillance technologies such as GPS pose, Zuboff (2019), proposes the emergence of 'surveillance capitalism' within society. Zuboff (2019: p.18) claims that this variant form of capitalism underpins the digital world and seeks to "nullify the elemental rights associated with individual autonomy". Zuboff (2019: p.26) notes that "surveillance capitalists asserted their right to invade at will, usurping individual decision rights in favour of unilateral surveillance and the self-authorized extraction of human experience for others' profit".

Whilst the issue of autonomy remains at the forefront of an ethical debate pertaining to the use of GPS within the field of dementia, Torke et al (2008) among many other commentators (Berger et al., 2008; Elliott et al., 2009), have suggested that instead of focusing on an individuals' autonomy, one should be guided by the best interests of the individual living with dementia. Elliott et al (2009) found that care partners and the families of individuals living with dementia made decisions based on, and in line with, the individuals' personal history and what was in the individuals' best interests over autonomy.

Security

Security, being protected and free from danger, is perhaps the most important concern surrounding the ethics of using GPS technology to track and monitor an individual's location. From GPS data leaks to GPS spoofing, whereby fake GPS satellites broadcast signals to deceive GPS receivers (Feng et al., 2017), this technology has the potential to keep us safer, but at the same can put us at greater risk. Users often face a dichotomy between privacy and security (Michael et al., 2008). However, from the family care partner perspective, the most important value will always be the protection of life and safety of the individual living with dementia, irrespective of concerns surrounding privacy, freedom or autonomy (Landau and Werner, 2012).

Some view the involvement of GPS tracking technology to be a positive intervention for individuals living with dementia; through the creation of more secure environments, added freedom and the maintenance of their autonomy (Essen, 2008). However, others ponder the ethical dilemmas regarding GPS and the system being used as an intrusive technology and a move towards a "big brother state" of monitoring and control (Plastow, 2006), especially when the individual is unable to consent to its involvement in their care. The use of surveillance technologies, such as GPS, has been described as "Janus-faced" (Lyon, 2001), due to the ability for surveillance to empower and constrain. Lyon (2001) describes the advantages of using surveillance in terms of the security element and convenience factors as well as the benefit of increased ease of communication, factors often cited in defence of GPS technology within healthcare (Essen, 2008; Wan et al., 2014).

2.3.7 Additional ethical concerns

The use of GPS technology to track an individual can pose additional ethical threats. GPS technology raises many questions surrounding the ability of people with dementia to consent to using a GPS device (McCabe and Innes, 2013). Dunk et al (2010) comments that, ideally, GPS technology should be introduced when people are still able to consent to its use. Both practical and ethical challenges in obtaining the opinions of individuals living with cognitive impairment has resulted in a lack of perspective within the surrounding literature from the individuals themselves (Liu et al., 2018); a situation that presents an ethical concern in its own right. Additionally, ethical issues can arise regarding the collection and storing of big data as well as ownership of data, all controversial matters in modern society (Nakashima, 2018).

Like any form of technology, whether that be a computer or a mobile phone, there is a constant danger of technological dependence, whereby individuals become reliant on a device, system or product. Within the healthcare setting, overreliance on technology can result in several issues being raised; from moral and ethical concerns to questions surrounding additional risk and safety. Whilst studies (Bantry-White and Montgomery, 2014; Øderud et al., 2015) into the use of GPS technology in dementia care discovered care partners reporting a reduction in anxiety which enabled them respite from continuous caregiving, it simultaneously raises the point regarding reduced human interaction for the individual living with dementia and in some situations the devices can become a replacement for human contact (Yang and Kels, 2017). Whilst one of the positive contributions of GPS technology to the lives of those living with dementia is often seen as increased freedom and independence, Topfer et al (2016) reports on how results can be counteractive, whereby the use of the monitoring device has led to a reduction in personal contact with care partners and can lead greater social isolation (Topfer et al., 2016). It is true for most ethical considerations that the ultimate challenge lies in “permitting legitimate use without allowing misuses”

(Apte et al., 2019: p.5). The use of GPS technology to track and monitor the location of another individual must adhere to the same test.

It is important to note, however, that whilst ethical issues surrounding the use of GPS are important to consider, some studies have found that when consulted directly, people living with dementia and care partners are less interested in the ethical considerations of using GPS. McCabe and Innes (2013) note that participants in their study were more interested in the potential benefits of GPS devices rather than the ethical issues. Similar points of view are discussed in Landau et al (2010) with participants in agreement that no ethical dilemmas arise when GPS can be used to find a person living with dementia who has become lost. For Olsson et al (2012) the safe and secure environment that technology can create overshadows any prospective ethical concerns.

This first part of this chapter has presented a broad review of the literature and has contextualised the use of GPS within dementia care. Sections 3.1 through to 3.3 have provided the reader with an overview of dementia before turning the attention to the socio-political drivers and the forces that influence decision making, in terms of policy and practice. The review then considers the issue of access and disparities that exists between those can access technology and those who cannot. This part of the literature review concludes by considering the role of GPS within dementia care, how it works, how it is designed and the ethical issues regarding its use.

Whilst undertaking this literature review, it became clear to me that independent living was a key part of the subject area, and a comprehensive literature review investigating how GPS is used to support independent living was required. Part two of this chapter will present the results of a second literature review, conducted systematically, that identifies, selects and synthesises all research published that answers the question ‘how is GPS used to support living independently for people with dementia?’. This was done to avoid duplicative research and to ensure that all relevant studies were examined.

The second part of this chapter presents findings from a systematic review of the literature, reporting upon the use of GPS devices to support independent living. In considering 27 papers identified for inclusion, the review will reflect upon the use of GPS devices to support ‘safer walking’ by people living with dementia and consider the role that additional GPS features such as geo-fencing can play in helping those diagnosed with dementia to live independently. The themes of control, autonomy and freedom are then outlined before a discussion of the drawbacks and limitations associated with the technology is conducted. This section concludes with a discussion about how GPS can support both the individuals living with dementia, and their care partners, to live independently, in the place of their choosing, for as long as possible.

2.4 Systematic review

This systematic review of the literature was conducted between January 2019 and June 2020 utilising the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines for review. PRISMA seeks to improve the reporting of systematic reviews and Meta-Analyses through the use of checklists and flow diagrams (see figure 6) (PRISMA, 2015). The PRISMA checklist was used to explore the characteristics of each included study focused on the rationale and purpose of the study, the participants involved, the technological intervention used as well as the ethical considerations and the outcome of the study.

2.4.1 Eligibility Criteria

For an article to be deemed eligible for inclusion it had to meet the following criteria:

1) Written in English.
2) Be concerned primarily with the use of GPS technology as a form of assistive technology, whilst the paper must have contained designated search terms within its title, keywords or abstract.
3) Published within 10 years of the commencement of this review.

2.4.2 Sources

The search strategy for this review utilised 9 repositories, listed in table 2 below, alongside the discipline:

Table 2: Search repositories

Database	**Discipline**
Medline (PubMed)	*Medical*
ProQuest	*Health and Medical*
ScienceDirect (Elsevier)	*Scientific, Technical, and Medical*
Taylor & Francis Online	*General (Multidisciplinary)*
OneFile (GALE)	*General (Multidisciplinary)*
Nursing & Allied Health Database	*Health and Medical*
JSTOR	*General (Multidisciplinary)*
CINAHL	*Medical*
ABI/INFORM	*Business*

In addition to the above, the reference section of included papers was reviewed to further increase the pool of related articles.

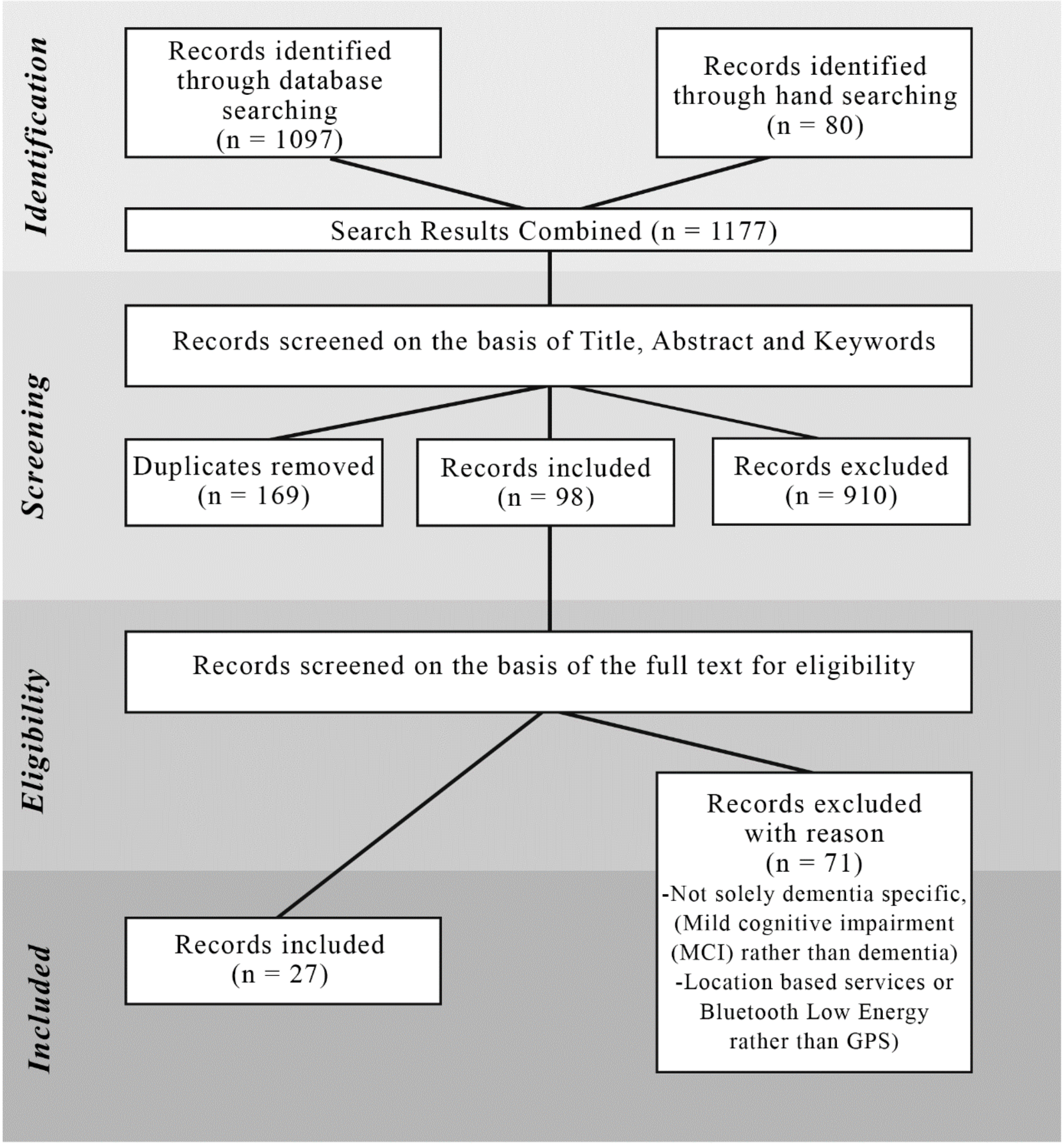
2.4.3 Search strategy

The key search terms used in this systematic review were as follows:

“Global Positioning System”, “Geolocation”, “Geo-fence” (OR “Geofence”) alongside “Dementia” OR “Alzheimer’s”. The abbreviation “GPS” in place of “Global Positioning System” was excluded from search strings due to the simultaneous occurrence of GPs (General Practitioners) among the results.

2.4.4 Study Selection

Figure 8: PRISMA flow diagram for systematic review



This systematic review of the literature yielded 1177 results across research databases and through hand searching. Following a process of reviewing articles based on title, abstract and keywords and through the removal of duplicates, this figure was reduced to 98. Full text screening then took place, based on the inclusion criteria for this search, a further 71 were removed. In total, 27 papers were included in this systematic review.

2.4.5 Characteristics of included studies

Four continents were represented by studies (27) included within this review (Europe, Asia, Oceania and North America); the majority were conducted within Europe (20). Most studies were conducted between 2012 and 2015 (15), with only 6 of the included studies produced in the last 4 years. When considering the inclusion of people living with dementia directly, only 11 studies offered an insight into their views and perspectives.

2.4.6 Appraisal

The quality of included studies was assessed based on the Critical Appraisal Skills Programme checklists (CASP UK, 2018). The checklists include items such as: study aims, population, method, results, and analysis. Each study was appraised based on the checklist criteria below, and details collated in tabular format (See tables 3 and 4).

Table 3: CASP Checklist for Qualitative Studies (CASP UK, 2018)

Are the aims clear?
Is the qualitative methodology appropriate?
Is the research design appropriate to address aims?
Is data collection appropriate?
Has an appropriate recruitment strategy been applied?
Has the relationship between researcher and participants been adequately considered?
Are ethical issues taken into consideration?
Was data analysis sufficiently rigorous?
Is there a clear statement of findings?
Is this valuable research?

Table 4: Included studies

Study (Year)	***Country***	***Sample Size***		***Methods***				***Study Setting***	***Use of Geo-fencing***	***Perspective***	***Brief outline of findings***
		Overall number of participants	***Participants living with dementia***	***Questionnaire***	***Observational***	***Interviews***	***Focus Group***				
Hettinga et al (2009)	Netherlands	4	4		X			Community		Individual living with dementia	This research considered the effectiveness of a GPS system alongside how participants responded to familiar voices or alarms whilst way finding.
Faucounau et al (2009)	France	2	0	X				Community		Family care partners	Found the need for involving individuals living with dementia and their care partners in the design process for technologies. Concluded that care partners have a positive attitude towards technologies that can be used to support independent living.
Bantry-White et al (2010);	UK	10	0			X		Community		Family care partners	Most carers preferred to use tracking as a back-up option, however, in low-risk situations GPS was used to preserve the independence of the individual living with dementia. Care partners

											reported an increase in feelings of reassurance and enhanced the sense of independence for both the care partner and individual living with dementia.
Dale (2010)	Norway	6	0			X		Community		Family Care Partners	Found a number of issues related to usability that adversely affected the usage of a GPS system within dementia care, namely, system stability, secure fastening, size, user interface issues and varying GPS-reception.
Landau et al (2010)	Israel	68	0				X	Community		Family and professional care partners	Reported that for family carers there is no ethical dilemma regarding the use of GPS within dementia care, with protection of life cited as key. This study found that safety outweighs autonomy and privacy, with professional practitioners reluctant to intervene and recommend this service.
Oswald et al (2010);	Germany	19	6		X			Community		Individuals living with dementia and Family Care Partners	Reported findings related to the impact GPS has on out-of-home mobility, considering the relationships between outdoor mobility, behaviour patterns and wellbeing, as well as examining the ethical implications.
Chen and Leung (2012)	Taiwan	37	0	X		X		Community		Family care partners	Utilised a range of ‘lost seeking devices’ including GPS devices in

											an attempt to explore the needs of users and what impacts user choice. Reported that choice depended on the educational level of the care partners.
Dahl and Holbø (2012)	Norway	9	0				X	Care Homes	X	Professional care partners	Findings highlighted professional care partner concerns about how GPS technology is used within dementia care and how such concerns often relate to design aspects or features.
Pot et al (2012);	Netherlands	66	33	X				Community		Individuals living with dementia and Family Care partners	When using GPS devices, care partners felt less worried, whilst reporting that half of participants living with dementia experienced more freedom & were less worried when outdoors. A quarter of participants living with dementia were outdoors more frequently and a fifth had less conflicts with their care partners.
Werner et al (2012)	UK	152	16			X		Community		Individuals living with dementia, Family care partners and individuals living with MCI	Highlighted the importance of maintaining out-of-home mobility following a diagnosis of dementia, reporting a link between cognitive status and time spent walking in relation to care partner burden.

Zwijsen et al (2012)	Netherlands	17	0			X		Care Homes		Professional care partners	Professional care partners reported the differing ways surveillance technology such as GPS can be used within dementia care, for general safety, for additional safety and for an increase in freedom for an individual living with dementia. This study also reported on potential limitations of the technology, from the inability to prevent falls, speed of assistance, reliability of product and privacy concerns.
McCabe and Innes (2013)	UK	20	12				X	Community		Individuals living with dementia and family care partners	Safe walking devices can be used to increase independence with family care partners understanding the benefits of reducing risk and addressing safety concerns.
Nauta et al., (2013)	Netherlands	4	2	X				Community		Individuals living with dementia and healthcare professionals	Reported on the effectiveness of GPS in returning an individual living with dementia home safely when lost through the use of a 'TalkMeHome' system. Such a system provides an individual living with dementia directions when lost, with these directions relayed to them by a care professional.
Bantry-White and Montgomery (2014)	UK	10	0			X		Community		Family and professional care partners	Reported on the involvement of the person living with dementia in decision-making processes, reporting on various ethical

											dilemmas that are encountered by care partners when introducing a GPS tracking system.
Mao et al (2014)	Taiwan	72	0	X				Community		Family Care partners	Considered the usefulness of GPS technology within dementia care. Found that high useful indicators of AT (including GPS devices) were devices that had an intuitive interface, were familiar, offered ease of use and simplified activities.
Milne et al (2014)	UK	20	8			X		Community	X	Family Care partners and Individuals living with dementia	Reported on how GPS can be used to facilitate safe walking, whilst considering the impact on care partner anxiety and the extent in which GPS has enabled people living with dementia to remain at home, in the community. Found that there is little evidence about the acceptability, effectiveness or cost-effectiveness of GPS within dementia care.
Wan et al (2014)	Germany	21	0			X		Care Homes		Family and Professional Care partners	Flexibility and the ability to adapt to differing user needs in each specific context are required when designing such technology for use within dementia care.
Gibson et al (2015)	UK	39	13			X		Community		Individuals living with dementia and	Reports upon the access and barriers to assistive technology such as GPS within dementia care.

										Family Care Partners	
Lin et al (2015)	China	10	0		X			-		-	Utilises a disorientation detection method that detects outliers in a person’s GPS trajectories in an attempt to promote safer walking.
Øderud et al (2015)	Norway	416	208	X		X	X	Community		Family care partners and individuals living with dementia	Found that GPS can provide increased safety for persons with dementia and their care partners. GPS technology can also help maintain autonomy, freedom and independence.
Olsson et al (2015)	Sweden	6	3		X			Community		Individuals living with dementia and family care partners	The system (passive positioning alarm and technical support) decreased the levels of worry for family care partners.
Lee (2017)	US	14	0			X		Community		Family care partners	Reports upon the usability challenges of wearable GPS technology within dementia care.
Liu et al (2017)	Canada	90	45	X				Community	X	Family Care partners	How care partners can be used to provide proxy responses for dementia clients in a study on the acceptance of GPS technology. Findings show technological acceptance was high and participants would likely continue to use GPS. Peace of mind and reduced anxiety was experienced by care partners.

Megges et al., (2017)	Germany	36	18		X			Community	X	Individuals living with dementia and Family Care partners	Found that use of the GPS device was infrequent among participants, however, participants expressed interest in purchasing the product. Found no significant change regarding factors such as technological willingness, caregiver burden, or perceived self-efficacy throughout the 4-week testing period.
Williamson et al (2017)	Australia	12	6	X				Community		Family care partners	Findings showed safety as being the main benefit identified by participants, with acceptability influenced by factors such as device features, ease of use, cost, appearance, the reliability of data, health condition of the person living with dementia and the care partners familiarity with technology.
Bartlett and Brannelly (2019)	UK	35	15			X	X	Community		Family care partners and Individuals living with dementia	How people living with dementia experience and deal with vulnerability when outdoors. Such feelings of vulnerability may attempt to be hidden by the person living with dementia. Findings illustrate the impact that solutions such as GPS has in terms of inclusion, empowerment and wellbeing.
Johannessen et al (2019)	Norway	10	0				X	Community		Homecare professionals	Although such technology can enhance safety, reliability is key,

											with the solution also being required to adapt it to the user's abilities, skills and resources. Not limited to people living with dementia nor GPS (using the term telecare instead).

2.5 The use of GPS to support independent living

This systematic review of the literature found that GPS can be used to support independence in numerous ways and from differing perspectives. The majority of studies (16 of the 27 included in this review) suggest the outcome of using GPS tracking for individuals living with dementia is an increase in perceived freedom with an emphasis on themes such as inclusion, independence and empowerment of individuals living with dementia (Øderud et al., 2015; Bartlett and Brannelly (2019); Milne et al (2014); Bantry-White and Montgomery (2014); Nauta et al., (2013); McCabe and Innes (2013); Bantry-White et al (2010); Oswald et al (2010); Pot et al (2012); Zwijsen et al (2012); Williamson et al (2017); Olsson et al (2015); Werner et al (2012); Gibson et al (2015); Faucounau et al (2009); Hettinga et al (2009)). When assessing the priorities of care partners, and in some cases the individual living with dementia, Bantry-White and Montgomery (2014) highlighted the view that physical safety will always take precedence, irrespective of the needs of independence, autonomy, freedom or identity.

2.5.1 Definitions of independence

To establish the value GPS technology can have in terms of facilitating independence, the definition of independence must be considered. For many, independence means doing things alone, avoiding reliance on others and maintaining a sense of control (Morgan et al., 2012; Shippee, 2012; Sixsmith, 1986). However, especially among older people, there is a recognition that help is at hand if needed, with their understanding of independence to be accepting help as a means of remaining independent, this latter definition is particularly pertinent within dementia care, as it must be understood that to seek help is not an admission of failure to be independent (Abbott and Fisk, 1997; Ball et al., 2004). As understanding of dementia as a condition improves, positive outlooks on the disease simultaneously rise; that people can live well with dementia. Additional definitions relate the concept of independence to subthemes such as the ability to socialise, a sense of belonging, Self-identity, not being a burden, a fear of institutionalisation and remaining living in one’s own home (Croucher et al., 2007). The last of these subthemes is what this systematic review seeks to explore. For many older persons, their home symbolizes their independence and provides them with a means of maintaining control and freedom over their movements, thoughts, and decisions (Abbott and Fisk, 1997; Mack et al., 1997;

Means, 1997; Parry et al., 2004; Sixsmith and Sixsmith, 2008; Krothe, 1997). GPS technology seeks to extend the length of time that an individual can continue living independently in their own home, however, the extent is still open to empirical enquiry.

2.5.2 Safe walking

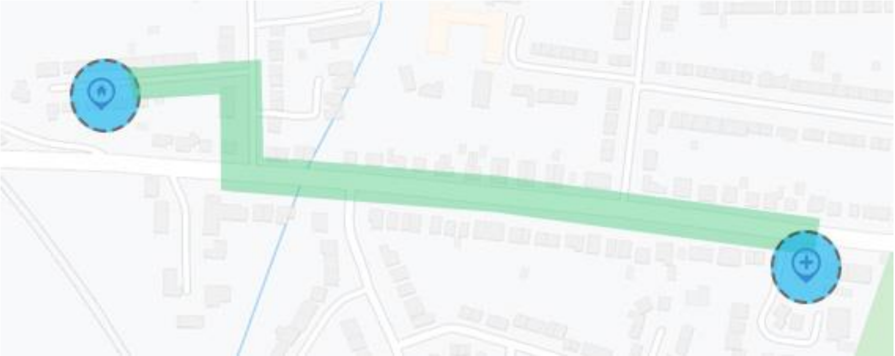
The term ‘safe walking’ has come to be used to refer to the ability for an individual to walk independently whilst being steady on their feet and has led to the development of technologies to assist in this activity. The phrase ‘safe walking’ (or safer walking) is often accredited to Marshall and Allen (2006) who found the term ‘wandering’ to be negative as it implied a sense of purposelessness. Marshall and Allen (2006) argued that walking by people living with dementia should be encouraged and not feared as it holds meaning to the person living with dementia and carries with it many benefits. Individuals living with dementia often express a need to stay active, with 'safe walking’ being able to offer a source of exercise, pleasure and independence (McCabe and Innes, 2013). ‘Safe walking,’ and retaining out-of-home mobility following a diagnosis of dementia, has been linked to enhancing a person's quality of life and can take place through alternative methods; the first, a device carried upon the person and tracked via a third-party (e.g. a care partner) and the second through use by the individual living with dementia, to aid them when navigating (Werner et al., 2012). Evidence suggests that GPS technology can be used to support ‘safe walking’ within dementia care (McCabe and Innes, 2013; Bartlett and Brannelly, 2019; White-Bantry et al., 2010; Milne et al., 2014; Doughty and Dunk, 2009; McKinstry and Sheikh, 2013). One study considered that such ‘safe walking’, using a GPS device, should only be carried out by "safe pedestrians"; with prerequisites for using devices being that the individual can take care and handle the traffic when walking independently (Øderud et al., 2015).

GPS technology can facilitate safe walking through the use of geo-fencing or predetermined routes the individual living with dementia can follow, safe in the knowledge that should they become lost or disorientated, they can be easily found, and thus promote independence. Such technology encourages a healthier lifestyle and mindset, with daily walks aiding strength and mobility, which in turn can promote and support independence. Nauta et al. (2013) harnessed the technology to support safe walking through voice commands, relayed to the individual living with dementia by a care professional. The data gathered by GPS devices can also be beneficial in facilitating ‘safe walking,’ with Lin et al. (2015) investigating the use of locational data to analyse movement patterns and behaviours by people living with dementia, to further our understanding of disorientation.

2.5.3 Geo-fencing capabilities

Geo-fencing can be defined as the act of installing a virtual boundary around a geographical location, this enables a user to be notified should the GPS tracker leave the set perimeter. The feature can be set-up in different ways, for example, 4 papers made use of the function to assign virtual ‘safe zones’, whereby an area is drawn by the user to indicate a boundary on a map, this could perhaps be the residence of the person living with dementia (Megges et al., 2017; Milne et al., 2014; Liu et al., 2017; Dahl and Holbø, 2012). In this example, a chosen user would be alerted should an individual leave the confines of their home. An alternative use of geo-fencing lies in assigning a ‘safe route’, this could perhaps be one that a person travels regularly, for instance, the path from their home to the local shop. Similarly, a chosen user would be alerted should the individual living with dementia stray from this chosen route.

Figure 9: Two ‘safe zones’ point A and point B, alongside a ‘safe route’ highlighted in green.



Geo-fencing capabilities enable the individual living with dementia to continue conducting daily tasks and activities unaccompanied. The use of geo-fencing within included studies differs, with one study utilising geo-fences for the knowledge of the individual living with dementia, whereby they themselves acquire their locational data and can continue performing activities safe in the knowledge that they are travelling along the correct route (Hettinga et al., 2009). This practice works similarly to Satellite

Navigation in cars, with the purpose being to keep an individual on track to complete their desired course (Hettinga et al., 2009). Other studies have opted for this data to be accessed solely by the care partner, programmed in a way so that the care partner is notified should the person within their remit of care leave the predefined area (Megges et al., 2017; Milne et al., 2014; Liu et al., 2017; Dahl and Holbo, 2012). Geo-fencing has also been linked to a reduction in care partner anxiety and worry, as well relieving the feelings of being a burden on the individual (Megges et al., 2017). Wan et al., (2014: p.3991) found that whilst geo-fencing (or 'digital fences') is, in theory, an extremely useful function, usage of this feature among family care partners was scarce, with those in institutional settings favouring this function. Professional care partners in the Wan et al. (2014) study proposed improving geo-fencing functionality to allow for structuring within a zone, the inner part being a green section (safe zone), the middle sector would be yellow (meaning a care partner is alerted, person has left the safe area) and the outer ring being red (meaning action is required immediately, the individual living with dementia is in danger).

Additionally, Geo-fences can be designed in a manner to only alert a care partner within a set time period, with alerts being relaxed during certain times, when a care partner would expect an individual living with dementia to be out of the house doing activities. It is worth noting that the Dahl and Holbø (2012) study concluded that, in practice, geo-fencing functionalities on the devices used in this research failed due to inaccurate positioning, with care partners frequently experiencing false alarms. Such inaccuracies caused great annoyance to care partners and gradually resulted in a loss of confidence in the technology. Inaccuracies and lack of reliability of geo-fencing systems was also reported by Megges et al., (2017). However, advancements in technology may have solved such errors experienced by previous participants, with issues such as indoor signal blockages potentially being resolved through the use of indoor positioning systems (IPS) (Dahl and Holbø, 2012; Ali et al., 2019).

2.5.4 Autonomy and Control

The literature reviewed placed great emphasis on the role of choice within independence. Independence, from a care stance, may often be viewed as being self-reliant and being able to conduct physical tasks alone (Hillcoat-Nalletamby, 2014). Alternatively, independence can be seen as having control over how help is provided, with an understanding and acceptance that support, in some circumstances, will always be required (Ball et al., 2004). This is where the concept of choice comes into play, with included studies offering alternative viewpoints on who is responsible for making the final decision regarding utilising GPS within care. Studies by Landau et al. (2010) and Bartlett and Brannelly (2019) found that the individual living with dementia should retain choice over whether or not to use a GPS device, whilst others report that control should always remain in the hands of the care partner (Bantry-White and Montgomery, 2014; Lee, 2017; Faucounau et al., 2009). Faucounau et al. (2009) found that, ultimately, an individual living with dementia will make decisions based on the wellbeing of their care partner, particularly when their care partner is a member of the family. The rationale behind the decisions for the care partner to assume control stemmed from the primacy of safety, personality, and relationship factors (Bantry-White and Montgomery, 2014).

When making a claim about how GPS can promote independence, many studies offer a comparison with alternative methods of care for individuals living with dementia (Bantry-White and Montgomery, 2014; Ali et al., 2019; Liu et al., 2017). Studies evaluating the use of GPS devices often draw comparisons between a GPS device or a method of physical restraint, such as locked doors, with constant care partner supervision listed as an additional method (Bantry-White and Montgomery, 2014; Zwijsen et al., 2012).

2.5.5 Independent living

GPS technology provides a care partner with the ability to track the geographic location of the person in their remit of care on demand, thus reducing the need for constant supervision or, for instance, side-by-side walking. The availability of GPS devices as a form of telecare enables ‘care at a distance’, giving people living with dementia the opportunity to remain independent in their own home, delaying long-term care (Øderud et al., 2015).

The success and limitations of GPS as a form of telecare with conflicting perspectives is interesting to consider. One argument directs that GPS telecare can promote independence and improve interaction through the facilitating of ‘safe walking’ and the ability to remain in the community (Lin et al., 2015). Contrastingly, the argument has been made that GPS technology has the potential to increase social isolation, particularly reducing the interaction between individuals living with dementia and care partners as well as social care professionals due to reductions in the necessity for visiting (Topfer et al., 2016). Øderud et al. (2015) refutes this stance, claiming that a reduction of personal contact was not experienced by care partners despite the intervention of GPS allowing them to know the person under their care was safe.

2.5.6 Peace of mind

The literature suggests that peace of mind is one of the overarching benefits gained through using GPS within dementia care (Øderud et al., 2015; Bartlett and Brannelly, 2019; Landau et al., 2010; Liu et al., 2017; Bantry-White and Montgomery, 2010; Pott et al., 2012). Authors have found that this state of freedom from worry and anxiety can be gained by both the care partner and the individual living with dementia (Øderud et al., 2015; Dale, 2010; Olsson et al., 2015).

2.5.7 Confidence from the perspective of the individual living with dementia

Research exploring the perspective of the individual living with dementia found that they reported feeling safer knowing they were being tracked (Liu et al., 2017; Dahl and Holbø, 2012; Johannessen et al., 2019). The individual living with dementia has reported that they experience a greater sense of confidence and reassurance that, should they become lost or disorientated, someone has knowledge of their geographical position (Bantry-White and Montgomery, 2014; Liu et al., 2017). This increase in confidence can enable those living with dementia to do ‘normal’ things or ‘activities of daily living’, with one study citing this increase in reassurance leading to individuals undertaking activities such as walking, shopping and gardening unaided (Bantry-White and Montgomery, 2014). Similarly, this theme is also present when care partners discuss their perspective on life, with care partners reporting how devices can bring aspects of normality back to their lives, they can get on with everyday tasks safe in the knowledge that their loved one is safe and free from harm (Werner et al., 2012).

2.5.8 Confidence from the perspective of the care partner

Due to the nature of GPS devices, benefits can only be gained when care partners make use of such products. Confidence, from the care partner side, plays a crucial role in the acceptance to adopt this technology**,** care partners must have confidence in permitting to the increase in independence such devices could afford the individual living with dementia. Bantry-White and Montgomery (2014) reported a third of care partners interviewed aspired to enhance independence through the use of GPS but due to the perceived risks, they felt unable to do so, citing it as being "too difficult". This difficulty comes when putting the technology into practice alongside their everyday lives, with care partners expressing concerns for placing their trust in unfamiliar technology given the severity of risks the person under their care could face.

Trust and accountability in the technology itself has been reported as vital obstacles that must be overcome if GPS technology is to succeed within dementia care (Dahl and Holbø, 2012). From the care partner stance, they must have absolute trust in the technology working correctly if they are to adopt this technology into their everyday lives and their programme of care. Studies have highlighted how this assurance is slow to be earned, with care partners often feeling hesitant or anxious towards the use of devices, building trust slowly, activity by activity (Liu et al., 2017; Olsson et al., 2015). Olsson et al (2015) found that independent outdoor activities increased for participants living with dementia in the later stages of the study as care partner trust in the system simultaneously increased. On the other hand, the study by Dahl and Holbø (2012: p.579) found that following the occurrence of device failures, participants began to question whether they understood the basic premise for using GPS technology to track individuals living with dementia.

It seems pertinent to note, however, that the timing of the introduction of GPS plays an important role in how GPS devices can support independence. Other research suggests that the progress of dementia symptoms has an impact on the successful use of GPS, for example, care partners and individuals living with dementia that had already lost confidence in walking and conducting activities independently felt the device had been too late in arriving (Milne et al., 2014; Pott et al., 2012).

2.5.9 Changing purpose of the device

In terms of how independence is gained, the benefits of devices may change over the course of an individual's dementia journey. What starts out as an intervention to be used as a backup strategy should a person become lost or disorientated, may change in nature to a 'safe walking' device and ultimately become a device for safety and security to enable the person to remain living in their own home (Bantry-White and Montgomery, 2010). Similar findings are reported in Miguel Cruz et al (2021), who discuss the stages of dementia and the different needs this technology is required to meet. Whilst the product lifespan (the duration of time between the product being sold, to when it is discarded) of GPS devices within dementia care is unknown, the differing uses have been widely documented by included studies. Lorenz (2017) reported upon concerns with mapping technology onto the dementia care pathway, this research found that early stages technologies are aimed at supporting people to live independently, with later stages aimed predominately at safety. However, it was suggested in Lorenz et al (2017) that technologies have a short period of usefulness due the progressive nature of dementia, with care partners at times being unwilling to engage with learning new technology as it may soon become redundant.

Further research is required to revisit previous participants to review how their needs changed and whether or not the devices adapted to such changing needs. One study by Øderud et al. (2015: p.8) did explore the differing reasons as to why participants stopped using the provided GPS device with "no longer able to perform outdoor activities" as the most common explanation given. An alternate reason for abandonment of the device was the transfer of a participant to a nursing home that did not facilitate independent outdoor activities (Øderud et al., 2015). Arguably, in both scenarios, a GPS device could remain a vital piece of technology, even if the role changed from a tool that increases freedom, towards a device solely used to locate a missing individual living with dementia.

2.6 Resource Implications

From a financial perspective, 2 studies included in this review considered the economic benefits that can be gained through the use of GPS (Liu et al., 2017; Milne et al., 2014). Such studies investigated the savings that can be made in relation to the cost of care as well as from a resource saving standpoint; in terms of reducing the costs related to support services should a person become lost (Liu et al., 2017; Milne et al., 2014). Additionally, respite from constant care was a theme found amongst included studies that consider the value of GPS from the perspective of the care partner. The theme of 'care partner burden' was reported in several studies, with the study by Liu et al. (2017), describing how the care partner and the individual living with dementia encouraged each other to use the GPS device to address aspects of care partner burden. 4 studies considered the impact that GPS technology could have with regards to mitigating care partner burden that is experienced when an individual living with dementia becomes disorientated when leaving their home (Bantry-White and Montgomery, 2014; Werner et al., 2012; Liu et al., 2017; Lee, 2017; Gibson et al., 2015).

2.7 Understanding user needs

Products or services that are designed around users and their needs are more likely to be used and result in more positive outcomes (UK Government, 2017). Within dementia care, there is no 'one size fits all' approach, with care partners requiring an intervention that can be tailored to their personal needs and preferences. In line with theories surrounding usability, four studies included in this review have identified the role that user acceptance can play in terms of usage and the value that GPS devices hold within dementia care (Megges et al., 2017; Morgan et al., 2012; Liu et al., 2017, Dale, 2010). Should a device go unused due to factors such as; the suitability of the product, the difficulty in learning how to use the device, expectations vs outcomes or indeed the reliability of the technology, any potential value that could be gained is lost.

The literature also considers how assistive technology needs to be adaptable and responsive to individual needs of the user. This was reported in several studies that evaluated the success of technology within dementia care, for Dahl and Holbo (2012), they recommended that GPS technology be flexible to suit these different needs. Similar findings were reported by McCabe and Innes (2013), which was one of the first studies to consult directly with people living with dementia regarding the use of GPS devices. Olsson et al (2013: p.8) reported that care dyads require a tailored 'service' for each user based on their needs, abilities, knowledge and skills. In the wider discourse surrounding assistive technology use for people living with dementia, Rosenberg et al (2012) found that flexibility is a prerequisite for technology to enable it to be integrated successfully into existing habits. McCabe et al (2021) discusses how a personalised approach to the use of technology within dementia care is necessary, that recognises each user may have different needs and wants.

2.7.1 The suitability of devices

Studies exploring user acceptance of GPS Technology have looked at the degree to which devices have suited the client's direct needs and are therefore considered appropriate to complete the task at hand (Megges et al., 2017; Morgan et al., 2012; Liu et al., 2017). Suitability could range from the accuracy of devices, to the format in which the technology is delivered, for example some users may find a device that is worn around the neck inappropriate and may prefer a wristwatch style product. Mao et al. (2015) suggests that a care partner plays a significant role in influencing what devices the person living with dementia uses, citing them as fundamental to the acceptability process. Care partners are able to provide vital insight into the difficulties of everyday lives, failure to consider the suitability of a device could lead to a higher rate of abandonment of the technology, or potential misuse of products (Mao et al., 2015).

2.7.2 The ease of learning how to use GPS

Learning is often considered one of the fundamental usability attributes, especially where older users are involved. Published work has found that the degree to which a care partner can operate a device will define its success in terms of adoption of a product (Liu et al., 2017; Chen and Leung, 2012). Lee (2017) reported that 71% of participants heavily relied on a step-by-step instruction manual for assistance, with this acting as a consistent tool for users who felt that the technology was not intuitive. Indeed, Mao et al. (2015) similarly stated that an intuitive design is central to a device's usefulness, with users being hesitant of technology that requires new learning. For others, however, the user-friendliness of a device is a secondary issue to concerns surrounding the safety and security of individuals living with dementia (Liu et al., 2017). The study by Liu et al. (2017) found that users (the care partners) had experienced that the devices were hard to use but persevered anyway. It is unknown why the users persevered, given the difficulties they faced in using the technology.

2.7.3 Reliability of the technology

As highlighted above with regard to false positive alarms, technical problems reduce the user's trust and confidence in the technology (Megges et al., 2017; Dahl and Holbø, 2012). In order to maximise user trust in the technology and allow for both individuals living with dementia and care partners alike to have the upmost confidence in using GPS alongside care, the risk of device failure must be mitigated as much as possible (Zwijsen et al., 2012). Research has shown that one such negative experience, in terms of device failure or glitches, can result in rejection of this technology as an intervention (Dahl and Holbø, 2012).

2.8 Drawbacks of the technology

Despite the plethora of benefits GPS technology can provide to dementia care, studies have also reported on the potential limitations found when using GPS devices. Bantry-White and Montgomery (2014) found one care partner considered the technology stigmatising, labelling such devices 'big brotherish' and 'emasculating'. Worries surrounding privacy and surveillance were shared in other studies with the term "socially undesirable" used in the Bantry-White and Montgomery (2014: p.224) study whilst evaluating potential privacy concerns that the technology is open to (Øderud et al., 2015; Bartlett and Brannelly, 2019; Mao et al., 2015; Zwijsen et al., 2012).

2.9 Summary of findings from systematic review

2.9.1 Findings

This review aimed to explore the effectiveness of GPS technology as a tool for supporting independence for people living with dementia. Findings from this systematic review demonstrate that GPS technology has value and worth in this area, with a range of evidence presented that shows how GPS can assist a person to remain independent, in a place of their choosing, following their diagnosis of dementia. This review reports on how this independence for people is achieved, by supporting 'safe walking' and using functionality such as geo-fencing and positioning reports, as well as how this technology can empower individuals living with dementia by facilitating greater autonomy, choice, and control over their lives, whilst simultaneously providing peace of mind to care partners. Findings also consider the potential barriers to supporting independent living, reviewing discussions made in the literature surrounding the role of confidence from both the perspective of the care partner and the individual living with dementia. Barriers were also examined in relation to the technology itself, from the standpoint of reliability and the necessity to understand and plan for a user's needs, as failure to consider requirements of this technology may lead to GPS technology being ineffective in its ability to support independent living.

2.9.2 Review limitations

Limitations to this review are acknowledged as being: Firstly, the search strategy of section 2.4.3 presents the search terms that were adopted for this review. Search strings were developed to contain both a technological component (the Global Positioning System technology) and a connection to dementia care and support. As stated in 2.4.3, the abbreviation "GPS" was excluded from search strings due to the simultaneous occurrence of GPs (General Practitioners) among the results. This issue only presented itself once searching commenced and did mean that many irrelevant papers were initially screened by title before excluding GPS as a viable search term. A concern is that papers may have been missed during searches that utilised the GPS abbreviation in their title or abstract. Variations on the technological component of the search strings were therefore not consistently integrated, alternative phrasing such as 'tracking technology', 'location-based service' or 'locator device' could have been used. Additionally, this review only considered records written in English, potentially missing key texts that explored the effectiveness of GPS technology in supporting independent living that have been published in another language.

2.9.3 Limitations of reviewed research

The studies reviewed varied greatly regarding characteristics, with the number of participants included ranging from just 2 care partners to over 240 participants, with that said, the vast number of studies conducted offered low representation of individuals living with dementia in the research, with under 40% of participants (in the papers reviewed) having a diagnosis of dementia. Studies rarely made note of the specifications of devices included in the research, making it difficult to draw comparisons between studies conducted over a timescale of around a decade, especially where features such as accuracy, functionality or reliability come into play. Additionally, studies failed to revisit participants to gauge how the technology has helped or assisted them following the conclusion of research. This has made it difficult to accurately assess the technological rate of abandonment and the usefulness over time of the technology as the individual continues upon their dementia journey.

Following the conclusion of the review of the literature, I felt it pertinent to provide the reader with a detailed description of person-centred care, its origins, and elements. This is discussed in section 2.10 which follows.

2.10 Person-centred care

This section seeks to bridge the results of the literature review and the next chapter which details the project's research design, to afford the reader an understanding of Person-centred care. The term 'person-centred care' has become the hallmark of good quality care and service provision for people living with dementia (Brooker, 2004; Downs, 2013; World Health Organization, 2012). A person-centred care approach emphasises that 'the Person Comes First' and has become central to UK government policy, featuring in the National Dementia Strategy (Department of Health, 2009; Downs, 2015). By putting the person first, person-centred care seeks to ensure that an individual is a seen as a valued human and social being throughout their dementia journey (Downs, 2015). The approach focuses on 4 key aspects of living with dementia: Personhood, their psychological needs, social psychology and the person's perspective (Downs, 2015; Kitwood, 1997). The origins of person-centred care stem from seminal work by Carl Rogers (1951) who established person-centred therapy inspired by Maslow's (1943) *hierarchy of needs*.

Maslow's (1943) hierarchy of needs is a five-stage model, depicting the psychological needs and growths of an individual in a hierarchical pyramid with needs categorised as: physiological, safety, love and belonging, esteem and self-actualization. The model observed that every individual had the capacity to move towards self-actualisation, although progress in meeting those needs could be thwarted by challenges such as loss of employment or divorce (Maslow 1943). These needs are described in the following ways:

1.**Physiological needs** were defined as the most important needs, necessary for basic survival, such as food, shelter, clothing, warmth.

2. **Safety needs** are seen as security, order, law, stability and living without fear.

3. **Love and belongingness needs** described as feelings of belongingness, such as friendship, trust, and acceptance.

4. **Esteem needs** are categorised as (i) esteem for oneself and (ii) respect from others.

5. **Self-actualization** needs are seen as an individual realizing their personal potential and self-fulfilment with life.

Figure 10: Maslow's hierarchy of needs (Maslow, 1943)

Rogers (1961) developed Maslow’s theory of human motivation to focus on individual’s subjective understanding of their own situation, this was seen as a marked departure from psychodynamic and behavioural approaches of the day. The pivotal focus of Rogers' (1961) theory is the notion of self and the way an individual perceives, believes and values oneself. Rogers (1995: p.102) stated:

> *“The only reality I can possibly know is the world as I perceive and experience it at this moment. The only reality you can possibly know is the world as you perceive and experience it at this moment.” (Rogers, 1995: p.102)*

Rogers (1961) brought a new approach to therapy by recalibrating the historical power balance between therapist and client, to seeing both parties as equals, with the therapist showing unconditional positive regard and empathetic understanding. A person-centred approach to care ensures that individuals are supported, facilitated, and enabled to communicate and share decisions about their own care within an environment of mutual respect (Rogers, 1961).

The term ‘person-centred’ was later adopted by Tom Kitwood (1997) who reconsidered dementia care based around the ‘5 fundamental psychological needs’, illustrated in the figure below.

Figure 11: An adaptation of Kitwood’s (1997) 5 Psychological needs

Kitwood’s (1997) model considers what a person living with dementia needs. Whilst everyone has these psychological needs, an individual living with dementia may be more vulnerable and less likely to be able to take action themselves to fulfil these needs. It is important to note that for a person to fulfil one of these needs may require the fulfilment of others, this is summed up by Kitwood saying “the distinctions are arbitrary; the boundaries are blurred” (Kitwood, 1997: p.81). Kitwood (1997: p.84) also describes the “virtuous circle” that can occur when one of these needs is fulfilled, with such fulfilment influencing other needs too. As for each of the 5 Psychological needs, Kitwood maintains that individuals living with dementia need comfort to “remain in one piece when they are in danger of falling apart” (Kitwood, 1997: p.82). A sense of attachment is required to overcome the ‘strange’ experiences they find themselves in, with attachment helping to create a connection and feelings of closeness with others. Inclusion is needed both in care and in life, in order to create a sense of belonging and acceptance, with Kitwood (1997) reporting on the decline and retreat that is experienced should this need not be met. Occupation is the need to be involved in a way that “draws on a person’s ability and powers”, to unlock a source of fulfilment and satisfaction (Kitwood, 1997: p.83). Finally, for Kitwood (1997: p.83) individuals living with dementia require the need for identity and a sense of continuity and “a story to present to others”. The fulfilment of the “whole cluster of needs” results in the enhancement of a person’s feeling of self-worth, of being valuable and valued (Kitwood, 1997: p.84).

In terms of a definition of person-centred care, whilst the meaning varies, Kitwood (1997) proposed that to be labelled person-centred, the care model must incorporate 4 basic elements:

1) **Valuing** people with dementia and those who care for them.

2) Treating people as **individuals.**

3) Looking at the world from the **perspective** of the person with dementia.

4) A positive **social environment** that the person living with dementia can experience relative wellbeing.

For Kitwood (1997), person-centred care is the sum of all 4 elements, with each element having equal precedence, each contributing to meet the needs of the individual.

Kitwood’s work was found to be influential in progressing the concepts of person-centred dementia care on both a national and international scale, however, scholars in the field have also highlighted limitations in Kitwood’s philosophy (Dewing, 2008). Dewing (2008: p.9) found his work to be problematic, citing issues related to rigour, the application into practice, as well as Kitwood’s overall personhood philosophy, leading to Kitwood’s ideas being labelled as “an unfinished body of work that is not refined”.

Academics in the field have attempted to build on Kitwood’s work, for example Bartlett and O’Connor (2007, 2010), who argue the notion of ‘social citizenship’. Bartlett and O'Connor (2007) suggested Kitwood's (1997) view on personhood was limited and excluded how the socio-political sphere impacts upon daily life for a person living with dementia. They argue the case for ‘social citizenship’ that builds upon Kitwood's (1997) principles of personhood to encompass the view that individuals are full members of the community with equal rights. By recognising this, it would *“ensure people with dementia were seen and treated as people with power, specifically people* *with the power to instigate and shape the research agenda"* (Bartlett and O'Connor, 2007: p.112). Bartlett and O'Connor (2007) discuss the historical roots of personhood and citizenship and the differences between the two lenses. The main contrast being related to power and the lack of power that is often given to some people within society. They also recognise the limitations of both lenses, with personhood being unable to explain principles of power, relations and citizenship thus being unable to fully recognise individuality (Bartlett and O'Connor, 2007). They propose that personhood and citizenship should be combined to create a "broader lens for dementia practice and research" (Bartlett and O'Connor, 2007: p.115). The following definition of social citizenship was offered by Bartlett and O'Connor (2010: p.37):

> *"a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level"*.

Writing at the same time as Kitwood, Steven Sabat (1992, 2001, 2002) along with fellow psychologist Rom Harré (1992), proposed a social constructionist theory of selfhood in people living with dementia. Sabat (1992, 2001, 2002) argued that selfhood can be analysed in three different forms: Self 1, Self 2, and Self 3. Self 1 is the self of personal identity. It is expressed verbally via personal pronouns ("I," "me," "mine," "my," "our") or visually through expressions. This form of self reflects each person's single point of view of the world; continuously forming the narrative of their life. For Sabat (2001), this form of self remains largely intact throughout a person's dementia journey.

Self 2 considers a person's physical, mental and emotional attributes and characteristics, both past and present, as well as their beliefs and desires about them (Sabat, 2001; Kelly, 2010). Sabat (2001) discussed how this form of self can be restricted and unrestricted. When restricted, perceptions about oneself are current and in the moment. When unrestricted, a person can consider how their attributes and characteristics are in the present, how they once were and how they may be in the future. Like Self 1, Sabat (2001) argues that this form of self can remain intact throughout a person’s dementia journey but can be lost through the way others view and treat a person living with dementia.

Self 3 is the ‘social persona’ and considers how a person presents themselves publicly to others or how they are presented by others. This form of self may change to reflect the social circumstances and situation a person is in. Self 3 is co-constructed and altered through interaction with others and is therefore more vulnerable to damage and loss than selves 1 and 2. “Malignant positioning” is one such way those selves 2 and 3 can be lost or damaged and results in people living with dementia feeling depersonalised and losing their sense of self-worth (Sabat, 2001). Sabat (2003) argues that when such malignant positioning occurs, a person living with dementia loses their social identity and rights, becoming a ‘patient’, and viewed by the rest of society as ‘less able’ and therefore inferior.

When relating person-centred care to the literature reviewed above, GPS, as a form of assistive technology, can promote person-centred care and could be used to help to facilitate the 5 Psychological needs described by Kitwood (1997). Using Kitwood’s model, and existing evidence in the literature, GPS can be used to promote inclusiveness, identity, comfort, occupation and attachment by allowing people to maintain their lifestyle, independence and importantly be able to remain in their own home. By considering the benefits of using GPS, it could be argued that the technology can also be used a tool to promote personhood and selfhood, through recognising a person’s social identity, rights and abilities and enabling them to fully participate in society. In response to Sabat’s (2001; 2003) theory of selfhood and malignant positioning, if used correctly, GPS could counteract instances of negative stereotyping and the views that people living with dementia are ‘less able’ following their diagnosis. In terms of a person’s social health, GPS can provide an individual living with dementia opportunities to stay connected to society and ensure that they have the chance to take part in activities that they enjoy and are meaningful to them (Alzheimer’s Society, 2020c).

There are discussions in the literature regarding the consequences of using technologies that track a person’s movement; with Dahl and Holbø (2012) highlighting how such devices contradict the philosophy of person-centred care. This contradiction is seen to occur due to the reduced privacy people living with dementia have when using such technology (Hughes et al., 2008), in addition to the perceived loss of human dignity and stigmatization (Astell, 2006; Marr, 1989).

2.11 Gaps found in the literature across both reviews

This section of the chapter will highlight gaps in reviewed research and demonstrate how my study seeks to address these gaps. Firstly, there was a paucity of evidence related to the cost of GPS devices. Studies (reviewed in section 2.5) cite the benefits of using this technology for people living with dementia, however, few examine what happens when a care dyad cannot afford such devices and whether other options are available to them. Part one of this chapter review considers the digital divide and gaps in access to assistive technology (section 2.3.3), however, little attention has been paid to such issues in studies into the use of GPS within the field of dementia. Similarly, the cost effectiveness of the technology with respect to the amount of usage gained is rarely explored. This study seeks to obtain data which will help to address these research gaps, using off-the-shelf GPS devices.

Despite the importance of the acceptability and usability of GPS devices, as found in section 2.7.1, studies to date have not included participants living with dementia and their care partners in the selection of such technology. These insights and perspectives could prove vital when it comes to finding technology that is appropriate for the end users (those that make use of the devices). The design of the first phase of this study, which will be explained in greater detail in the chapter that follows, will attempt to change this and contribute to new understandings in this area. The two searches of the literature conducted in part 1 and 2 of this chapter revealed few studies that examined why people living with dementia and their care partners reject this technology or issues of underutilisation, overutilisation and overreliance of GPS technology.

The systematic review, presented in section 2.4, found a lack of mixed method studies that make use of geographic information system (GIS) technology, with a need for more research that follows on from the work on Oswald et al (2010) in utilising the geographical data that can be generated through the use of GPS within dementia care. The systematic review recommends that future research should consider the potential financial effects of GPS, in terms of the long-term costs of providing good quality dementia care and support. A further gap in research was found relating to longitudinal studies that examine how the role of the GPS device may change during a person's dementia journey.

2.12 Summary of Chapter

To summarise, this chapter has reviewed the literature available to date, commencing with a broad evaluation of dementia, the challenges facing those living with the condition, an overview of assistive technology and how GPS has found its way as intelligent assistive technological solution within dementia care. During the initial literature review process, it became clear that the use of GPS to provide support for independent living was an integral part of the topic. I therefore decided to conduct a second literature review, systematically, that explores this is greater detail, to avoid duplicative research and to ensure that all relevant studies have been examined. The second part of this chapter presented this systematic review, focussing on how GPS can be used to support independent living, including the benefits and drawbacks of the technology. This chapter contained a section exploring person-centred care; its origins and elements, before discussing the links between the approach of putting the person first and the use of GPS technology within dementia care. The purpose of this section was to bridge the results of the literature review and the next chapter, which will demonstrate how a person-centred approach is adopted in my research process. Chapter two concluded by summarising the gaps identified through my reviews of the literatures and how this study seeks to address some of these gaps. Having examined existing literature and provided the reader with the background within which this research is conducted, I will now proceed to discuss the design of this study.

CHAPTER 3

RESEARCH DESIGN

CHAPTER THREE: RESEARCH DESIGN

The previous chapter presented a review of the literature and reported multiple gaps in knowledge relating to how off-the-shelf GPS devices can be used within dementia care. This chapter introduces the research design for this study, focusing on the approach taken, methods of data collection, methods of data analysis as well as important ethical considerations, before concluding with my own reflections on the design of this research.

This study had two distinct phases:

- **Phase one**, a consultation session, designed to explore the views and opinions of individuals living with dementia, and their care partners, on a range of selected off-the-shelf devices, through the use of a focus group.
- **Phase two**, the main research study, designed to build upon the findings from the consultation session. During this phase, the device selected by the participants of the focus group is used by participants for a period of 3-months, alongside their everyday lives. Interviews are used to gather data before and after this period of use.

3.1 Methodology

This study adopts a qualitative approach to research. The rationale behind designing this research using qualitative research methods is described below.

A qualitative approach holds a focus on meaning, using inductive logic in which theoretical ideas and concepts emerge from the data collected (Robson and McCartan, 2016). This approach favours context and perspective, in lieu of numerical data or statistical analysis. Importance is placed upon understanding phenomena, as described from the perspective of participants and witnessed from within their setting. Value is placed on openness, receptivity, and reflexivity (Robson and McCartan, 2016). This research approach is best summarised by this quote from Yilmaz (2013: p.312).

> *"An emergent, inductive, interpretive and naturalistic approach to the study of people, cases, phenomena, social situations and processes in their natural*

> *settings in order to reveal in descriptive terms the meanings that people attach to their experiences of the world".*

As one of the main aims of this study was to explore the experiences of participants living with dementia and their care partners, from their perspectives, an interpretivist qualitative approach was applied. The decision to conduct this study from a qualitative stance, rather than opting for a quantitative approach was due to the limited nature of quantitative research in examining perspectives. Wheeler and Holloway (2002: p.24) argued that a quantitative approach, whilst useful and valuable, "neglects the participants' perspectives within the context of their lives". If this study had adopted a quantitative approach, the participants' varying perspectives and experiences would have to fit established and predetermined response categories, whereas this research set out to uncover and capture diverse and personal viewpoints in the participants' own words (Yilmaz, 2013). By focusing on their experiences, this will provide a deeper appreciation of the challenges of living with dementia and where this technology can impact their lives. These challenges may include any potential barriers concerning support for living with dementia, as well as focusing on the understandings of dementia from those with first-hand experience of the condition.

3.1.1 Applying an interpretivist approach

An interpretivist paradigm underpinned the design and conduct of this study. The origins of interpretivism can be traced back to the 18th century and the philosophies of Giambattista Vico, who advocated for a distinction between the natural and social world (Ryan, 2018). Central to this school of thought is the understanding that social experiences form our perceptions of truth and reality (Ryan, 2018). Interpretivist approaches have also been influenced by the German philosophical frameworks of hermeneutics and phenomenology, with Blaikie (1993; 2004) citing the works of Max Weber, Alfred Schutz and Georg Simmel as instrumental to the development of interpretivism (Blaikie 1993; Lewis-Beck et al, 2004). Hammersley (2013) discusses how interpretivism came to challenge positivism and quantitative methods during the 20th century, noting the influence interpretivism has had on qualitative research.

In terms of a definition of interpretivism, Blaikie (1993: p.124) describes it as *"the study of social phenomena that requires an understanding of the social world that people have constructed and which they reproduce through their continuing activities*". Other definitions concur with this, with Berger and Luckmann (1966) noting how the interpretivist perspective is concerned with exploring the meaning that people may attach to their experiences, including an emphasis on how these meanings are created and negotiated, with the overarching objective of gaining new insights into their lived experience.

When taking an interpretivist stance to research, Blaikie (2007) states that the researcher does not set out to test or prove a particular theory or hypotheses. Instead, the first step is to try and discover how social actors conceptualize the phenomenon, before moving towards uncovering the *“meanings (interpretations), motives (reasons) and justifications (rationalizations) they give for their actions and those of others in the situation”* (Blaikie, 2007: p.59). Similarly, Robson and McCartan (2016: p.25) considered that, for interpretivists, the task of the researcher is “to understand the multiple social constructions of meaning and knowledge”.

Interpretivism was adopted for this study because of the belief that meaning exists through the lens of people’s experiences. It is through taking an interpretivist stance that I was able to focus on how the social world is interpreted by those experiencing it (Robson and McCartan, 2016). Adopting an interpretivist perspective afforded me an enhanced understanding of the social reality of living with dementia, by exploring the unique perspectives and subjective experiences offered by the person living with dementia and their care partner. Interpretivism uses qualitative research methods that focus on an individuals’ beliefs and motivations. In keeping with this, I chose to deploy the methods of interviews and focus groups, to generate knowledge from multiple perspectives. The three components to the knowledge being generated by this study were:

1. The views of the person living with dementia.
2. The views of the care partner.
3. The researcher’s interpretations.

3.1.2 Underpinned by the theory of person-centred care

This study also adopted a person-centred approach to research, building upon the seminal work of Professor Tom Kitwood (1993, 1997), who highlighted that the lived experiences of dementia offer a valuable and vital contribution to research (Meiland et al., 2017; McCabe and Innes, 2013). This approach replaces archaic forms of dementia care and understanding, that predominately sought to restrict and devalue the person's individuality and personhood.

Kitwood (1997: p.8) brings in the concept of *personhood* and defines it as:

> *"a standing or status that is bestowed upon one human being, by others, in the context of relationships and social being. It implies recognition, respect and trust."*

Kitwood (1997) maintained that the individual should be viewed as a person, not demarcated by their condition, stating that when referring to an individual living with dementia it should always be the PERSON with dementia rather than shifting the balance to the condition itself and labelling them as a person with DEMENTIA (Kitwood, 1997: p.7). More contemporary definitions of personhood (Higgs and Gilleard, 2016; Dewing, 2007) within dementia care substantiate Kitwood's views, emphasising how influential his method of placing an individual's personhood at the epicentre of dementia care still is today. He defined personhood as a status that "implies recognition, respect and trust" (Kitwood, 1997:8).

The value that a person-centred approach has to this study can be summarised by the following quote from Kitwood:

> *"When you've met one person with dementia, you've met one person with dementia"* (Kitwood cited by Alzheimer's Society, 2019c: p.10).

The interpretivist approach focusing on the experiences of living with dementia, from a person-centred stance, informed and guided this study. The 'expert through experience' perspective was added through co-production with people living with dementia and their care partners. The design of this study was co-produced, with the views and insights of people living with the condition in phase 1 shaping the research undertaken in phase 2. Co-production is about working together and conducting research with those who use it and is an important step in moving away from a 'them and us' culture and recognising how invaluable lived experiences are in research (Alzheimer's Society, 2021). McConnell et al (2019) reports upon the benefits of co-production in dementia research, arguing that co-production enhances the appropriateness and relevance of research.

3.2 Sampling and recruitment

It is understood that the processes of sampling and recruitment are integral to the designing of a research study, with such procedures involving defining the population of interest and asking willing participants that adhere to the eligibility criteria to partake in the study (Mirick et al., 2017; Pettus-Davis et al., 2011). The processes of sampling and recruitment that were deployed in each phase of this study are described below.

Phase 1

Purposive sampling was used to identify and select participants for the focus group. The inclusion criteria to partake in this phase, that was determined to produce a sample that was representative of the population, was as follows:

(1) Belong to a group known as 'dementia associates' within the university.
(2) Have experience as an individual living with dementia, as a care partner or as a former care partner.

The group of individuals, known as dementia associates, from The University of Salford's Institute for dementia were selected due to their knowledge and experience within this area of research. This panel of dementia associates is comprised of individuals living with dementia and care partners, who have become experts through experience, advising and informing research and knowledge translation activities at the University since its establishment in 2014 (Bowker et al., 2020; Innes et al., 2021). As well as selecting participants based on their knowledge and experience, factors of availability and willingness to participate were also taken into consideration. Bernard (2002) and Spradley (1979) placed significance on sampling based on the participant's ability to effectively communicate their views and experiences, selecting individuals who are "observant, reflective and articulate - who know how to tell good stories" (Bernard, 2002: p.156). However, within dementia research it is important to recognise that participants may communicate in different ways, individuals living with dementia may communicate nonverbally (Kitwood, 1997), but all offer valuable insights and knowledge.

There were around 20 dementia associates when recruitment for phase one took place, with all associates expressing interest in providing their views and opinions on GPS technology, subject to their availability to partake. Dementia associates represent a diverse range of ages, genders and roles, with representation coming from individuals living with dementia, care partners and ex care partners. In total, 15 dementia associates were invited to take part in the session, I deliberately invited more associates than necessary as I understood the many demands upon their time, with many committed to other groups and sessions that the Institute runs.

Recruitment took place in February 2020, two weeks before the focus group was planned, with each individual being given a leaflet that provided essential details, alongside a participant information sheet and accompanying consent form. Unfortunately, due to the death of a member of the dementia associates' panel and the funeral coinciding with the focus group, the session was rescheduled to the next available date. The rearranged date also coincided with the media coverage of the outbreak of the COVID-19 pandemic across Europe, resulting in many potential participants to decide to commence shielding, resulting in their absence from the focus group. Ultimately, 3 participants took part in the session: two individuals living with dementia and one care partner. Due to the uncertainty of the pandemic, the focus group could not be rearranged again and I took the decision to push ahead with the rescheduled date. I decided that I would review the data gathered during the session and decide if a second focus group was necessary. Additionally, I was actuely conscious of timescales, since the second phase of this study was dependent upon findings from the first, it was necessary for phase one to be concluded as soon as possible to allow for the ethical approval process, recruitment, training and the staggered 3-month usage period for phase 2.

Phase 2

A process of convenience sampling was used to identify and select participants for the main research study. A dementia support group in my local area made contact following the publication of the University of Salford's Institute for Dementia newsletter. The newsletter had detailed my PhD study and upon viewing this, a leader of the dementia support group contacted me seeking more information and querying the possibility of me presenting my research to the group. Following a presentation to the group, the aim was to recruit members directly to my study, based on their willingness and ableness to participate.

I sought to recruit a total of 16 participants for this study, 8 dyads of individuals living with dementia and their care partners. The testing period would be staggered to allow me to provide ongoing technical support to participants. The period would begin with 4 dyads testing the device, then following a month of testing, the second half of dyads would begin the testing period. Figure 12, showing a timeline for the main research study, reflects this. If more than 8 dyads expressed an interest in being recruited to this study, I would have recruited on a first come first serve basis.

Following the outbreak of the COVID-19 pandemic, the design of the second phase of research was adapted to limit face-to-face contact, and to take into account social distancing measures and to adhere to both local and national restrictions. With the group presentation unable to take place due to limits on the number of people gathering indoors, an alternative strategy was implemented. It was proposed by the organisers and leaders of two local dementia support groups that they could act as gatekeepers and promote my study to members. Members of the group that expressed an interest would then agree for their details to be passed to myself, and I would make contact to further promote the study and potentially recruit them.

Following conversations with the organisers and gatekeepers to these two groups, it became apparent that the number of eligible members would not be sufficient. In addition, due to national lockdowns, shielding and government issued stay at home orders, the groups were not planning to meet face-to-face in the foreseeable future, and they had not yet migrated the group to operate remotely. Therefore, it was decided that recruitment and the advertising of the research study would target more dementia support groups in the local area. An additional 12 groups in the local counties of Cheshire and Greater Manchester were approached. Whilst replies to attempts at promoting the study from these 12 groups were received, many of the groups were still not meeting remotely and as a result, the study was still lacking adequate numbers of participants.

The recruitment strategy was then expanded, and the study was adapted to enable participants from across the United Kingdom to take part, provided that they could adhere to the inclusion criteria. The study was made contact-free, with it proposed that devices would be posted to interested care dyads, and initial and follow-up interviews would take place over the phone. To further boost the number of individuals invited to partake in the study, the DEEP network were approached. DEEP is a network for people living with dementia across the UK and seeks to engage and empower individuals living with dementia *“to influence attitudes, services and policies that affect their lives”* (DementiaVoices.org.uk, 2021). Following a conversation with the UK Coordinator for the DEEP network, they agreed to publicise the recruitment material across their platforms, along with details on how to join the study. Similarly, the Alzheimer’s Society were approached, and they agreed to promote the study across the Dementia Voice social media channels. Alterations were made to the ethical approval for this study to factor in this new method of recruitment.

In the end, 35 dementia support groups across the United Kingdom were approached: 30 in England, 2 in Wales and 3 in Scotland. Most of these groups were found using the Alzheimer's Society’s (2022) online ‘Find support near you’ tool, a dementia directory which can be used to display local support services for people living with dementia and their care partners. In this new approach, brought about by the COVID-19 pandemic, the gatekeeper of the dementia support groups became an important component of the process to recruit participants to this study. It was important that the gatekeeper valued the research topic and recognised the importance of the findings (Mirick et al., 2017). Where recruitment from groups was successful, group leaders (the gatekeeper) appeared supportive of this project and motivated to help facilitate recruitment.

3.3 Phase 1 design and data collection

3.3.1 Consultation Focus Group

Historically, focus groups experienced strong development in the field of market research, where group discussions were used to explore issues such as branding, packaging and product choice (Finch and Lewis, 2003). Focus groups are now considered a mainstream method across social science research. There is a plethora of literature surrounding the use of a focus group format, with the popularity of this technique on the rise, largely due to the growth of participative research (Ochieng et al., 2018). As a novice researcher, it took a great deal of deliberation in weighing up the benefits and limitations of using this data collection method, given the sensitive and emotive topic of dementia and individual experiences of dementia being discussed in an open arena. One of the overarching advantages to this approach is the fact that it is quick and cost-effective, with the ability to capture a wide range of views within a short period of time. Additionally, focus group discussions allow for a flexible collection of data, utilising the natural interaction between people alongside the influence and elicit discussion generated from such.

Combining the benefits gained through interviewing and group interaction, focus group discussion presents an opportunity for participants to collectively develop ideas, "bringing forward their own priorities and perspectives" (Smithson, 2000: p.116). Du Bois (1983) suggests focus groups have the potential "to create theory grounded in the actual experience and language of the participants", a statement that runs parallel with the aims and objectives of this study. Morgan and Krueger (1993) observe that participants may gain enhanced feelings of support and empowerment speaking in a group with others who share similar experiences, this particular benefit may have greater significance to people living with dementia (Wilkinson, 2002). Morgan and Kreuger (1993) also discuss the benefit of focus group styled discussions in terms of exploring the degree of consensus on a given topic. Whilst the main aim of the discussion was to illicit unique insights and experiences into how and why participants select technology, the focus group also provided an opportunity to see if participants were in agreement on a GPS device that would be suitable for people living with dementia and their care partners. This idea of consensus building is discussed in more detail in section 4.3.

Many benefits will only be gained if the focus group is moderated effectively, therefore it is imperative that the facilitator possess certain skills (Gibbs, 1997; Kitzinger, 1995). Taking this into account, for the role of focus group moderator, I underwent communication training through the University's researcher development programme. Alongside this training, I had built up relationships with members of the associate panel at the Institute for dementia, by regularly volunteering at groups, and I feel that this established a basis of trust between us and allowed them to speak openly in my presence. Through regular contact with groups at the Institute for dementia, I also understood the overall dynamics of the group, this afforded me an awareness of personality traits and where there could be a tendency to go off topic or where certain limitations may arise. Because the participants had a familiarity with the research process as a whole, as well as with each other, the setting the focus group took place in, and indeed myself, made for a very relaxed session, where participants could share openly and honestly.

In terms of examining weaknesses of this approach, the literature often cites the confines of a focus group discussion to include instances whereby one participant becomes too vocal and overpowers the voices of other and as such dominates the discussion (Smithson, 2000). Morgan (1988) highlights the issue of having reduced control over the data that is gathered under this format, whereby the role of the facilitator is merely to prevent the digression of discussion. As the facilitator is prevented from influencing the views and opinions of the group, the results (the information produced) are largely dictated by the group. Such data can be 'chaotic' resulting in data analysis being more difficult to conduct (Morgan and Krueger, 1998).

Having examined evidence relating to the use of focus groups in social science research, I decided that this would be a good fit for my study as it utilised the following aims:

- To generate in-depth understandings of the use of 'off-the-shelf' GPS technology within dementia care and explore the perspective and experience of the individual living with dementia, care partners and former care partners.
- To act as a consultation stage to inform and shape the wider project.
- To capture the interactions between participants, as well as when participants voice their own views, opinions and experiences (Finch and Lewis, 2003).

During the focus group, discussions focused on a range of issues that they considered important to them, and whilst initial questions were asked to spark conversation and debate, my role as the focus group facilitator was merely to moderate and prevent the digression of the discussion. The focus group employed tactics to ensure that everyone's voice could be heard, with the "I want to speak please" cards used during this session. Yellow cards (as seen in figure 13) were utilised to allow for those individuals for whom words were not forthcoming, to also share their views and insights. It has been found that these cards allowed the conversations to be balanced and permitted everyone to feel more equal and more confident during conversations and were employed as a way of creating space for people to find their voices (Litherland, 2019).

3.3.2 Focus group size

The literature suggests that focus groups should not be too small as this may limit the total range of ideas and experiences (Morgan, 1988). On the other hand, during large focus groups, the discussion may be harder to facilitate and could result in a limited opportunity for each participant to share their insights and observations. Morgan (1988) asserts that smaller groups have the potential to produce more detailed data from each participant, although this comes at a cost to the range of ideas produced from larger focus groups. In terms of numbers, Robson (2002) recommends between 8 and 12 participants, whilst other academics such as Krueger (1994) make the argument for smaller groups of between 5 to 7 people. Based on these suggestions and through reviewing similar studies that have adopted a focus group format (Dahl and Holbø, 2012; Landau et al., 2010), I chose to involve a group of 8 participants for this phase of the study. I felt this number would sufficiently provide a range of views, whilst at the same time providing enough space to hear said views within the timing of the session. Unfortunately, only 3 participants were able to make the rescheduled date for the focus group. Whilst at the time I was conscious of the range of insights and experiences that such a small group would provide, on reflection, this size of the group was ideal. In-depth conversations took place throughout the session and all participants were able to engage in discussions and voice their ideas and opinions about the topic. All participants were able to agree on the device they felt was most suitable, offering their rational for selecting the device, with these views going on to influence the second phase of research.

3.3.3 Selection of devices used in the focus group

Before the commencement of phase 1 of this study, a rigorous selection process for devices to be used in the focus group had to take place. This process, illustrated through the flow chart in figure 10 below, took place between January 2019 and September 2019 and was comprised of several steps. The purpose of this procedure was to examine the range of off-the-shelf devices currently available online, comparing the features and specifications of each device before narrowing down the list of potential products to a more manageable number; these chosen devices were then shown to participants of the focus group.

The selection process began with a wide search of available technology, yielding 157 results on 3 online marketplaces, as well as through a hand search of other websites that were known to me. The first step in the process was to remove duplicates, upon reflection this was more difficult that first perceived, as identical online products are often resold masked by different branding. Following this step, I compared product results to a definition of “off-the-shelf” that I had previously established. As a result, a large number of devices (74) were dismissed due to their availability, with many products advertised online shipping from China, with an estimated delivery date of 1-2 months, or a cost that exceeded the maximum.

This definition of “off-the-shelf”, alongside relevant items found in the literature, was used to shape the device inclusion criteria table, which can be seen below. The next stage involved comparing the specification of found devices, to the established inclusion criteria (table 4). This criterion assessed products based on battery life, functionality such as geo-fencing, alert options, 2-way voice chat and waterproofing. The literature review revealed that the size and weight were found to be important factors to consider in the process of selecting a device (Dale, 2010; Landau et al., 2010; Hersh and Johnson, 2010). Accuracy reliability was also seen as an important issue when undergoing this process. Using the global average as an indicator of how accurate a device may be, an inclusion criterion was set at 12.3m when outdoors, devices that failed to adhere to this distance would be classed as too inaccurate to be included in this study (gps.gov, 2017; Hersh and Johnson, 2010). In total, 52 devices were removed on the basis of their size, weight or accuracy.

From this stage, 21 products were selected for a form of beta acceptance testing, whereby I ordered devices and conducted a series of physical tests to determine the products acceptability. Beta acceptance testing is where a product is tested by an experienced user in a “real environment” (Dolan and Matthews, 1993). This included undergoing real-world scenarios with products, assessing the performance, reliability and the Graphical User Interface (GUI) of the associated application provided with the device, the testing table to see how devices performed in tests can be seen in

Appendix 2. 7 Devices were selected for use in the focus group study (3 were omitted due to being of similar style), with devices that scored higher in beta testing preferred. The flow chart situated below depicts this process that was followed.

Figure 12: Flow chart showing how the devices were selected for this study

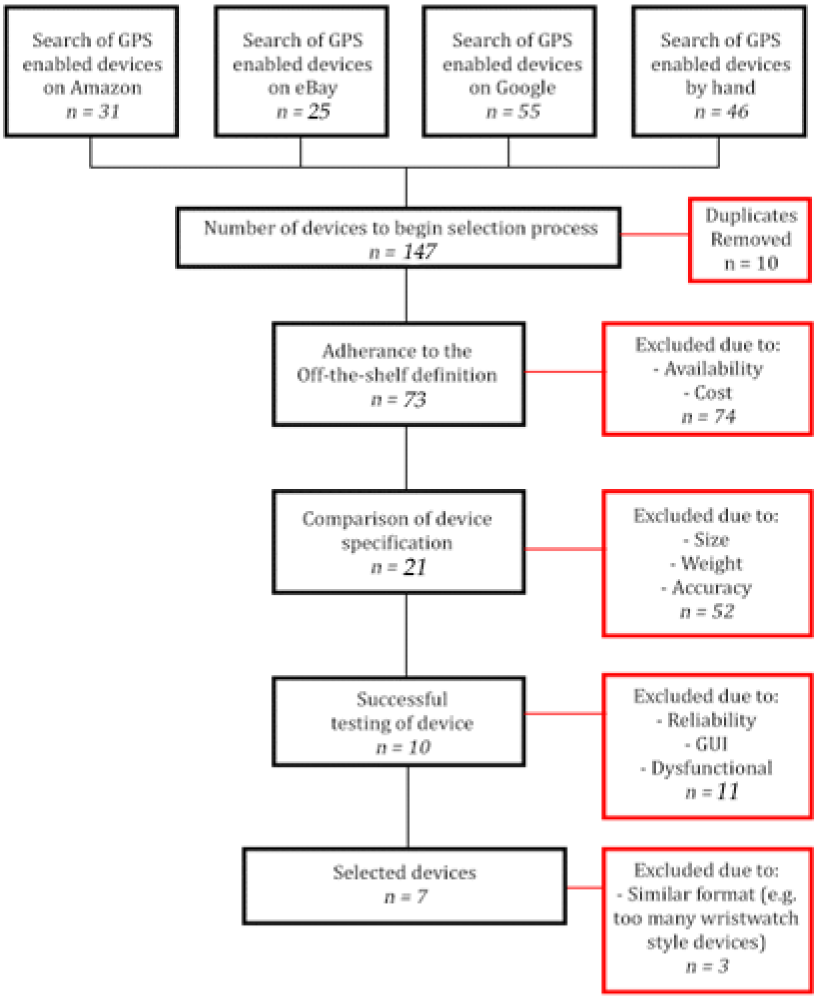
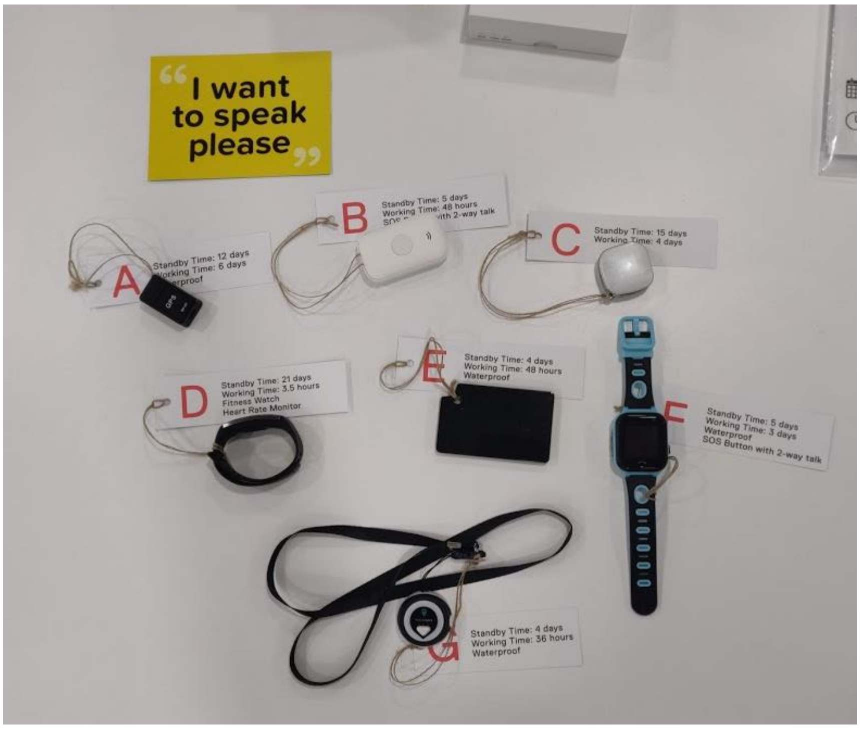


Figure 13: Selected devices on display to participants of the focus group



The following table reflects the initial predefined characteristics that was used to identify potential GPS tracking products.

Table 5: GPS Device Initial Inclusion Criteria Table

Criteria	Inclusion	Exclusion
Time delay for pinpointing GPS location	Active (Real time)	Near-real time, offline mode, Passive
Size of device	≤ 77 mm x 45 mm (H x W)	>77 mm x 45 mm (H x W)
Weight of device	< 70g	≥70g
Compatibility	iOS, Android	Other less well-known operating systems including KolibriOS, Firefox OS, Slax, Ubuntu for Phones, ReactOS, Tizen OS, Tails, Qubes OS
Accuracy of GPS (Outdoors)	Position of tracking unit pinpointed to ≤12.3 m (gps.gov, 2017)	>12.3m
Cost of device	< £50	≥ £50
Length of battery life when using GPS (WT)	≥3 hours	<3 hours

Length of battery life when on standby (ST)	≥24 hours	<24hours
Age of device	Within the last 10 years, due to issues surrounding compatibility, accuracy and size.	Older than 10 years
Type of device	Watch, Hidden unit, Pendent, Insole 3 categories: Mobile phone devices, worn devices and carried devices (Williams et al., 2011)	Chip
Coverage	Indoor and Outdoor, Outdoor Only	Indoor Only
Geofencing capabilities	Yes	No
Removable	Yes	No
Rechargeable	Yes	No
Mobile phone Generation	1G, 2G, 3G, 4G	
Availability	Delivered within 14 days	Estimated delivery date longer than 14 days

3.4 Phase 2 design and data collection

Phase 2 forms the main research study and involved dyads using the selected GPS tracking device (chosen by attendees of the focus group) for a period of 3 months alongside their everyday lives. I used an interview guide to conduct two semi-structured interviews (see box 1 and 2 below). These interviews occurred at two points in time; one prior to the period of use, to explore initial views, opinions and experiences, and the second one following the period of use to investigate the lived experiences of using the technology.

The term ‘care dyad’ is used to represent the pair of individuals required to participate in this study; the person living with dementia, and their nominated care partner. This technology requires two people to function; the person carrying the GPS tracking device and a second individual responsible for monitoring the location of the device.

3.4.1 Interviews

In-depth interviews are the most widely employed method when conducting qualitative research (McIntosh and Morse, 2015; Robson and McCartan, 2016) and have been found to be the most frequent method used for collecting data from individuals living with dementia (Clarke and Keady, 2002).

Clarke and Keady (2002) identified a set criteria for use when involving individuals living with dementia in data collection. The purpose for this criteria was to enable them to articulate and express their perspective in a way that affirms confidence in the data collected (Clarke and Keady, 2002). The criteria, and how it relates to this study, is as follows:

1. Sufficient engagement to allow confirmation of issues raised. To adhere to this criteria, Phase 2 features repeated interviews, conducted before and after a period of using the device.
2. A mutually trusting relationship. This study takes place over a sustained period of engagement, whereby a rapport was built between the researcher and participants.
3. A collaborative approach with the person with dementia, allowing a mutual process of agenda setting
4. Minimising anxiety and tiredness. Within this study, factors such as the duration and location of where data collection occurs was considered, with interviews kept short to reduce possible fatigue of participants.
5. Augmentation of data collection. This is achieved through visual prompts and corroboration with the family care partner.
6. Emotional engagement by the researcher so that the person is clearly valued, and knows that they are valued, for their knowledge.
7. Detailed attention must be paid to reliable data recording, using observational recordings as well as tape recordings.

(Clarke and Keady, 2002).

Likewise, Foggart (1988, cited in Wilkinson, 2002), holds the view that interviews with individuals living with dementia should be kept relatively short, and held in a location that is familiar to the person living with dementia, with Keady (1999) arguing that interviews should be restricted to 45 minutes. In this study, the duration of interviews were approximately 30 minutes long.

The second phase of this study utilised semi-structured interviews, to investigate the personal perspectives of individuals living with dementia and their care partners. The decision to adopt this interview method of data collection was based on the following benefits.

Suitability

Semi-structured interviews are often viewed as most suitable when the interviewer "is closely involved with the research process", with this type of interview often favoured by small-scale researcher projects (Robson and McCartan, 2016: p.290). Whilst it was acknowledged that interviews can be more time-consuming to conduct and analyse, as opposed to alternative methods, it was felt that the rapport that can be built with participants was pivotal in gaining the rich in-depth data required (Robson and McCartan, 2016). This enabled me to explore complex issues and reveal different understandings of participant's experiences (Wilkinson, 2002). Interviews are also a commonly used and successful research method in other lived experience studies (Innes et al., 2014; Innes et al., 2021).

Flexibility

Semi-structured interviews can be tailored and personalised to the participants, providing an opportunity to collect data in an individualistic way, recognising the uniqueness of experiences of the condition. This individualistic means of data collection reflects the person-centred approach that underpins the ethos of this study.

Structure

The use of an interview guide enabled me to keep discussions on track but probe when necessary. Interview guides direct the topics of conversation that will be covered, providing the default wordings and the order of questions, however, they may be changed to fit the flow of conversation (Robson and McCartan, 2016).

3.4.2 Preparation - Interview Guide Development

When writing the questions used to guide the interviews in this study, I was mindful that accessibility and support for individuals living with dementia must be maintained throughout the research process (Morbey et al., 2019). I ensured that the wording of the questions, seen in boxes 1 and 2, would be in lay persons terms and the length of questions have been kept short. The interview guide used appropriate language and dementia terminology throughout.

An introductory statement was included in the research guide to remind participants about the general focus of the interview and study. When formulating recommendations for conducting interviews with people living with dementia, Cridland et al (2016) proposed that it is good practice to repeat this general focus at various stages of the interview. Cridland et al (2016) cites the use of warmup questions to “ease” people living with dementia into the discussion, this technique can help enable a rapport to develop between researcher and participant.

Box 1: Initial interview guide

- Before the information session, had either of you ever heard of the term GPS tracking technology?
    - (Follow up Question) Has GPS ever been recommended to you?
    - If yes, have either of you ever experienced using GPS tracking technology before?
- Could you describe some of the activities you do now, both together and separately?
- (Question for person living with dementia) How do you feel about someone knowing where you are at all times?
- (Question for care-partner) How do you feel about being able to see where [the person living with dementia] is at all times?
    - Follow up Question: Do you think it will make you feel safer?
- (Question for care-partner) Do you think it would give you additional reassurances that [the person living with dementia] is safe, if you could track their location?
- (Question for person living with dementia) Do you think GPS tracking technology could provide you with greater freedom and independence?
- When do you think a GPS device would be useful to you?
    - And how often do you think you would use a GPS device? E.g. Going to the shops/Whilst on holiday/When travelling alone.
- Do you have any worries about this technology?

Box 2: Follow-up interview guide

- How often did you use the device?
- Could you describe some of the activities you undertook whilst using the GPS device, both together and separately?
- Do you think this device is something you will continue to use following the end of this study?
- How did you both feel about using the device?
    - (Follow up question) What worked well?
    - (Follow up question) What was difficult?
- (Question for person living with dementia) Did you find that this GPS device gave you greater freedom?
    - (Follow up question to Care Partner) Did this greater freedom give you an increase in worry?
- (Question for care partner) How did you feel about being able to know where [the person living with dementia] was at all times?
- (Question for care-partner) Did you find the device gave you any additional reassurances with regards the safety of [the person living with dementia]?
- (Question for person living with dementia) How did you feel about someone knowing where you are at all times (being tracked)?
    - Follow up Question: Did it make you feel safer?
- Did you encounter any issues when using the device?

3.5 Project flow and steps

The original design of phase 2 can be seen in the following flow diagram and timeline (figures 14 and 15). The design of this phase was revised twice, table 6 reflects the changes that were made due to restrictions and regulations brought about because of the COVID-19 pandemic.

Figure 14: Original design for phase 2 data collection

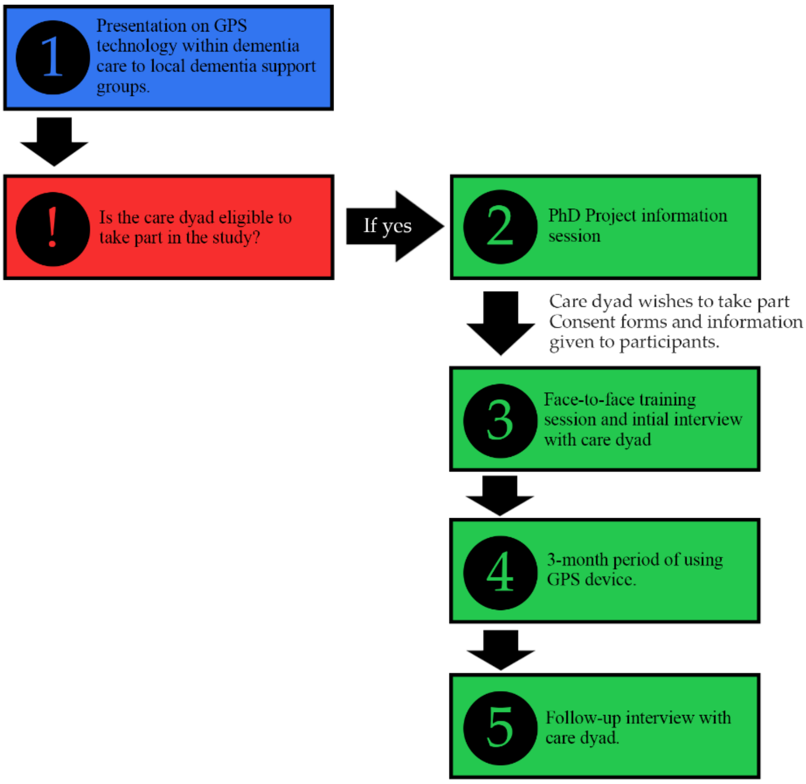
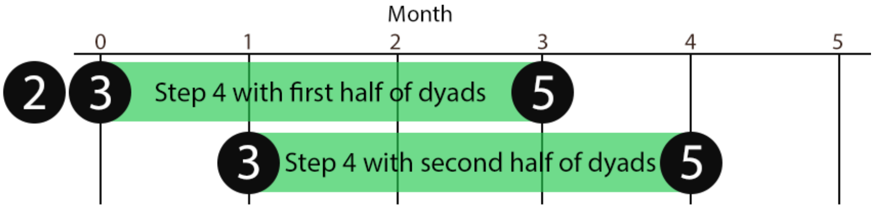


Figure 15: Timeline of phase 2, showing staggered start



Step 1: Project Promotion

As aforementioned, a local dementia support group contacted me and expressed an interest in becoming involved with this study. Once ethical approval was obtained, my goal was to make a general presentation on the use GPS technology within dementia care to the wider dementia support group, at a local community hub, where the dementia support group regularly met. At the end of the presentation, my intention was to promote my PhD study with a view to recruiting eligible dyads to the study itself.

To participate, both the individual living with dementia and their care partner must have adhered to the following established eligibility criteria:

(EC1) Reside at the same address

(EC2) Have internet access via a mobile phone or tablet device

Step 2: Information giving and recruitment

Step 2 of this design would have consisted of a face-to-face project information session regarding my PhD Study, in attendance at this session would have been eligible dyads recruited from the previous step. This session was due to take place in the community hub where the dementia group regularly met. At this point, dyads would have had more information regarding what GPS is, and how it can be used alongside their everyday lives, they would be better placed to make an informative decision as to whether this study would benefit them.

Data Collection

Data Collection would then take place in the subsequent 3 steps.

Step 3: Initial Interview

Step 3 would utilise a semi-structured interview, to extract as much in-depth data as possible prior to the testing of the GPS device. The intention was to sit down with both the individual living with dementia and their nominated care partner at the same time and discuss their views and opinions on GPS technology prior to the commencement of the testing period. Using the topic guides (seen in box 1 and 2 above), I would talk them through each question, note down their responses and be available to answer any questions they may have, this may include clarifying the wording of the questions or terms used within the questions. Questions would be directed towards both participants, or solely at the individual living with dementia or their nominated care partner. I felt that using this approach, as opposed to a self-administered style of questionnaire, would yield higher response rates.

During this first interview, questions would focus on the participants prior views and opinions of the technology, including any previous experience they may have in using GPS devices, or any lived experiences they have regarding issues that GPS seeks to mitigate. Participants would be asked to describe some of the activities they currently undertake, both together and separately, as well as situations they may find a GPS device would be useful to them. This approach, utilising a style of guided conversation, sought to generate rich, in-depth data based on the participants' lived experiences and their interpretations of the world.

Step 4: Period of use

At this step, Dyads would be given the GPS device selected by phase 1 participants (1 x V-Multitracker Trakisafe) to use over a period of 3 months, along with training as to how to use the device and a manual (written in simple language and including a visual guide). During this period, I would be on hand to provide technical support to participants, via email, phone, or should they wish, in person, and answer any questions they have about the technology or the study itself. In terms of data collection, I would seek consent from participants to take note of questions, queries and concerns throughout this testing period as well as consent to use data related to activities undertaken during this stage.

Step 5: Follow-up interview

Using the same format to the process described in step 3, Dyads would be interviewed by myself after the testing period has concluded. The follow-up interview sought to capture the opinions of participants following the conclusion of the study.

During this interview, questions would focus on the participants describing the activities they conducted whilst using the GPS device, how often the device was used, what worked well and what was difficult. Several questions would follow on from questions initially asked (in step 3), to draw links and comparisons between the two sets of data. See boxes 1 and 2 above for the interview guide used in this step.

3.6 Changes due to COVID-19

Due to COVID-19, declared a pandemic by the World Health Organisation in March 2020 (WHO, 2020), the basic format for phase 2 remained the same, however, to limit the occurrence of face-to-face contact the following amendments were made to the design of this research.

Table 6: How phase 2 was revised to respond to COVID-19 challenges

	Original design	**First revisions**	**Second revisions and final design**
Step 1	In-person presentation on the	In-person presentation replaced and instead	Expanded to include dementia support

	use GPS technology and recruitment at local dementia support groups.	provided by the gatekeepers of local dementia support groups on my behalf. Contact details of interest care dyads would be passed on to me.	groups and organisations nationwide.
Step 2	PhD Project information session held at the venue where groups meet.	Information session would take place over the phone, where more details of the study are provided to those interested.	A custom-built website was added to further promote the study and provide interested care dyads with information[4].
Step 3	Face-to-face training session and initial interview with care dyad	Training would take place at the home of the participant, a COVID-19 risk assessment would be conducted to ensure this could take place safely. The initial interview would take place in-person following the training session.	All face-to-face elements of the study were removed. Training sessions and technical support were still one-to-one, however, held remotely over the phone and using the custom-built website. Initial interview would take place over the phone[5].
Step 4	3-month period of using the GPS device		This step was amended to include a 'familiarisation period' of 1-month on top of the 3-months, to enable the care dyad to get used to the technology and receive any technical support or additional training.
Step 5	Follow-up interview with care dyad held in-person		Follow-up interview with care dyad held remotely over the phone.

A staggered start to phase 2 was still utilised, with participants commencing the 3-month period of using the selected device at 3 different stages (1st: 3 care dyads, 2nd:

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[4] www.dementiatech.info

[5] Participant information sheets, consent forms and physical copies of the user manual were posted to participants, along with stamped addressed envelopes to return consent forms. Following the return of consent forms, interviews with care dyads took place over the phone.

3 care dyads, 3rd: 2 care dyads). This allowed focused technical support to be delivered as well as enabling me to transcribe interview recordings as I gathered them. For example, I was able to change features on the website and user guide based on the feedback of the first set of care dyads. This agile approach also afforded me opportunities to reflect on my interview technique and alter the wording of questions, or the order they are asked in, based on what I felt worked well for the 1st set of care dyads.

3.7 Development of a website, training programme and user guide

As explained above, prior to the outbreak of the COVID-19 pandemic, the aim was to provide face-to-face training alongside a hard copy of a 'user guide' that would be written in lay person terms. Changes to the methodology (as outlined in table 6) resulted in a custom-built website and online training programme being developed to assist participants in learning how to use this technology. Drawing on my experience in web development, gained during my undergraduate degree in computing, the website was written in HTML, JavaScript and CSS, with a key objective being to make the site simple, concise and user friendly. I adopted a single-page approach to developing the website, with all the information required by the participants situated on one page.

The website was developed in three stages, based on objectives that were gradually added following the announcement of further COVID-19 restrictions:

1). The first objective was creating a webpage that could display key information about the study and provide access to download the participant information sheet, consent form and user guide. This site would also allow users to contact me for advice or ask technical questions.

2). To incorporate an 'online training' feature, in the form of a repository of demonstrative videos that showed users 'how to' conduct certain procedures on the device. The first set of videos included tutorials such as 'How to: Power on the device' and 'How to: Charge the device'. Following user feedback, additional videos were added or amended that demonstrated more complicated features that could not be easily described in the user guide.

3). To enable users to request to join the study and to provide additional information through the format of blog entries.

The final design (that can be viewed at www.dementiatech.info) met all three of these objectives. The user was able to scroll through a single webpage where information was gradually displayed to them, taking the user on a journey from key information about the PhD project to requesting advice and technical support. Screenshots of the website showing the different features that were developed can be seen from figures 16 through 20. When selecting a name for the website I was conscious of how the website could be repurposed in the future if the content was found to be useful. More information about both the website and user guide can be found in sections 3.7.1 and 3.7.2 respectively.

3.7.1 Participant support - Online material

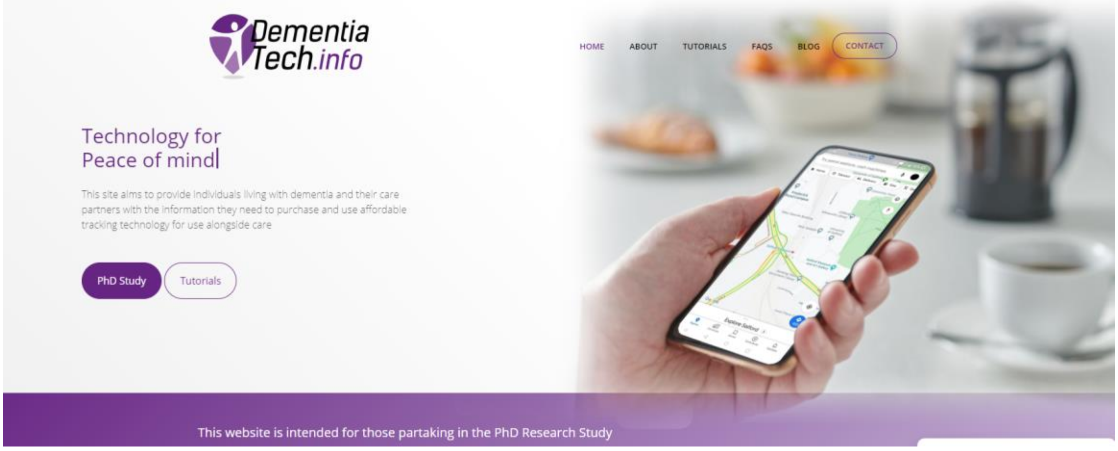
When altering the design of this study to take into account social distancing constraints and limitations to face-to-face engagement, I proposed implementing a method of online support for participants. I built an online platform (figures 16 to 20), to be accessed by participants through the URL https://www.dementiatech.info/. This custom-built website and online learning tool contained the following features:

- Information on the study in general: This provides an overview of the PhD study, detailing the projects aims and objectives
- User guide: A downloadable pdf document showing users how the devices work, the available functions of the devices as well as useful tips, presented in a simplified, easy to read format with step-by-step images. A physical format of this guide would also be given to participants.
- A series of video demonstrations to aid the user: Each feature or function is demonstrated in its own video, available by clicking the relevant image on the website, this can be seen in figure 18.
- FAQs or ‘frequently asked questions and answers’ section: This feature of the online content provides the user with the facility to view questions asked by other users or to ask their own question, via the dedicated form.
- A blog: The website features a blog section, whereby I can update participants with relevant information in the form of informal text entries, see figure 19.

- Contact forms: Users/participants may ask questions or request further technical support; form entries are sent directly into my university email account.
- Live chat function: Additionally, users may ask questions or request technical support using the live chat function situated in the bottom corner of the site, with replies sent directly to my university email account. Figure 17 shows the minimised chat function, and the arrow represents what happens when the user clicks for more information or enters a message. The users are informed if I am currently online and available to answer a question/query immediately, if the status is set to offline the user enters their email address or phone number, to be contacted with a reply at a later point.

Due to further changes made in light of COVID-19 restrictions and the removal of all face-to-face elements of the study, an additional 'join' section was added to the website to direct those who wished to partake in the study to a relevant area (see figure 20). It was found that 3 care dyads utilised this feature of the website to register an interest in taking part in the study.

Figure 16: Screenshot of landing page

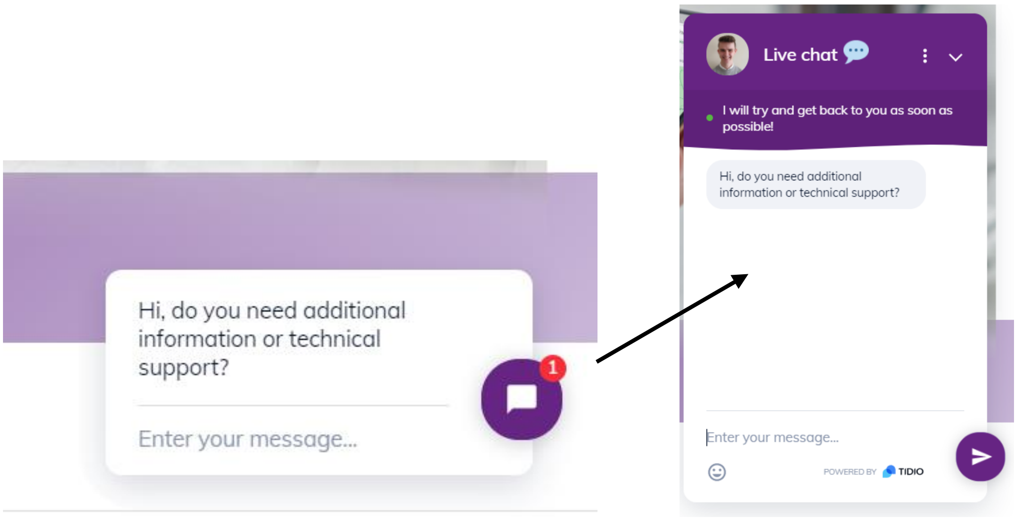


Technology for
Peace of mind

This site aims to provide individuals living with dementia and their care partners with the information they need to purchase and use affordable tracking technology for use alongside care

This website is intended for those partaking in the PhD Research Study

Figure 17: Screenshot of live chat function



Hi, do you need additional information or technical support?

Enter your message...

I will try and get back to you as soon as possible!

Hi, do you need additional information or technical support?

Enter your message...

Figure 18: Screenshot of video demonstrations

Device Tutorial

Below are a series of video tutorials on how to use the V-Multi Tracksafe by Vodafone. Being used in this study

Hi, do you need additional information or technical support?

Enter your message...

Figure 19: Blog feature

20.10.2020: First Blog Post

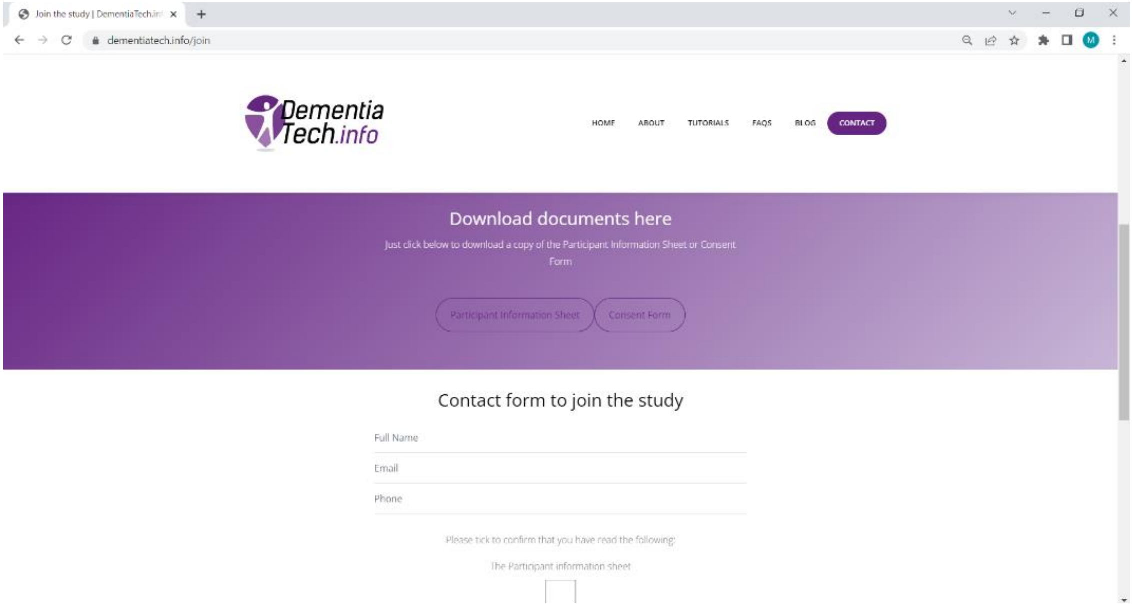
Welcome to my first post

In this first post, I thought I'd take the opportunity to explain more about the technology itself. GPS technology has been around for over 40 years, but only began its mainstream public use in 2000, when the US government stopped intentionally scrambling satellite signals therefore allowing accuracy to increase from around 100 meters to under 10 meters.

Since then GPS technology has become more reliable and more accurate and is now built into a lot of the technology we use today. This development of the technology has enabled accessibility to increase, with GPS devices now available for under £10

Type a keyword and hit enter

Figure 20: Section to register an interest in joining the study



Download documents here

Just click below to download a copy of the Participant Information Sheet or Consent Form

Contact form to join the study

Please tick to confirm that you have read the following:

The Participant information sheet

☐

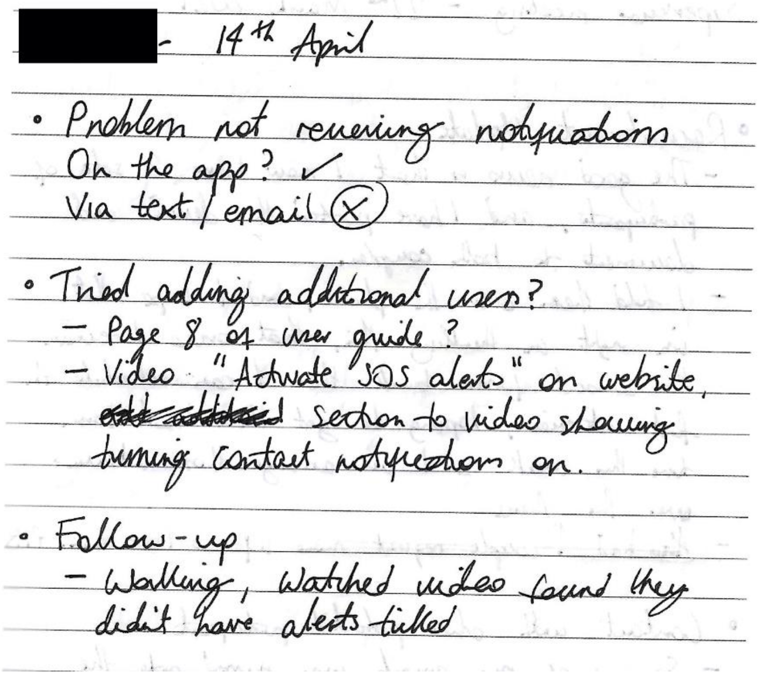
3.7.2 Participant support - User guide

During the initial design of this study, it was proposed that a physical user manual would be provided to participants, written in lay persons terms, to detail the basic functionality of the device used in this phase. The guide can be seen as Appendix 5 and covers procedures such as powering on the device, charging, and setting up geo-fences. Following the completion of the guide, the material was given to older people, who may represent potential users, for review. This was done to ensure the wording of the guide was appropriate for an audience unfamiliar with the technology.

3.7.3 Engagement with website, training programme and user guide

During phase 2, I sought feedback from participants on the website, training programme and user guide. This was to ensure that all materials were fit-for-purpose and helpful to participants in their journey into learning how to use this technology and their continued use of devices. I found that care dyads interacted with materials in different ways and to differing extents. For example, for three care dyads the instructional videos were found to be extremely important to them and one care dyad reflected in follow-up interviews that without this resource, they would have struggled to ‘get to grips’ with even some of the more basic tasks like charging the device. During the 1-month familiarisation period, 2 care dyads contacted me to report challenges that they faced when learning how to use the devices. I have included the notes (figure 21) I took from one such instance and the advice or directions I provided them with.

Figure 21: Notes showing directions offered to one care dyad who were experiencing a problem



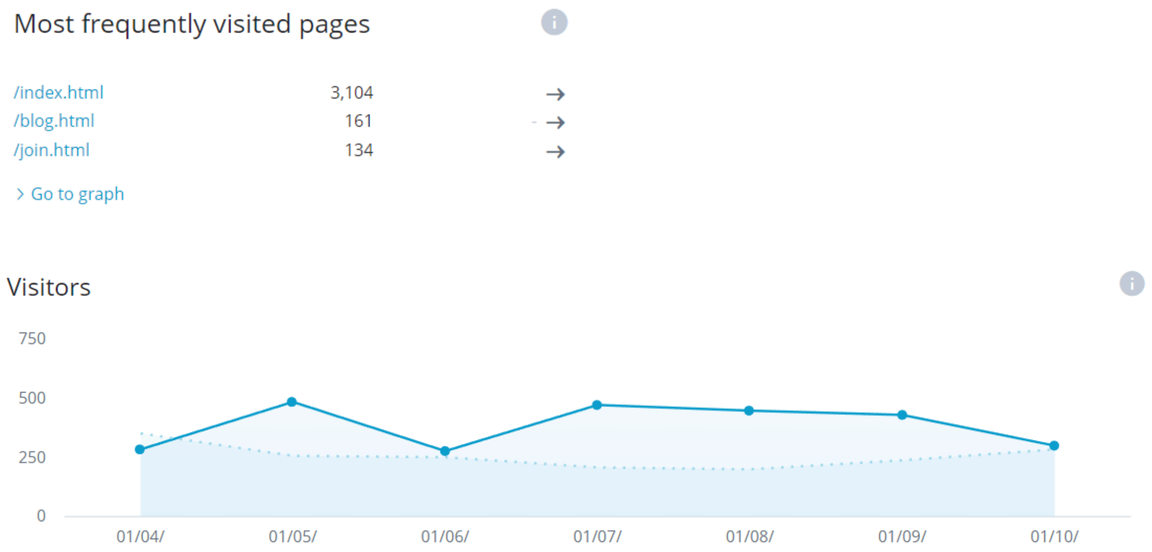
[redacted] - 14th April

- Problem not receiving notifications
  On the app? ✓
  Via text / email ⊗
- Tried adding additional user?
  - Page 8 of user guide?
  - Video "Activate SOS alerts" on website, ~~add additional~~ section to video showing turning contact notifications on.
- Follow-up
  - Working, watched video found they didn't have alerts ticked

In figure 21, the problem is diagnosed as the care partner was unable to receive notifications via text or email when the SOS button on the device was pressed. Whilst information on how to do this was included in the user guide, the participant was still unable to locate the section of the settings where this could be changed. I recommended the participant try watching the ‘How to: Active SOS alerts’ YouTube video embedded on the website. The participant subsequently tried this and during a follow-up conversation with them, they reported that the device was working again as expected. The participant commented that the video had helped them to understand the instructions better than the written instructions.

I have also included in figure 22 data that represents usage statistics during the period phase 2 was taking place. It must be stated that since the website URL was widely distributed, many of these site visitors may have been users simply interested in finding out more about the study rather than participants seeking further education resources. However, the data does show an increase in visits at a stage when 3 care dyads commenced their familiarisation period of using the technology.

Figure 22: Website analytics



Most frequently visited pages

/index.html	3,104
/blog.html	161
/join.html	134

3.8 Data handling and analysis

With the permission of participants, and with informed consent, the focus group of phase one and the interviews conducted in phase two were audio recorded using encrypted Dictaphone devices. For phase one, Dictaphones were situated around the table where participants were gathered to discuss the devices in front of them. Should a participant have not wished to be recorded, field notes would have been taken as an alternative. Telephone interviews for phase 2 were audio recorded, with permission of each participant obtained and transcribed verbatim. For each phase of this project, participants were assigned a unique code so that I, the researcher, was able to differentiate between participants, however no identifying information was included. This unique code was changed to pseudonym names during the writing-up of chapters 4 and 5.

Analysis of the focus group, initial interviews and follow-up interviews all utilised a process of thematic analysis as described by Braun and Clarke (2006). Braun and Clarke (2006) propose a 6-step approach to thematic analysis which involves identifying, analysing, and reporting themes within the data. Table 7 below depicts each of the 6 steps.

Table 7: Braun and Clarke's (2006) process of thematic analysis

Step	Description

1: Familiarising yourself with your data	This step required me to immerse myself in the data, by reading (and re-reading) through the transcripts made whilst making notes of initial impressions.
2: Generating initial codes	During the second step, I began the process of labelling and coding words, phrases and quotes that appeared interesting and meaningful.
3: Searching for themes	The next step is the start of the interpretive analysis of the codes that I found. I filtered out the most important codes before collating them into potential themes.
4: Reviewing themes	Potential themes were then reviewed, the most important themes are distinguished, and links are established between the themes. This is perhaps the stage I struggled with most as I questioned whether to combine, separate, or discard potential themes. Once themes were identified, I generated a ‘thematic map’.
5: Defining and naming themes	Step 5 required me to refine and define the themes and potential subthemes. I decided upon clear theme names and definitions that tell the story of each theme.
6: Producing the report	The final step involved writing the report in a way that communicated the results of the analysis and relates to the research question and academic literature.

The process of thematic analysis undertaken for both phases utilised an inductive approach to analysis, where the themes that have been identified are strongly linked to the data itself (Braun and Clarke, 2006). I opted for an inductive approach to ensure that themes were ascertained directly from the views, opinions and lived experiences of people living with dementia. Throughout this study I have sought to ensure that people living with dementia are included in the research and their voices used to shape the project, this inductive process allows the themes to reflect their contributions.

3.8.1 The thematic analysis process

Using the framework proposed by Braun and Clarke (2006) and outlined above I conducted thematic analysis on both the focus group transcripts and initial and follow-up interview transcripts. To assist in this process, I utilised the NVivo software for qualitative data analysis. The program aims to support researchers by allowing them to classify, sort and arrange data whilst examining potential relationships. Using this software, I began the inductive ‘coding’ procedure. The interpretivist research paradigm that was adopted for this study fitted well with the use of NVivo, providing various tools to assist the approach to data analysis. NVivo supported me in adopting an interpretive technique to coding, that involved me reading through each transcript line-by-line and assigning labels to parts of the data I thought was particularly relevant. During this step, using the NVivo memo function I took note of sections of information that stood out, recording my initial ideas, insights, and interpretations. This organised the data and was a crucial step in adding meaning to the data that I had collected in each phase.

Through coding and making ‘nodes’ (a collection of references that are all related and gathered in one place), I was able to look for emerging patterns and ideas. After transcripts were coded, further re-coding took place within NVivo as I sought to refine the codes and eliminate overlapping or redundant codes. This resulted in overarching themes emerging from the data. Further refinement took place on the themes that had been generated. NVivo was invaluable in the process of thematic analysis as it enabled me to visualise my data and the relationships that existed between themes. NVivo was then used to extract participant responses into what would become my data analysis chapters of 4 and 5.

3.9 Ethics

This study received ethical approval from the University of Salford research ethics panel and took into account the following:

3.9.1 Confidentiality and anonymity

Protecting the privacy of a participant, through maintaining their anonymity and confidentiality is integral to ethical research. To manage anonymity and confidentiality, this study took certain steps in line with established research ethics guidelines from organisations such as the Social Research Association (SRA), The British Sociological

Association (BSA), as well as the ethical framework published by the University of Salford.

Throughout the study I sought to ensure that the rights of the research participant were always respected. The names of participants were changed to ensure no accidental disclosure of a participant’s identity could occur. The process of storing and protecting data used in this study were central to maintaining confidentiality and anonymity. In terms of data protection, I ensured that all Personal data would be collected and used in accordance with GDPR legislation. I was aware of data minimisation and as such, I only collected the data that was needed for this project, with every effort being taken to anonymise the data at all times and any information that could be used to identify the participant was removed.

3.9.2 GDPR

Throughout this study, I sought to ensure that all Personal data was collected and used in accordance with Data Protection legislation including the DPA and GDPR. Participants were made aware that consent, that will be unambiguous, can be withdrawn at any time by any participants in this study. As a researcher, I am aware of data minimisation and as such I sought to only collect the data that was needed for this project, with every effort being taken to anonymise the data at all times, also any information that could be used to identify the participant was removed.

I am aware that it is critical to ensure integrity and confidentiality and as such, I took the following efforts to safeguard integrity and confidentiality, until such data was deleted and disposed of securely:

For paper-based data and hard media including copies of any recordings, it was:

- Kept in a lockable cabinet when not in use.
- Coded and anonymised to prevent any breach of confidentiality.

For electronic data, it was:

- Stored on an encrypted external hard drive when in transit and stored on my University of Salford one-drive account.
- Coded and anonymised to prevent breaches of confidentiality.

- Not displayed where third parties could inadvertently view it.

At all times, I acted in full compliance with GDPR and FOI legislation. In accordance with article 5(e) of the GDPR, Data was only kept for as long as it is necessary to do so. Following the transcription of audio recordings, recordings were erased. Should a participant have wished to be withdrawn from the study, data collection would have ceased immediately.

3.9.3 Safeguarding

It was acknowledged that, if a participant was to indicate that they or someone else was in danger of significant risk of harm or I suspected it, then I would have to share that information with my supervisory team, or the relevant authority. The same procedure would be followed if I had suspected any criminal activity. All participants were informed of these safeguarding issues prior to data collection.

Whilst phase two presented additional risks in terms of exposure to unfamiliar equipment, with a risk of harm or risk of getting lost whilst using the device during the period of use, participants were asked to only use the device alongside their everyday routines, conducting daily tasks that they would normally do so without the presence of GPS or being tracked. The device therefore only served as an added tool. Participants would also be trained in how to use the selected device, during this training and demonstration of the device, participants were able to ask any questions or queries they have, with an online platform created to aid the participant in seeking advice or requiring guidance.

The device used in phase 2 of this study underwent testing (carried out by myself) and had been selected by individuals living with dementia and their care partners based primarily on the simplicity of use. Participants were also given a user guide, written in laypersons terms, which concisely explained how to use the device and its associated features. I was on hand to answer any questions or assist with any concerns and provide additional information throughout the 3-month period of using the selected GPS device. Changes, because of COVID-19, brought in an online component, with a website added to provide additional support to participants throughout the study. The global pandemic also resulted in other issues such as the occurrence of shielding for people who are clinically vulnerable from COVID-19. Government guidance advised those shielding to stay at home as much as possible, only leaving their home for medical appointments, exercise or if it is essential (NHS, 2020c). This advice was released in March 2020 and the implications of these instructions, in relation to my study, resulted in individuals living with dementia and their care partners limiting the amount of time spent outside their home.

3.9.4 Dewing (2007) Process Consent in participative research

Consent is an ongoing process (Dewing, 2007). Capacity and consent are therefore considered to be fluctuating. Consent in both phases was formalised by the signing of a consent form, although formal and non-formal cues were always respected. If it was suspected that consent may have been withdrawn, data collection would have ceased immediately, and the consent process would have been reviewed. As this doctoral study involved a group containing individuals living with dementia, a method of process consent, related to gaining informed consent and assent was followed. Dewing's (2007: p.15) work on informed consent has shaped the approach to consent in research. The method for achieving consent for people living with dementia enables inclusion in the research process through a 5-step approach. The 5 steps, and how they have been used in the design of my research, are described below:

1. *Background and preparation*

Dewing (2007:15) asserts that this first step is vital in a bid to prevent the researcher taking "short cuts" as it involves seeking clarification regarding permission to access an individual living with dementia, whether that be from staff, relatives or named individuals. Dewing (2007) confirms that this 'gatekeeper' permission is not always required but does result in added transparency with regards to the researcher's intentions, as well as acting as a reminder that the researcher has a duty of care towards the individual living with dementia. Dewing (2007) further notes how this element in the process ensures the researcher has some knowledge regarding the individual living with dementia, with this background step setting context.

In terms of this study, for phase one, I worked within a familiar environment for both myself and the participants of the focus group. All participants were recruited from a group of 'dementia associates' from the university's Institute for dementia, where I volunteered at one of the groups (SIDS café[6]) (Innes et al., 2021) for around 10 months prior to the commencement of the focus group. I also presented my initial PhD research ideas at an Associate Panel meeting. This familiarity enabled me to have prior knowledge of all potential participants. This knowledge included an understanding into how individuals wished to be engaged with and the best, most effective, forms of communication.

2. *Establishing the basis for consent*

Dewing's (2007) second step is concerned with establishing a basis for capacity to consent. It is understood that capacity is situational and variable. Dewing (2007) proposes that the researcher endeavours to find out how the individual living with dementia usually consents to care or other activities on a day-to-day basis.

3. Initial consent

At this step in Dewing's (2007) method, information regarding the study will be provided to the potential participant in greater detail. This element of the method attempts to ensure that the information given is appropriate and helps the individual living with dementia to understand what the purpose of the research is. For this study, I was aware that all information given to the potential participant must be presented in a suitable and accessible format. I ensured throughout the data collection phases that I did not rely upon non-verbal objection as an assumption that consent has been given.

4. *Ongoing consent monitoring*

This element of the process is concerned with the revisiting of consent and thus forms the process component of Dewing's (2007) approach. Dewing (2007) described this step as "ensuring initial consent is revisited on every occasion or even within the same occasion". I adhered to this element throughout, beginning with the signing of the

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[6] SID'S Café is a monthly dementia Café held at the Salford Institute for dementia, providing individuals living with dementia and their care partners an opportunity to meet other people affected by dementia. The Café often runs a series of talks and presentations, alongside activities (Innes et al., 2021).

consent form and continuing throughout on an ongoing basis, observing verbal and non-verbal cues and acting upon these where necessary. If I had suspected consent may have been withdrawn, I would have ceased data collection, only analysing the data gathered up until the point in which I believed consent to have been withdrawn.

5. *Feedback and support*

The final step attempts to improve the process, whereby concerns regarding the participant are relayed back to care partners or staff where necessary. However, confidentiality must remain a priority (Dewing, 2007).

3.9.5 Application for Ethical Approval

Before the commencement of data collection, separate ethical approval was sought for each phase from The University of Salford Research ethics panel. The application for ethical approval required certain documents to be viewed by a panel, including: a risk assessment form detailing potential hazards faced because of undertaking this research, a data protection checklist ensuring I was familiar with data protection legislation and procedures, a draft of the participant information sheet, participant recruitment material, participant consent form and a draft interview guide to be used in the focus groups. The application also required a valid DBS check certificate, since the study involved participants who may be considered vulnerable. Ethical approval for phase 1 of this study HSR1920-008 was approved on 23rd December 2019, a copy of the approval letter has been attached in the appendices (appendix 6). Ethical approval for phase 2 of this study HSR1920-088 was approved on 3rd July 2020, a copy of the approval letter has been attached in the appendices (appendix 7). An amendment for ethical approval of phase 2 was sought in November 2020 to take into consideration changes of the study as a result of the COVID-19 pandemic, this amendment was approved on 4th December 2020 (see appendix 8).

3.9.6 Adapting documentation

When formatting the documentation, including forms used in this study, I was mindful that accessibility and support for individuals living with dementia remained pivotal throughout the research process (Morbey et al., 2019). My study involved the modification of all documentation to make it suitable and appropriate for the needs of all potential participants in the study. Documentation used in Phase 1 and 2 included elements such as an image of myself next to my name on the participant information sheet and consent form, to enable the participant to be made further aware of who the person undertaking the research was. A larger font size was used, with keywords formatted in bold, and simple language and short sentences used throughout.

3.10 Reflexivity and positionality

“Research is a process not just a product” (England, 1994: p.82), with this process involving reflecting upon and learning from research experiences. This section of the chapter considers the reflexive accounts of my research journey, highlighting my experiences, thoughts and feelings when designing and undertaking this research.

Whilst definitions and approaches vary, according to Ahern (1999), reflexivity involves two processes; the first being one of self-reflection and the subsequent identification of the personal feelings and preconceptions held by the researcher, with the second process being the ability to put aside such feelings and preconceptions. Positionality, however, is how people are defined and their "specific position in any context as defined by race, gender, class, and other socially significant dimensions" (Maher and Tetreault, 1994: p.22) considering factors historical, political, social, and cultural in nature (Louis and Barton, 2002). This section will consider my awareness of what it means to be reflexive, taking into account my positioning, past personal experiences, beliefs, biases and my own personal intentions in relation to the study.

It is understood that the background of the researcher impacts and influences all stages of a study, from initial scoping exercises to the design of the study itself, including how data is collected and interpreted (Kacen and Chaitin, 2006; Punch, 1986). From the earliest chapter of this thesis, I have clearly set out my own ambitions and influences for this research. Prior to conducting this research study, my background is rooted in technology and the field of computer science, in particular, software development. Experiences in this domain have afforded me insights and understandings into the processes required to design and produce technology similar to that found in this project. I have first-hand knowledge of the shift towards agile approaches to software and hardware development, an approach that favours a client or stakeholder being closely engaged in the development phase. This agile philosophy is one that influenced the design of my study. In relation to the technical selection of devices to be used in phase 1, I established a rigorous process of selection, which was informed and guided by my own technical knowledge. However, I found that this also brought about personal challenges, in particular the ability to explain technology in laypersons terms. During the focus group of phase 1, participants asked a range of technology-based questions and, at times, it was difficult for me to phrase a response in a manner that would be understood and meaningful to them.

Following the completion of the phase one consultation focus group, I took the opportunity to reflect on what worked well and what could be improved upon. I felt that given my inexperience to this method of data collection, my mediation of the session was successful. The participants' familiarity with the focus group format and the research process added significantly to the success of the session, in which all attendees actively participated, and I was able to gather a large amount of data in a fairly short timeframe. I also had an existing relationship with participants recruited to this phase of the study, having volunteered at the dementia café they all attend, throughout my studies. This enabled me to build an effective rapport with attendees, creating a trusting relationship, and I felt participants were able to freely disclose their lived experiences, concerns, and worries without fear of judgment.

The interview transcription process served as a useful opportunity for me to be reflexive during phase 2. Aided by the staggered start to this phase, I was able to transcribe verbatim each interview with care dyads immediately after the discussion took place. By doing this, alongside taking notes during interviews about participants' comments and my thoughts, I was able to refine how I conducted interviews, the approaches taken and the way I asked questions.

Over the course of the 4 months that I was in contact with care dyads, I built a successful rapport with them. As I was responsible for all aspects of this study, from recruitment to the interviews, as well as facilitating the ongoing technical support throughout the period of use, I was acutely aware of how vital an effective connection with care dyads was for their continued involvement. Their relationship with the technology was, in some cases, dependent upon their trust in me as a researcher and a teacher. I stayed with them throughout their journey from initial interest which included the questions and queries they had in relation to the technology, through to learning how to conduct each function and using it in their daily lives. I shared their frustrations when they struggled as well as sharing in their delight upon succeeding in using the technology. I strived to motivate them and tailor the way I explained how certain features worked, learning that some care dyads required step by step guidance whilst others simply wanted reassurance that they were operating it correctly. I also felt upset when one care dyad felt that they could no proceed with the study, but this disappointment wasn't due to study recruitment and participant retention, it was because they had previously explained to me how important this technology could be for them. The benefits were there to be gained, however, their self-efficacy and the lack of belief in their own technical skills impeded them and served as a barrier. It is barriers such as these that this study has sought to remove.

This brings me to the values and beliefs that I hold, and how these may have impacted upon my analysis. As previously stated in section 1.2, my background is not as a social scientist, it lies in computer science and management studies. Prior to this study I gained knowledge in how computer systems work and theories of software and hardware design and development. Computers, and technology in general, were an essential part of my upbringing as the late 1990s and early 2000s saw the spread of the Internet, caused by an increase in access and availability. Due to my upbringing, and as evidenced in my undergraduate studies, I have been driven by a desire that technology should be accessible and available to everyone. Whether it be teaching my grandparents how to operate their new TV, or purchasing their first smartphone for them, my intentions were to ensure that nobody felt left behind by technology. Many of these values and beliefs form an essential part of this thesis, as I concentrate on solutions to narrow the digital divide, because I believe that the digital divide emphasises the socio-cultural inequalities that exist in our society.

Monthly Supervision meetings with my supervisory team, held in person at the university prior to the outbreak of COVID-19 and moving to a remote format via Teams during lockdown, were essential to aid the processes of reflexivity and positionality. Especially as a novice researcher, my supervisors were able to provide me regular, ongoing feedback and encourage me to reflect upon the work I had submitted to them. During these meetings I was able to put questions to my supervisors and they were able to challenge my understandings, helping me to build upon existing knowledge and skills in this area and the methodological underpinnings for the study. The supervision records written following each meeting documents the decisions taken by me and my feelings towards them.

3.11 Summary of chapter

In summary, this chapter has provided an explanation of the design of this research study, including the study's methodology, how data was collected in both stages and the processes that were taken when handling and analysing the data. This section of research design detailed the process of thematic analysis that was undertaken in both phases. One of the major aims of this project was to make use of the wealth of knowledge held by individuals living with dementia and their care partners, by exploring the lived experiences of dementia. This chapter has sought to facilitate this through the chosen methods and methodology. Both phases were designed to guarantee that people living with dementia are an essential part of the study; this is not research 'about them', or through the use of a proxy to explore what people with dementia might do, this research sought to ensure that their voice was heard, understood, and had an impact. This chapter also discussed the challenges and obstacles brought about by the COVID-19 pandemic and how I quickly and efficiently responded and adapted to allow research to continue in light of government restrictions and constraints on face-to-face contact with participants. Attention is also given to the ethical considerations that were made when designing this research, considering issues of consent and the process by which consent would be gained and reviewed. Similarly, this study aimed to ensure the confidentiality and anonymity of participants,alongside discussing the concerns regarding data protection. In this chapter I have charted my journey and research process, as this impacts upon the data collected and my presentation of the findings that begin in the next chapter.

CHAPTER FOUR

PHASE 1 – CONSULTING PEOPLE LIVING WITH DEMENTIA AND CARE PARTNERS ON OFF-THE-SHELF GPS TECHNOLOGY

CHAPTER FOUR: PHASE 1 - CONSULTING PEOPLE LIVING WITH DEMENTIA AND CARE PARTNERS ON OFF-THE-SHELF TECHNOLOGY

4.1 Introduction

This chapter details phase one of this study, a consultation focus group consisting of people living with dementia and care partners, to gather in-depth views, opinions, and insights on a range of off-the-shelf GPS technology. During this session, participants were shown 7 off-the-shelf GPS devices, all available for under £30.00. Participants had the opportunity to seek more information about each device, including functionality, however the cost of each device was not disclosed to participants. This chapter (in section 4.2) will detail the 5 themes that were identified following analysis of the data, including: Safety for the person living with dementia, freedom and independence for the person living with dementia and care partners, how the technology needs to adapt to the dementia journey, practical considerations for users and finally, cost burden.

4.1.1 Introducing the participants

As previously stated, phase 1 consisted of a consultation session focus group with individuals living with dementia and care partners. Participants were recruited from a panel of ‘dementia associates’ at the University of Salford’s Institute for Dementia. The group known as ‘dementia associates’ have been involved in advising on different aspects of research and engagement since their foundation in 2014 (Bowker et al., 2020). The group were formed with an aim of raising awareness of dementia and contributing to improving the lives of those living with the condition (Bowker et al., 2020). Table 8 below details the pseudonyms adopted for each participant as well as their identified role/experience of dementia.

Table 8: Participant Characteristics for phase 1

Pseudonym	Role
Ethel	Person living with dementia

Jane	Person living with dementia and former care partner
Edna	Care Partner

4.1.2 Introducing the devices

As demonstrated in Chapter 3, (section 3.3.3) a rigorous process was adopted to condense the range of off-the-shelf GPS devices available on online marketplaces to a more manageable size to put to participants of the consultation focus group. The aim was to present off-the-shelf GPS devices of different styles and types (for example pendent design, wristwatch format or a device that could be carried on the person) and of various shapes and sizes. My intention was also to ensure that participants did not feel overwhelmed with a vast number of devices, since I sought to ensure that each device could be discussed in turn during the hour-long session. In total, 7 devices were displayed to participants, should none of the 7 devices appeal to those present at the consultation session, the focus group would have been re-held with a new set of devices. Each of the 7 off-the-shelf devices are shown in table 9 below.

Table 9: Devices used in the consultation focus group

Device A	**Device B**
 Waterproof GPS tracker Type: Carried Battery Life: ST 12 days, WT 6 Days	 GPS tracker with SOS button for 2-way talk Type: Carried Battery Life: ST 5 days, WT 2 days
Device C	**Device D**
 GPS lanyard with 2-way talk Type: Pendant Battery Life: ST 15 days, WT 4 days	 GPS Fitness Wristband Activity Tracker Type: Wristwatch Battery Life: ST 21 days, WT 3.5 hours

Device E	**Device F**
 Credit card GPS tracker Type: Carried Battery Life: ST 4 days, WT 2 days	 Waterproof GPS Watch with 2-way talk Type: Wristwatch Battery Life: ST 5 days, WT 3 days
Device G	
 Waterproof GPS Multi-tracker Type: Pendant Battery Life: ST 4 days, WT 1.5 days	

4.2 Thematic analysis of phase 1

Thematic analysis of phase 1 explores the views and perceptions of the focus group held in March 2020. This study adopts an outline for thematic analysis similar to that proposed by Braun and Clarke (2006) that considers identifying, analysing, and reporting themes within the data through a six-stage approach that begins with the researcher familiarising themselves with the data. Initially, I familiarised myself with the data by reading through the transcripts made whilst making notes of initial impressions, before again reading and then rereading through the transcript in full, line by line, using line numbers to assist this process. Secondly, I began the process of labelling and coding relevant words, phrases and quotes, followed by filtering out the most important codes before categorising them into themes. The step that followed involved deciding upon the most important themes and establishing links between them. This section represents the final step of interpreting and discussing the findings.

When looking at the lived experience of participants in this study, the context of themes is important, as it relates to their personal dementia journey. This point was conceptualised within the focus group by several participants who verbalised on several occasions that everyone has different needs, and the device needed to "speak" to these individual needs. They felt that everyone's needs were so different that it would be difficult to find a device that could meet everyone’s needs; “One size doesn’t fit all” in view of their lifestyles. Many of the themes discovered in this analysis are interconnected.

Thematic analysis for phase one utilised an inductive approach to analysis, where the themes that have been identified are strongly linked to the data itself (Braun and Clarke, 2006). Rationale behind adopting an inductive approach was to ensure that themes were ascertained directly from the views, opinions and lived experiences of people living with dementia. Throughout this study I have sought to ensure that people living with dementia are included in the research and their voices used to shape the project, this inductive process allowed the themes to reflect their contributions.

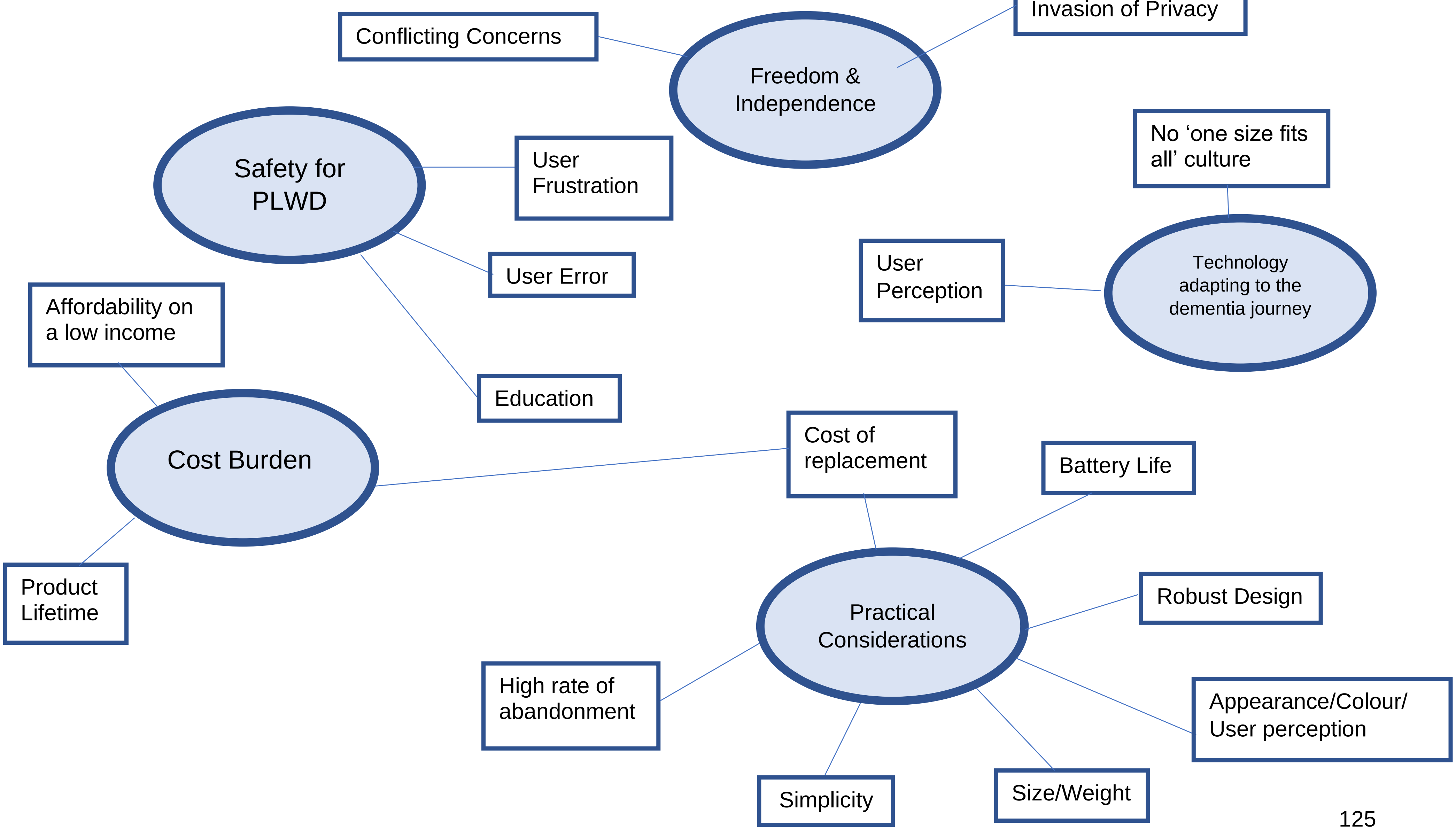


Figure 23: Thematic map of phase 1

Table 10: Thematic analysis themes and sub themes

Superordinate theme	Sub themes
Theme 1 **Safety for PLWD**	User error User frustration Education
Theme 2 **Freedom and Independence for PLWD and Care-partners**	Conflicting concerns Invasion of privacy
Theme 3 **Technology adapting to the dementia journey**	No ‘one size fits all’ culture User Perception
Theme 4 **Practical Considerations for users**	Size/weight Appearance/Colour/User Perception Simplicity High rate of abandonment (non-use) Battery life Cost of replacement Robust design
Theme 5 **Cost burden**	Product lifetime Affordability on limited income

THEME 1: Safety for Person living with dementia

The theme of safety for the person living with dementia was paramount to all participants, this reflected their feelings of anxiety and worry in case the device failed in any way. Specifically, participants referred to user error that was, at times, attributed to the dementia. Below are 3 sub themes that emerged from the qualitative data gathered:

Sub theme: User Error

Participants voiced a concern that they may forget to turn the device on, or indeed forget to take the device with them, and saw this as a major safety concern. Whilst one participant attributed this to the dementia, another, who was not living with dementia, admitted that it was quite natural for her to forget things

> ETHEL: “*you see for me I could easily forget to put it on, or switch it on, in fact I could even put it through the wash [laugh].”*
>
> EDNA: *“I can take my coat off and forget where I’ve put it, or leave it in a pocket, I am always doing those sorts of things”*

Those living with dementia were worried about causing malfunction, in terms of activating the SOS alarm feature at inappropriate times and causing worry to relatives or care partners.

> ETHEL: *“You see, my son is always telling me ‘mum you’ve pressed the wrong button again, what do you want this time’”*
>
> JANE: *“My dad presses everything, the carer on call is always coming out because he’s always pressing something”*

During the discussion, Jane refers to “having less things that can go wrong”, this issue may coincide with the design of the device, in that they may be alluding to having less features or functionality, to reduce the potential chance of user error occurring.

> JANE: *“So how many numbers can the button call, I wouldn’t want to worry lots of people if I pressed it. I am probably better having less things that can go wrong”*

This point coincides with theories found in relevant literature (Holzinger et al., 2011), arguing that simplicity enhances performance with regards to technology aimed at older adults. There is often a high rate of abandonment in complicated technology, where users simply stop using potentially vital technology, such technology often seeks only to address functional needs whilst failing to understand the complex reality of people’s lives (Langley et al., 2020).

Sub theme: User frustration

During the session, concerns were raised by those living with dementia that they themselves would destroy the device through frustration and incomprehension. Those living with dementia agreed that if they were confronted by devices with multiple functions, then this would be a cause for concern, as they lacked the patience to deal with technology that appeared complicated. One participant spoke about how she frequently threw things on the floor, or stamped on them, if she could not easily operate or use the item. She accepted that this was not an ideal coping mechanism, but her point was that this often occurred. She said:

> ETHEL: *"I know what I am like, I mean for me, If I got angry with it, I would probably throw it and stamp on it. It needs to be simple and strong, and it needs to be cheap, as if I destroy something which was a £100, I won't be very popular. At least if its only £30, it isn't as bad."*

Another participant raised a similar point surrounding complicated technology and their frustrations at not being able to understand it:

> JANE: *"I get annoyed and I throw things, because I just can't do it and then I feel stupid"*

This subtheme of user frustration undergoes further exploration during analysis of the theme of robust design.

Sub theme: Education

Learning how to operate devices correctly presented itself as an issue for some participants coinciding with concerns raised in relation to user frustration and technological literacy. Participants expressed anxiety that their failure to use this technology efficiently and effectively could impact their own safety and the safety of those they provide care for.

> JANE: *"Yes its exactly like with a phone, I'm now getting mixed up but it is not something you can get mixed up with"*

Edna discusses fears of being left behind by technology, before remarking on what she has done to try and prevent this from happening. For Edna, whilst she has learnt how to use some technology, she still felt there were areas that required more education to help keep her knowledge current.

> EDNA: *"But it is like I always say, we weren't brought up with this technical stuff, I've done my best to learn bits, so I wasn't left behind, but I need to learn more"*

Participants expressed a desire to further understand how the technology works, with the care partner reassuring those living with dementia that they were not alone with such concerns, with technological literary presenting itself as an issue for many older people. The issue of education also arose when participants discussed concerns surrounding choice when it comes to technology, with an agreement between attendees that they would opt for something that is recommended to them. This was because they felt that they did not have the technical knowledge to make that decision by themselves. The importance of technological literacy and learning are discussed in the review of the literature, with the digital divide presenting a risk of a significant number of care partners, older adults and individuals living with dementia lacking access to technology and services despite the vital support they might offer (Dahlke and Ory, 2020).

Summary of theme

The overarching theme of safety encompasses the sub themes of user error, user frustration and education. Safety was of pivotal concern for participants who identified as a care partner. Individuals living with dementia were predominantly worried about how their own user error could contribute to the success of these devices, highlighting previous experiences where they had caused worry to friends and relatives by not being able to use technology in practice.

THEME 2: Freedom and Independence for PLWD and Care-partners

The theme of freedom and independence permeated throughout several conversations during the focus group as the device was seen as a way of generating freedom whilst maintaining their safety and reducing the amount of worry felt by care partners. Participants spoke of their need to remain independent and at times how this conflicted with care partners views. Those living with dementia appreciated the validity of those worries but whilst also asserting the fact that they needed their independence. Therefore, a device was seen as a way of addressing these concerns and enabling them to maintain independence.

Sub theme: Conflicting concerns

Participants talked about their need for freedom, and how this was countered against the concerns that their care partners had. It was acknowledged that their care partners' fears were realistic and reasonable, but they did not want these worries to curtail their freedom and autonomy.

> *ETHEL: "I know my family worries, but I can't not go out. And I go out a lot. I think something like this (referring to the devices on display) would be really useful, just to stop them worrying. I'm right in thinking, you don't have to press anything to see where I am? He could see where I was, and I could press this if I need to, a bit like the alarm thing I have. I think these are a really good idea"*

Alternatively, the technology could present an opportunity to address conflicting concerns or needs. An example of such may be through the existence of care partner burden and anxiety, and the ways that GPS technology has been found to alleviate such issues, as well relieving the feelings of being a burden on the individual living with dementia (Megges et al., 2017).

Invasion of privacy

These concerns were also discussed in relation to surveillance and privacy. Whilst this focus group served as a tool of education for some participants, as they discovered new ways in that the technology could be used within dementia care, they were all aware of the fundamental purpose of the technology.

> ETHEL: *"[Whilst examining devices G and B?] Yes, this does appeal to me, can I turn it off or is it always tracking me?"*

Whilst the above quote from participant, Ethel, may have been referring to user error in turning the device off, participants did make reference to the extent, range and control regarding who was tracking their location on-demand, as can be seen below:

> JANE: *"So how do you know its tracking, does your care partner track you?"*
>
> ETHEL: *"How can you see who's tracking you?"*

> EDNA: *“Yes they’d have to have an iPhone or a computer to track you”*

Whilst participants expressed concerns that they could not tell if a device was tracking or not, contextually, these comments were linked to their concerns surrounding whether the device was actually working, rather than identifying whether or not their locational data could be compromised, and an invasion of privacy was taking place.

Summary of theme

Participants were primarily concerned with the ways these devices could increase their freedom and independence. Whilst there was a link to the impacts of having greater autonomy, in relation to care partner worries, participants implied that reducing care partner anxieties was of greater concern to them.

THEME 3: Adapting to the dementia journey

Participants discussed the need for a device to be able to be flexible and adapt depending upon the needs of the user. Some participants made reference to the ‘dementia journey’, suggesting that the devices that may be suitable at the beginning of an individual’s dementia journey may change and therefore a device needs to be versatile.

> EDNA: *“We were saying some would cope differently with a watch, Like I said it depends on the type of dementia they’ve got, how they can cope with anything, some might be able to cope with one thing”* … *“It might be suitable early on for one like a watch type, that would have worked for my husband before I had to start locking the door and not letting him out, maybe that’s what I’m saying, once it gets to that stage, maybe one like this [device D] is suitable for someone like [Lists 3 other dementia associates living with dementia], who are still able to go out and about and then it needs to be looked at what is suitable, what is the best for them.”*

The quote *“everyone copes differently”* (Edna) is pertinent when discussing this sub-theme and indeed the superordinate theme of changing needs. Participants recognised that everyone’s needs were different, for example, Ethel would take off a wristwatch style design whereas Ethel wouldn’t wear something around her neck. They also understood that these preferences may change as their dementia journey progressed. One participant provided an anecdotal reference to another member of the dementia support group who had a GPS tracking device for use whilst they went shopping, although, the purpose of the device may have changed now as they conduct less tasks independently and tend to only go shopping alongside their care partner. However, the device may still be of use should the individual living with dementia become lost.

Sub theme: no ‘one-size-fits-all’ culture

All participants were impressed with the additional accessories that came with one of the products (device G), stating that the versatility in the number of ways the device could be used would be a massive incentive to purchase the product. Participants noted that some users may not like wearing a device around the neck, others would want to be able to conceal the device, and some may want the device to be easily accessible. Device G enabled the user to choose how they wear the device, a lanyard is included so the device could be carried around the neck, a belt clip is also given to enable the user to wear it on their belt, or a carabiner should they wish to connect the device to their bag or clothing. One participant stated *“[This one does everything] so I have changed my allegiance to this one [G] looking at the accessories that go with it”* (Ethel).

> EDNA: *“[Observing device G] I do like the belt one, and that could be put on a bag, or anything… So that’s why I like this one with multiple uses”*

One of the main reasons it was believed that device G was selected by participants for phase 2 of this study, was due to the multifaceted nature of the device. Participants were impressed with the versatility in design and saw this device as an ‘all-inclusive’ device that would maintain its efficacy as their needs change.

Sub theme: User perception

It is believed that perceptions in relation to this technology are changing as the use of GPS is becoming more widespread within society. One participant of the focus group remarked how the technology is present in other products such as phones or watches. This furthers the ‘normality’ narrative described previously in this analysis.

> EDNA: *“I know some can do that on their phones, [Name of dementia associate] has it, I think its part of her watch and they can track her”*
>
> ETHEL: *“We had something similar in search and rescue, we could pinpoint someone’s phone”*

In terms of the perception of value that resonated from the discussion, the needs and expectations of participants can be broken down into 3 concepts of value:

Functional Value

Participants understood what the devices could offer them in terms of functionality, and they understood the solution GPS tracking technology could provide. This differed from participant to participant, but one spoke of the ability to attend more conferences, safely, for a longer period of time.

> ETHEL: *“I could take this with me when I go to conference… they then be able to pinpoint exactly where I was, my exact location”*

Financial Value

All participants of the focus group agreed that the devices displayed in front of them were available to be purchased at a reasonable price point, with some being unable to see why the devices used at this focus group session were available at only a fraction of the cost that non-off-the-shelf devices are listed for.

> ETHEL: *“I can’t see why these are so much cheaper then, what do they not have that the ones you said were £100 do?”*
>
> ETHEL: *“I suppose once I’d tried it, I would be tempted to buy another one. Depends how I would manage with it but that’s a possibility yeah. Because I leave everything everywhere”.*

The exact cost of devices was not disclosed to participants until the end of the focus group, to prevent cost being an influencing factor when selecting between the displayed products. This was done to ensure it was the functionality of the products that was being reviewed by participants. Participants were aware, however, that the maximum cost of each device was £30.

Social Value

In this study, social value may well coincide with the function value of the products, as participants recognised the ability of the devices to enable the user to connect more with others. Ethel saw the anticipated use and value of one of these devices coming from attending more conferences. Whilst they would already consider themselves a very sociable people, a GPS device could enable even greater freedom and reduce the consequential anxieties that come with it, from a care partner perspective. Another participant noted even the small tasks that could undergone whilst using such a device.

> JANE: *"one like this would be great for just going to the bank or shops"*

The social value of devices relates to independence and freedom, as well as practical value in completing activities of everyday life.

Summary of theme

This theme can be summarised by the quote: *"Yes, everyone is different aren't they, their needs are different"* (Ethel). This theme encompasses issues related to the need to prevent a 'one-size-fits-all' culture to designing or selecting these devices. Participants noted, on several occasions, how everyone *"copes differently"*, and what may be beneficial to some, may be less workable for others.

THEME 4: Practical considerations for users

Sub theme: Size/Weight

The size of the device was important to participants, but less so than some of the other attributes. Whilst it was important that the size was discreet and able to be carried or worn with ease, it was perhaps an attribute that could be compromised on.

One participant noted how the small nature of the device could lead to a lack of use and could be easily lost, stating:

> EDNA: *"And I think it is the smaller ones that end up [lost/forgotten about] in the drawer rather than a watch one"*

Participants wanted a product that could fit in a pocket however were mindful of then losing the device upon their person

> EDNA: *"with these that are put in a pocket, you then forget, hang on, where is it"*

In addition, one participant favoured a larger device as they saw the smaller device as a potential choking hazard for the grandchildren.

> ETHEL: *"I'm always being aware of the size around the grandkids, don't want it to be too small or I would worry that they could try to swallow."*

Bulkier devices were however considered inappropriate and perhaps drew attention to the purpose of the device, leading to stigma or vulnerability. One participant stated, *"the size of it looks a bit daft"* (Jane). It can be said that the general look and feel of a device was influential in the choosing of the device by participants.

Sub theme: Appearance/colour

At the beginning of the focus group, the items were initially judged on their aesthetic appearance, colour and whether they were considered 'childish', 'well-made', or attractive. The colour was assessed in terms of gender suitability, with participants commenting on if the colour of the item was suitable for women or for men, or whether the colours were too bright or too dull etc. Edna commented that her husband would not have worn something that was bright red.

Participants favoured devices that were considered gender neutral, with one device, a bright blue GPS tracking wristwatch being deemed childish, with one participant remarking that their husband, who lived with dementia, would *“never have worn that”.* The majority of devices were black or grey in colour, the black GPS watch was considered modern and *“looks normal, like a fit-bit watch”* (Edna). The point of modernity was considered by participants:

> JANE: *“It is a very modern one”* and *“I think you could wear it daily, it is, like, trendy”*
>
> EDNA: *“it looks very modern and you see lots of people wearing them”*

The idea of seeing other people, not living with dementia, wear a device similar in appearance is an encouraging one, that would improve the user perception around wearing a tracking device and perhaps lead to continuous use. Participants didn’t want a device that highlighted the nature of the product, reasserting the need for normalising these devices.

Sub theme: Simplicity

Simplicity was an important sub-theme emphasised at many points during the discussion and links heavily to other sub-themes such as user frustration and how quickly this technology may be abandoned.

Both care partners and individuals living with dementia expressed the need for devices to be simple, with few buttons, with participants being less concerned about functionality and favouring ease of use above all else.

> EDNA: *“Yes, a lot of us are only just getting the hang of our phones, so it has got to be simple and straight forward, we don’t want all these fancy things on it, keep it simple.”*
>
> ETHEL: *“I would definitely benefit from a simple one that just told people where I was”*
>
> EDNA: *“I think its all about the simplicity of using it, nothing complicated”*

As previously stated, the simple nature of the devices coincides with the idea of limiting or reducing the occurrence of user error and may be a factor in participant’s preferences of simpler technology.

Simplicity was also discussed in relation to preventing user frustrations, as easy to use and accessible technology was seen as a way to prevent the annoyance and discouragement felt when failing to understand or remember how something works.

> *JANE: "You see I have a problem with technology, I can't ever remember how to do things, If you set it that would be fine, but I cant remember, I have been on 3 computer courses and I cant remember. I can't follow instructions".*

Such concerns surrounding the simplicity of devices align with findings from the review of the literature to date. Studies by Liu et al. (2017) and Chen and Leung (2012) found the ease of use for a care partner to operate a device will define its success in terms of adoption of a product.

Sub theme: High rate of abandonment (non-use)

Abandonment is a serious problem facing assistive technologies (Petrie et al., 2018). Factors that often contribute to high rates of abandonment include functionality, worries over accuracy, privacy concerns, durability and usability (Petrie et al., 2018).

Whilst participants of this focus group generally linked abandonment to the cost of the devices, the most significant consequence of abandonment of assistive technologies is that over one third of purchased products are abandoned when they are still required (Dawe, 2006). Participants who identified as a care partner understood how important the continuous use of these devices was and stressed the vital concern for making these devices as simple to use as possible. Due to the nature of the devices, many of the factors of abandonment, listed above, would arise from the care partner, for example, if they did not understand how the devices work or had concerns surrounding the use of the devices.

> *EDNA: "I think like [Ethel] says, It has to be something quite simple really that does the job, because if it gets too complicated you get frustrated with it, I know my husband (who lived with dementia), he'd get frustrated if there are too many things going on at once"*
>
> *ETHEL: "…and at the end of the day, it is us that has to use it"*

Additionally, the rate of abandonment (the percentage that a user quits using a piece of technology before completing an intended task) coincides with the feelings of frustration described above, where individuals living with dementia describe “throwing” a device, they may indeed simply be referring to having nothing more to do with the device, bringing an end to its use.

Sub theme: Battery Life

Battery life was a key issue raised during the session, as this was coupled with concerns that they may forget to charge the device, and the battery capacity of the devices may not be adequate for their intended use.

Edna highlighted how the issue of battery life may be relevant some of the time, perhaps suggesting that as an individual progresses on their dementia journey, the pertinence of this theme may alter. Changes could be related to the length of time they leave the house for; individuals may no longer feel comfortable leaving the house for multiple hours and thus a longer battery life may not be required. On the other hand, battery life may rise to become a more relevant concern should a care partner fear an individual may have an increased chance of getting lost.

> EDNA: *“Yes that might not be suitable for some people, some of the time, because you can only be tracked for 3 and a half hours. That’s nowhere near long enough”*

Similarly, there were concerns surrounding the recharging of a device, with participants raising worries related to forgetting to place the device on charge. Participants recognised that many of the devices may require a care partner to ensure the device has battery, this however raises additional worries for individuals whom do not have a care partner who resides with them.

> JANE: *“So how does someone with dementia remember to recharge? that’s the other thing I just don’t remember things”*
>
> EDNA: *“A lot of these would need the help of a carer to make sure they are charged”*

All the participants were involved in dementia related groups, and some were engaged in making presentations around raising awareness of dementia. Therefore, it was important that the device did not restrict their lifestyles, by having a limited battery capacity. Participants discussed going out from early morning until late at night and so they ruled out devices with less than 24-hour capacity.

> ETHEL: *“You see I go out for hours, so maybe that’s not long enough [Referring to the 3.5hour battery life of device D] I can be out for the whole day”*

Participants showed a good level of technical knowledge regarding the devices in front of them, with battery capacity being an area they felt users should be consulted on when developing this technology for their use.

Sub theme: Cost of replacement

Cost was considered by participants when discussing how needs may change, as they wanted to avoid purchasing a type of device that may become obsolete as their needs change. With reference to dementia branded devices, participants noted how the price range of such products was expensive, particularly given how they may go unused, with one stating:

> ETHEL: *“possibly, it is a lot of money to just have, have like sitting in your drawer”*

One participant, Edna, discussed how the type of dementia plays a part in the selection of these devices, linking the cost of the product and its suitability. This point coincides with the sub theme of product lifetime, discussed below. Their comments were as follows:

> EDNA: *“I think another problem is depending on the type of dementia they’ve got can play a big part and to whether or not these, or the type of these things, are any use to them and I think that’s a major issue for a lot of people, especially when they can cost so much.”*

Cost was a further factor considered in relation to the robustness of the design, with one participant recalling their frustration with technology and how it can result in the product getting damaged.

> ETHEL: *"If I destroy something which was a £100, I won't be very popular. At least if its only £30, it isn't as bad."*

Cost, and the potential cost burden, is a theme explored in more depth below, however participants raised valid concerns relating to how this technology could be potentially expensive to replace. Participants living with dementia were particularly concerned about how expensive their own user error, or frustration with this technology, could be.

Sub theme: Robust design

The subject of durability was not a subject that I expected to be a prominent issue. However, participants raised the issue several times, in different contexts. One of the participants, living with dementia, expressed the view that the device should be strong and durable, and be able to be resilient to their frustrations. This was in the context of them becoming angry with objects when, because of their symptoms of dementia, they forgot how to use them correctly. Their views are perhaps best summed up in the following extract:

> ETHEL: *"I mean for me, If I got angry with it, I would probably stamp on it"*

This issue was also raised by a second individual living with dementia, who joined the focus group late and so was not privy to the view raised by Ethel above. This participant commented on how they would want a device capable of withstanding being dropped or thrown.

> JANE: *"I get annoyed and I throw things, because I just can't do it and then I feel stupid"*

Individuals living with dementia may not solely be commenting on robust design, but perhaps showing their awareness of how they might express their frustration if they are unable to use this technology, as such, the product would need to be able to withstand their protests.

Summary of theme

In terms of the theme of practical considerations for users, participants stated their desire for a device to be simple, modern looking and with the notion of normality emphasised by all. Overall, participants deem an acceptable device one that conceals its purpose, through shape, size, weight and appearance, however many also stressed the importance of the device not being too small as to become a problem in itself, through losing the device on the person, or perhaps forgetting to take the product out of items of clothing. This theme can perhaps be summed up with the quote "…at the end of the day, it is us that has to use it" (Ethel), a co-design experience in the process of creating, developing and selecting these devices is pivotal in increasing acceptance and lowering the rate of abandonment of this technology.

THEME 5: Cost burden

Sub theme: Product Lifetime

The issue of cost was raised in connection with the product lifetime of a device, meaning "*the time during which the product remains integer and usable for its primary function for which it was produced"* (Ertz et al., 2019: p.867). During the focus group, several participants made reference to the extent to which a device of this nature (one that tracks an individual) can be useful to an individual living with dementia and their care partner.

> ETHEL: *"I think as the [dementia] journey progresses, the things that you have chosen first might need to be replaced with something else".*
>
> ETHEL: *[On cost of products] "Especially when you just don't know how much you might use it"*

In addition, the cost of devices was brought up as a motivator in potentially purchasing more devices to increase safety and limit the occurrence of user error. Participants found that if a device was £30 as opposed to £150, they could purchase a few devices to store in, for example, different items of clothing, thus increasing the chances of an individual living with dementia taking a trackable item when leaving the house.

Sub theme: Affordability on limited income

One of the overall motivations for this study in general is the rising costs faced by those living with dementia and their care partners. Participants of this focus group recognised how these devices could prove to be a vital form of assistive technology within dementia care and therefore must be accessible for everyone.

> ETHEL: *"I think it is very important that these are affordable for everyone"*

Two participants also alluded to the concept of financial risk and how those on limited income may be unable to take a risk on an expensive device, regardless of the perceived benefits, without prior experience of using the technology.

> ETHEL: *"you would be more likely to take a chance for that price wouldn't you?"*
>
> JANE: *"yes, anymore and it is too much, like you were saying when you just don't know for sure how much you'll use it"*

This idea of 'taking a chance' on more economical off-the-shelf products is an interesting point and suggests that people could be dissuaded from adopting this technology due to large initial costs of acquiring it. This is a further example of the digital divide and how access to technology may be restricted for those who cannot justify large costs without experience of potential benefits.

Following the end of the discussion, the cost of each device was revealed to participants, with the participants reiterating the need for these products to be as low as possible. The current economic climate and the lower economic buying power that comes as a result of increased care needs are factors that must be taken into account when selecting devices of this nature. It is estimated that the cost of dementia in the UK alone is more than £34 billion a year, giving an average annual cost of over £32,000 per individual living with dementia (Alzheimer's Society, 2019a). Alzheimer's Society (2019a) reported that two-thirds of this cost is currently being covered by individuals living with dementia and their family. Solutions to reduce the costs facing individuals living with dementia should be sought, with the products presented to participants in phase 1 offering a practical alternative that, as one participant remarked, are more "*affordable for everyone"* than dementia-branded devices.

It has been reported that almost 2 million UK pensioners (16%) are now living below the poverty line (Age UK, 2020). For many older people, who are surviving on a state pension of £129.20 per week, the cost of dementia specific GPS devices are expensive, and priced out of reach for people on low incomes, with these items retailing at between £100 to £400. Similar reports also highlight the increasing problem of hunger and malnutrition in older people. In such times of austerity, the costs of devices that may enable people to increase their quality of life and live positively with dementia becomes a pivotal concern.

Summary of theme

Overall, the theme of cost can be broken down into several sub-themes, all of which highlight the importance of keep the cost of these devices as low as possible. When the cost of each individual device was disclosed to participants at the end of the session, they were surprised at how inexpensive some of the devices were and were shocked to find those that they perceived as the cheapest, were in fact not. I asked participants at the end of the session if the cost would have influenced their selection, and if now knowing the true price of each device, they would change their selection, to which they informed me they would not.

4.3 Consensus building

During the latter stages of the focus group, and once all members had reviewed each device in turn and considered its respective benefits and limitations, a consensus started to build around the device that was considered suitable for all members and one they felt met their unique needs and requirements. Following discussions about adaptability and the need for a device that is flexible in nature and able to change with them as they continue upon their dementia journey, device G was referenced by each member of the focus group as the device best placed to do this. I wanted to ensure that there was no pressure towards reaching an agreement and uniformity in the decision was not necessary should members have felt a different device was more appropriate for them. By the end of the discussion, each member had given their own account as to why device G was the most suitable of the devices offered in front of them, for Edna it was due to the accessories that came with the product, Jane also spoke of the multi-faceted nature of the device, whilst Ethel chose device G for its simple design. The process of reaching this consensus also involved participants ruling out certain devices. For example, device D was considered at one point to be a potential rival to device G due to its modern design, however, all participants agreed that device D lacked the battery capacity to be considered appropriate.

4.4 Summary of chapter

Chapter 4 has presented the findings from phase one of this study; a consultation focus group containing individuals living with dementia and care partners on a range of off-the-shelf GPS devices. A large proportion of the discussion was given to battery capacity, with participants stating a requirement for a device of this nature is adequate battery capacity. Participants opted for a long battery life that serves to promote increased independence, rather than restrict one’s actions. Participants found that any duration below 24 hours would be unsuitable and result in developing a new worry of limited battery life that may restrict their time spent out of their home. Participants recognised the need for these devices to be available for everyone, referencing the discussions surrounding the digital divide and digital inequalities made earlier in this thesis. Participants could see the value and benefits to be had from these devices, benefits that should be accessed by all. Participants also emphasised the need for technology to be straightforward, limiting the number of buttons on the device itself and reducing what the person living with dementia is required to do. Failure to consider this as a factor may result in user frustration and ultimately abandonment of the technology. Participants requested that this technology be multi-purpose, not to the point where devices are more complex, but to allow for the device to adapt to the user, particularly as they continue upon their dementia journey. As participants discussed the need for a flexible, multi-purpose device, a consensus started to build between participants that device G had the functionality and design that they were looking for in a piece of technology. At the end of the session, participants were asked if any of the devices in front of them were suitable for people living with dementia, and the reasons behind their selection. Device G was found by all participants to adhere to their requirements, as such device G was selected for use in phase 2, which is reported on in the next chapter.

CHAPTER FIVE

PHASE 2 – EXPLORING THE USE OF OFF-THE-SHELF GPS IN THE DAILY LIVES OF PARTICIPANTS

CHAPTER FIVE: PHASE 2 - EXPLORING THE USE OF OFF-THE-SHELF GPS IN THE DAILY LIVES OF PARTICIPANTS

5.1 Introduction

The aim of phase 2 was to provide 8 care dyads with a selected off-the-shelf GPS device for a period of 3-months and explore their lived experiences of using this technology. Two interviews were conducted with each care dyad, with the first taking place before the 3-month period, to gather data related to their initial views, concerns and experiences. The second interview, referred to in this chapter as the 'follow-up interview' took place after the period of use. The device chosen by participants of the consultation group was 'device G', Vodafone V-Multi Tracker, labelled online as "a Multi-Use Lightweight GPS Tracker" (Amazon, 2022). The device was chosen due to its perceived adequate battery capacity, simplicity and flexibility. Participants of phase 1 placed heavy focus upon the device having a long battery life in order to promote increased independence, rather than restrict one's actions. Participants considered that any duration below 24 hours would be unsuitable and would result in developing a new worry that their time spent outside their homes would be restricted on account of the limited battery life. Participants also wanted a device that was straightforward, with a limited number of buttons on the device itself (to reduce what the person living with dementia is required to do). Other requirements were for the device to be multi-purpose, to allow for the device to adapt to the user, particularly as they continue upon their dementia journey. For them, 'device G' satisfied their requirements, and they were impressed with the size, shape, weight and added accessories of the device. Device G can be seen in figure 22 below.

When analysing the data gathered from both interviews, I followed a similar approach as detailed in chapter 4. Using Braun and Clarke (2006)'s method for thematic analysis, this chapter systematically identifies, organises, and offers insights into patterns of meaning (or themes) across the data. This approach was chosen due to its flexibility and ability to provide a rich, detailed, trustworthy and insightful, yet complex, accounts of data (Braun & Clarke, 2006). Thematic analysis is also seen as a more accessible form of analysis, particularly for those early in their research career

(Braun & Clarke, 2006). Similar methods of data analysis have been adopted in relevant literature and found to be effective in providing in-depth detail into the views, opinions and lived experiences of people living with dementia and their care partners (McCabe and Innes, 2013; Bantry-White et al., 2010). Section 5.1.1 will introduce those who took part in the data collection for this phase. Section 5.2 presents the thematic analysis of initial interviews with participants, describing the 4 themes that were identified: Motivations for using GPS, Social participation, Previous experience of using GPS, The impact of the COVID-19 pandemic. Section 5.3 describes the two themes found through thematic analysis of the follow-up interviews with care dyads; the first theme is concerned with care dyad's relationship with technology whilst the second theme explores the outcomes of using GPS.

Figure 24: Off-the-shelf device chosen by participants of phase 1

DEVICE G - VODAFONE V-MULTI TRACKER

- WEIGHT: 20g
- SIZE: 42.1MM X 42.1MM X 16.4MM
- GEO-FENCING
- SOS ALERT BUTTON
- QUAD BAND GSM GSM850/
  GSM900/ DCS1800/ PCS1900
- POSITIONING METHODS: GPS, CELLULAR,
  WI-FI AND BLUETOOTH

COST: £19.99
MONTHLY COST: £2 (UNLIMITED USE)

SOURCE: AMAZON (2021)

5.1.1 Introducing the participants of phase 2

18 people participated in the second phase of this research, consisting of 9 care dyads and comprised of 7 Male participants and 11 Female participants. 16 participants were initially recruited to the study with another two expressing an interest in joining the project and were added to the study to account for potential attrition, taking the total to 18. Participants were located across the UK, the majority of care dyads resided in the North-West of England (5 out of 9). Table 11 below depicts characteristics of each

care dyad, where pseudonyms have been adopted for each participant. Table 11 also details each care dyad's familiarity with GPS, whether they had previously tried the technology, and, if so, via what medium. In the instances where care dyads had reported previous experience of using GPS, they had ultimately abandoned them for various reasons, further details of this are provided in theme 3.

Table 11: Participant Characteristics for phase 2

Individual living with dementia	Care Partner	Location	Care dyad relationship	Previous Experience of using GPS
Roger	Anne	North-West of England	Spousal	No
David	Patricia	South Wales	Spousal	No
Eileen	Joy	North-West of England	Siblings	Yes - GPS device
Peter	Winifred	North-West of England	Spousal	No
Ken	Liz	North-East of England	Parental	Yes – Mobile Phone GPS
Angela	Steve	East of England	Spousal	No
Pauline	Eric	North-West of England	Spousal	No
Barbara	Bernie	North-West of England	Spousal	Yes – GPS device
Janice	Gloria	South-East of England	Parental	No

5.2 ANALYSIS OF INITIAL INTERVIEWS

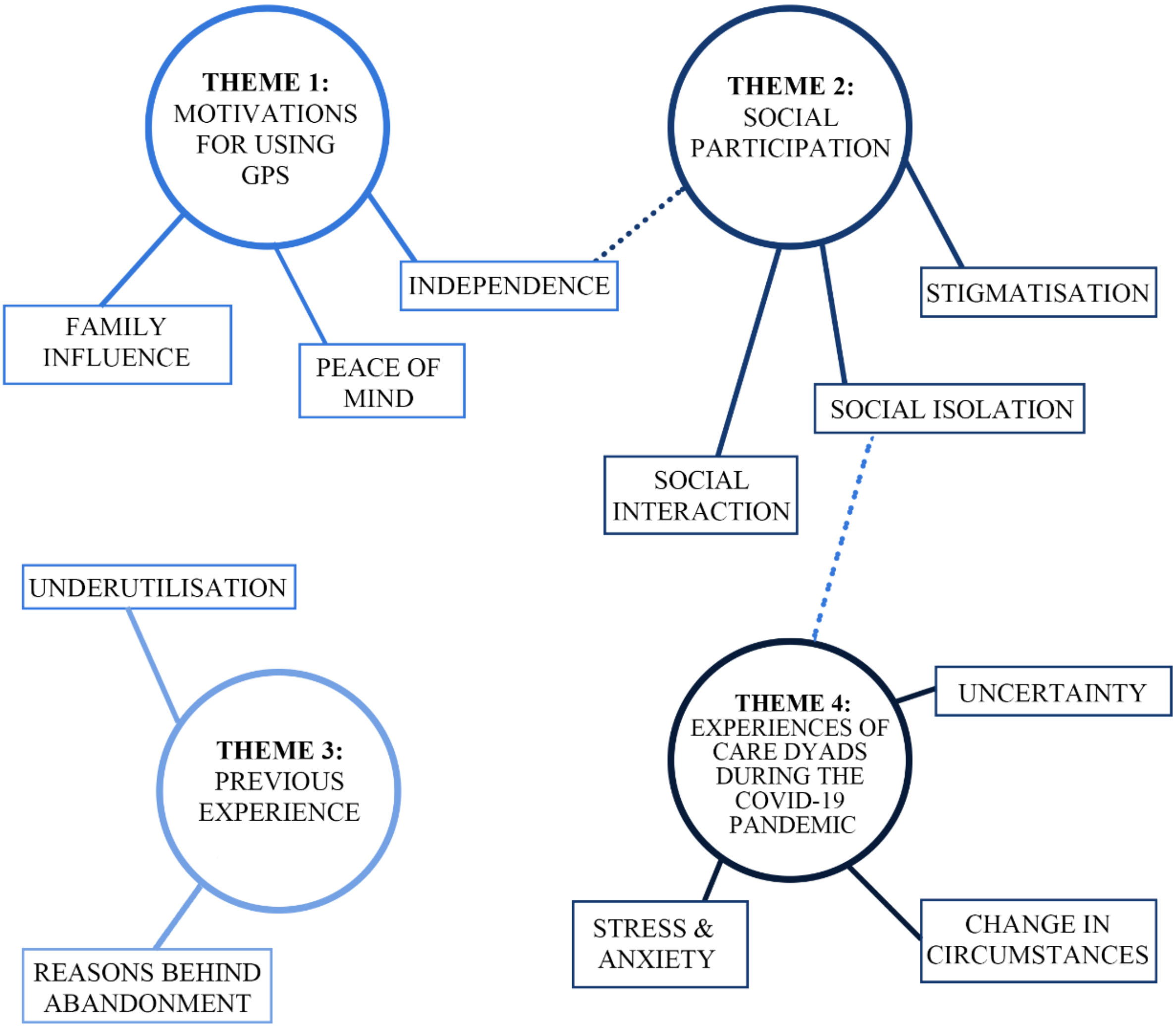
The first part of this chapter presents the themes that emerged following analysis of initial interviews with participants which took place prior to the three-month period of using the GPS device. One of the main objectives of the initial interview with participants was to gather rich, in-depth data related to participants initial views, opinions, and experiences of using GPS. Participants were asked questions related to previous use of technology, existing activities of daily living as well as interests undertaken both together and independently. Thematic analysis revealed four overarching themes in the data that are as follows:

1. Motivations for using GPS
2. Social participation

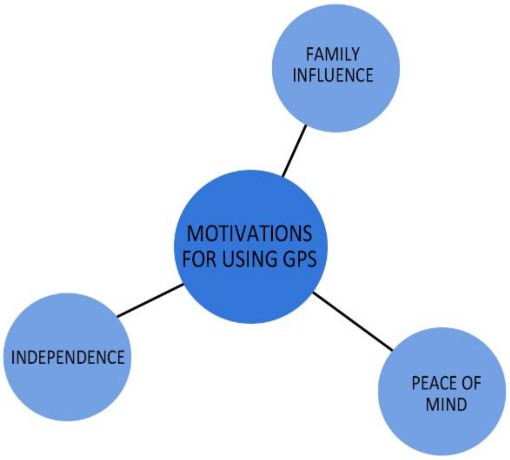
3. Previous experience of using GPS
4. Experiences of care dyads during the COVID-19 pandemic

The thematic map, showing the links between themes and subthemes is shown in the figure below.

Figure 25: Thematic map for initial interviews



THEME 1: Motivations for using GPS



Initial interviews with participants featured many questions related to what the perceived benefits of using GPS technology for individuals living with dementia and their care partners were. Participants discussed their personal motivations for giving the technology a try through my study and what they felt they had to gain by adopting this technology. This theme can be broken down into sub themes comprised of the family influences for adopting this technology and the perceived reduction in anxieties and greater peace of mind for both the care partner and the individual living with dementia. This theme also examines the reasons for adopting GPS based on the perceived increase in independence GPS may provide.

Subtheme: Family influence

Participants discussed the role that family members can play when it comes to selecting, learning and using technology. Accounts by care dyads showed that the adult children of participants had a crucial role in the decision-making process when any type of technology is involved. Families represented both a source of information, to introduce them to the technology, as well as acting as a support resource, providing technical assistance when required. For some participants, this support resource was vital for them to have the confidence to adopt new technology.

Four participants (all care partners) spoke of how they were referred to this technology by a family member, and two participants discussed how their children introduced them to GPS technology:

> *ANNE: Well, our daughter was going to try and get one [a GPS device].*
>
> *LIZ: …yes, we had, my son showed it us on my phone [Referring to the use of GPS using a phone's inbuilt GPS receiver]*

And another care partner, Winifred, reported their lack of up-to-date technical knowledge, how they were often slow to uptake technology, and how family members influenced what choices they may make when it comes to adopting technology:

> *WINIFRED: …it might be like most of this stuff that we get, because we don't stay very up to date with everything, the family does well with us showing us different things that we might need.*

These views expressed by Winifred, in terms of keeping up to date with technology, align with fears expressed by Edna during the consultation focus group in terms needing support to prevent being "left behind" by technology. Winifred's family act as this support source to help keep them up to date. Participants also spoke of how instrumental family members are in assisting them in the use of technology. Eric discussed a fear of getting this technology wrong and how their daughter was influential when it came to getting them involved in this study but was also on hand to show them how to use the GPS device step-by-step and face-to-face.

> *ERIC: …She [Eric's daughter] said she'd come round when the weather is nice and show us how to do it all. I said to her that you'd included that guide, which I flicked through and the pictures looked very helpful, sometimes it is just, you know, showing us which button to press, because I wouldn't want to get it wrong. That's normally how I learn how to do things like this, think I'm more of a visual learner, you know, lots of photos and directions.*

Here, Eric is not only pointing towards their reliance on family support when it comes to learning how to use technology, but also the necessity of visual instructions. This is an important insight into the lived experiences of using technology, with Eric detailing his learning style where he needs to see information to process it effectively. Eric foresaw the included user guide, developed with this particular user group in mind, as essential in order to be able to use this technology.

Other participants also communicated how family members act as a support resource when it comes to technology, citing their own lack of technical knowledge and skill. Winifred repeated earlier concerns that they do not stay up to date with technology, this was clearly a worry for her, that she would not be able learn how to use this technology. They (Winifred and Peter) commented on the significant role that their daughter plays in teaching them how to use technological devices.

> *WINIFRED: No, it is not something we know, to be honest we aren't very up-to-date on technology, we do bits and we can work our phone okay, but it's something we've always just left to [Daughter's Name] to sort out…*
> *PETER: … She's very good at teaching us how to use it*
> *WINIFRED: Yeah, she writes out instructions, for example how to get the recordings on the TV, but she thought this is something that we would be able to use, and I'm right in thinking that she can see it too?*

Anne also discussed how, in normal circumstances (pre-pandemic), their daughter was always on hand to teach them how to use certain technology.

> *ANNE: Normally, I just give my daughter a ring and say, [Daughter's name] I need you to come around and show me how to use this or that…*

Linking this comment made by Anne and discussions that will take place in a subsequent theme, the COVID-19 pandemic had disrupted how they receive technology support. The participants found, due to national lockdowns and stay-at-home orders, they were prevented from simply ringing up their adult children and requesting a face-to-face visit to show them how to use a piece of technology.

One care dyad discussed how family members may differ in their opinion of this technology and how this in turn influences the decisions taken by a care partner. Winifred, who was referred to this technology by one of their adult children, spoke of a difference in personal preferences amongst their children, resulting in a divide as to whether the uptake of this technology should be considered.

> *WINIFRED: But also like [Daughter's name] was telling [Son's Name], he's our son, that its safer than not having anything. [Son's name] was, a bit cautious, he thought that there might be too many risks in trusting this thing to work properly saying it is not worth the danger and it is just safer for dad to not be out the house on his own. But I think that's what we're trying to get across to him that at the moment we don't have anything, so surely anything is better than nothing, even if we do just use it like, just in case. Even if it only ever has to be used once, it is worth it.*

Winifred spoke of a difference of opinion between their son and their daughter on this technology, with their son viewing GPS as presenting unnecessary risk and their daughter suggesting the benefits of using such devices. These insights align with discourses in dementia literature, and the occurrence of debate between risk and reward. Whilst GPS has its proponents, arguing the ability for technology to provide greater freedom, independence and autonomy, others may be opposed to the technology due to fears of increased danger devices may put people living with dementia in. This can also be compared to views that will be discussed within this theme, for example within the next sub theme of 'peace of mind'. Whilst Winfred's daughter perceives experiencing peace of mind knowing the technology could help mitigate the dangers that her father faces, Winifred's son may view this differently and the technology may cause him additional worry and anxiety. These views expressed by Winifred's son also allude to a distrust of technology and a lack of confidence in the technology working as expected.

Subtheme: Peace of mind

Many participants referred to the additional peace of mind that they believed could be gained by using this technology, with this considered to be one of the main rationales behind adopting GPS technology. Care partners commented on how this technology could potentially provide them with respite from worry, as the technology would enable them to check the location of the individual living with dementia on demand.

> *ANNE: Well, I think it will definitely be handy for when he does go out walking, or to the shops, just to stop me worrying if anything else…*
>
> *MF: …so is it something that could give you more peace of mind that [Angela] is safe?*
> *STEVE: Yeah, definitely, that way should I go out anywhere I'd probably make sure she had it with her, so that I could see.*
>
> *PATRICIA: I think it would certainly be nice to know when you do go out where you go*
> *MF: So for giving you a bit of peace of mind that [David] is safe?*
> *PATRICIA: Yes indeed, I don't want to be using it all the time but just in that moment, I sometimes panic that, and yes it would just be nice to pick up the phone, see the dot and relax a bit.*

Patricia made reference to not wanting "*to be using it all the time",* touching on the potential over-reliance that may result from long periods of use. Such concerns were also discussed during the literature review of this study. Care partners understood that this technology may breach a person's entitlement to privacy, and care partners may attempt to reduce the amount they use a device to respect privacy, only relying on this technology when the safety of the person living with dementia is called into question.

Avoiding worry was seen as a major incentive of using this technology by both individuals living with dementia and their care partners. One individual living with dementia spoke of their desire to do what they could to lessen the burden of worry upon their care partner, regardless of any gains in independence or freedom:

> *KEN: I've always said to [Liz] that she's got to do what she's got to do, I don't want to be in the way and some of the things we had to talk about, we did at the very beginning when I didn't get as confused about stuff…*

Ken continued, adding that the concept of being tracked was of no concern to him, regardless of issues surrounding privacy.

> *KEN: if it helps [Liz] then it is a good thing, it doesn't matter to me, I'm not doing anything that is interesting to anyone else, but if that keeps [Liz] feeling better then that's what we've got to do. But I definitely feel better knowing that you [Liz] can get on and do your own things without having to worry about me.*

For Ken, the main potential benefit of this technology was to provide relief for their care partner, Liz, in terms of worry. Ken wished for this technology to relieve the burden that they felt they posed to the day-to-day life of their care partner. Similarly, speaking on behalf of Eileen, Joy felt that the individual living with dementia would want to try solutions that may prevent the care partner from worrying:

> *JOY: … But I suppose, sorry it has just got me thinking that, that it has got to be highlighted that she would want me to stop worrying, you know the peace of mind bit, and it won't work for everyone but not everything does. [Pause] The way I am, I think I have to worry about something, I just, I tend to find something else, if you know what I mean.*

Joy accepted that, as a care partner, they will always experience some form of worry and that new worries of using this technology may replace previous worries surrounding safety. Participants were asked if this technology presented any additional worries to them. This question was intended to probe for data related to concerns surrounding privacy, consent or ethical considerations but for participants who did express worries, all concerns related to newfound fears that, prior to the introduction of GPS, were not relevant to them.

> *STEVE: I guess it would tell me if [Angela] left wouldn't it?*
> *MF: Yeah it would, if she took the device with her*

> *STEVE: Yeah that’s it isn’t it, if she took it with her, so then I’m just going to end up worrying that she hasn’t…*
>
> *PATRICIA: I wouldn’t really say worries no, I think it could be very easy to misplace these things, but we like the size of it, it's very, very discrete. I suppose a worry might be that I forget to tell [David] to take it with him, maybe we could have a couple of them, so you definitely have one on you?*

For Patricia and Steve, the main worries they felt surrounded human error, and the person living with dementia forgetting to take the device with them when they left the house. This is one of the downsides of the technology, as if the device is used to promote independence, there is always going to be chance that human error prevents the device working as intended. There is also the potential of experiencing errors with the device itself, as explored by care partner Liz. Liz reported concerns surrounding trust and confidence in this technology, in particular, the fear of device failure which presented itself as a real worry for them.

> *LIZ: I think, like most things, you do worry that it doesn't work ... you are kind of placing trust in it, … and taking more risks, there is a sense of ‘you trust this device to work’ and if it didn't, it would probably worry me more.*

Liz states that device failures “*would probably worry me more”*. The impression given here by Liz is that in the event of device failures, the worry that she would experience would outweigh the usefulness of the device, making her worry more than she currently does. The *‘taking more risks’* Liz refers to may include the increased independence the technology facilitates. Anne also spoke of their fears regarding device failure but considered these against the alternative options available to them. Anne reasoned that without this device, the person they care for may be confined to staying indoors and whilst they may experience issues with the device, they recognised the device to be essential in preventing them from worrying when the individual living with dementia was outside independently.

> *ANNE: Well, I guess it is like most things these days, they could not work, but I also think it’s better to have it that not, and I know that neither of us like staying stuck inside all day and whilst we have had to for the last 12 months, we need to go out and about and I think this sort of thing is exactly what we need just for, for like you were saying before, in terms of stopping me worrying*

Anne did not wish the person they care for to experience social isolation, also making reference to the COVID-19 pandemic and the feelings of confinement and stress experienced by them both during periods of national lockdowns. For Anne, benefits were there for them both, in terms of preventing worry whilst facilitating independence.

An increase in the perceived safety of the individual living with dementia was reported by the majority of participants as the biggest perceived benefit of using this technology. This was noted by both individuals living with dementia and their care partners. One individual living with dementia commented:

> *MF: Do you think that this tracking technology could give you greater freedom [Ken]?*
> *KEN: I think for me it is more about being safer, because I know what could happen…*

Whilst this comment by Ken directly refers to "being safer", Ken may also be illustrating their views on reducing the worry that Liz may experience. Ken may be suggesting that their safety must always be of paramount importance for their care partner, irrespective of their own concerns surrounding freedom or independence. These views by Ken show the link between safety and peace of mind, suggesting that relieving the perceived burden that their condition places on their care partner is a main concern for people living with dementia. The role of GPS, as a tool to mitigate risk and the added peace of mind that comes with knowing where the person they care for is, is perhaps best summarised by the views of one care partner, Bernie:

> *BERNIE: Oh, I think it's all about that [using GPS to keep Barbara safe], I know there might be good and bad points, but for us its always going to be about safety… things like this this could be a guardian angel for people like us.*

Participants recognised the differing sides to the debate surrounding the use of GPS technology within dementia care, understanding the potential benefits to be gained as well as acknowledging possible weaknesses and limitations of the technology. For Bernie, along with other care partners, the argument boils down to safety, with participants believing that this technology has the potential to reduce the danger people living with dementia may face. Overall, providing additional peace of mind has been identified by care partners and individuals living with dementia as a key benefit of using GPS technology, and for many underpinned their desire to use this technology.

Subtheme: Independence

Care partners envisaged that this technology may facilitate greater freedom and independence for individuals living with dementia. Enabling such independence was highlighted by care partners as a motivator for using this technology. Independence was reported in different forms, for some, participants' greater independence meant individuals living with dementia could potentially complete activities of daily living (ADLs) alone. One participant commented on minor tasks and where they feel the person may benefit from GPS technology:

> *ERIC: [On increased independence for Pauline] Yes, I do, I think even just the little things that she can't do at the moment without me having to be there*

Another participant, Winifred, draws comparisons between how independence has been granted in the past, against the options now available to them using GPS. Winifred states that she has never stopped her husband from going out independently, however, this often comes at the cost of increased worry and anxiety for them:

> *WINIFRED: [On GPS providing more opportunities to leave the house] Maybe, yeah, because at the moment, well before we had this, the options I had was that he could go out, because I never wanted to feel like I stopped him, but whilst he was out, I would worry until he got back. Like I was saying before we, there isn't many times where we do things on our own, other than going for a little stroll maybe. Even then I think when it's nice out we'd go together. But it would be good for him to go and do things now on his own if he wants to. At least having the option is nice I mean.*

Participants also spoke to how these devices may empower individuals living with dementia, particularly when it comes to having an active role in everyday decision-making. For Anne, this technology presented an opportunity for Roger to become more involved and engaged in deciding what he wants to do and not to be restricted by the availability of Anne to accompany them.

> *ANNE: …I think in the long run this will mean that [Roger] can decide what it is that they want to do that day, it's not so much as whether I've got the time to go with them, and I think that when we get more, more confident at using it [the device], [Roger] could go on their own…*

Anne also comments on how, as their relationship with the technology is strengthened, Roger may experience more opportunities for social participation and have greater power over decision-making. One care dyad discussed the decision-making process that they underwent prior to the uptake of this technology:

> *LIZ: I’ve always said to dad that [using this technology is] up to him, when we were using the phone and before this, I explained the pros and the cons, and at the end of the day it is his choice…*

Liz reassured Ken that the choice whether to adopt this technology was theirs to make, supplying them the relevant information they needed to make an informed decision.

Two participants spoke of how the timing of introducing this technology plays a vital part in the level of independence gained.

> *JOY: …this could have really helped at the beginning, and I think other people in this position will know it is not necessarily long term, it will get to a point where even with this sort of stuff that they can’t be doing things on your own. Well, in our case at least.*
>
> *STEVE: This would have been really good for [Angela] early on.*

Joy understands that every situation or “case” is different and the level of independence that can be gained by using this sort of technology will vary. However, the timing of when this technology is used may be key. Joy and Steve both allude to the time sensitive nature of certain benefits, in particular, independence, suggesting that when an individual is further along the dementia journey, care partners may be uncomfortable granting independence, even whilst using this GPS technology. These findings further support the idea that GPS may not benefit everyone in the same way, and experiences of using GPS may differ depending on the unique characteristics and circumstances of the person living with dementia and their care partner.

One care partner discussed how their motivations related to adopting this technology stemmed from their desire to delay or prevent institutionalisation for the person living with dementia. Bernie spoke of seeking any solutions available to them if the result was Barbara being able to remain living at home.

> *BERNIE: For me the biggest thing will be if it keeps [Barbara] at home, because we don’t have a big family that can help out. Most of the time it is just me looking after her and I’m going to try to do that for as long as possible. But I can only do that if I know that she’s safe still living here.*

In the case of Bernie, his views intersected with the topic of peace of mind and using this technology to mitigate the risks the person living with dementia is exposed to. Bernie recognised that, whilst they wanted to delay or prevent Barbara relocating to institutional care, her safety was their paramount concern.

Greater independence was also inferred by care partners who perceived that this technology could provide them with a means to be more independent. Participants, identifying as care partners, discussed the ways that GPS devices could potentially enable them to complete their own activities alone:

> *BERNIE: But this could be great if it means that I can get out and about knowing [Barbara]'s at home*
>
> *ERIC: I think there's definitely a benefit to be had from my side, especially me getting on and doing the things I need to do*
>
> *ANNE: [On potential freedom gained for Roger] There's going to be freedom on both our parts*

Care partners expressed an idea of 'care partner independence' and how GPS technology may grant them more opportunities to conduct separate tasks. Whilst this concept may closely align with the idea of care partner respite, it could be argued that the views expressed by participants were not just solely about a break from providing care and the need of short-term relief, but rather related to having an opportunity to experience independence without the feelings of worry, guilt and anxiety. Participants also discussed how GPS technology could potentially aid them when it comes to establishing routines. Care partners touched on how establishing routines were essential when caring for individuals living with dementia, especially in terms of independence and autonomy.

GPS was also viewed as a possible tool to support participants in gaining or maintaining regularity in their schedules. For one participant, Anne, this was as simple as enabling Roger to continue his daily walk to the shops.

> *ANNE: …He's been doing that [daily trip to the local supermarket] for years, he enjoys getting out and it is useful for him to do … it would be difficult when I have to stop him".*

Anne acknowledges that at a point in her husband's dementia journey, she may be unable to allow him to undertake this activity alone. In this excerpt, Anne alluded to the notion of usefulness, with Roger's daily trip to the supermarket being part of his daily routine, Anne recognises Roger's need to feel useful. For others, such as Steve and Bernie, they saw GPS a method that could help care partners manage their daily schedules in a different way:

> *STEVE: I can never just go out on a whim, you always have to think ahead*…

> *BERNIE: [On when they feel this GPS device might be useful to them] …sometimes it might just be nipping out of the house for something, it would be nice to just be able to go there and then…*

Steve and Bernie may be suggesting that when caring for someone living with dementia, it is difficult to make impromptu decisions without careful planning. They perceived GPS to be a useful tool to enable the care partner to deviate from plans, which may help schedules to operate more smoothly.

Participants also reported on what happens when the sense of routine is lost, with these views surfacing mainly in relation to the difficulties they have experienced in adjusting to the changes brought about by the COVID-19 pandemic. Participants found that during the pandemic, due to quarantining and shielding, they had lost track of time, with a lack of a daily schedule making life uncomfortable at times. For one individual living with dementia, they associated the loss of routine to increased deterioration in their memory.

> *PETER: …I think my memory has got a lot worse since we've just been sat about doing nothing.*

Their care partner (Winifred) concurred, suggesting that the lack of mentally stimulating activities to do has enhanced their feelings of memory loss:

> *WINIFRED: It is hard for me to separate the different days because it is just doing the same things day in, day out. So, I can't imagine how bad it has been for him. It has been hard just finding something new to do each day.*

For another care partner, Anne, they alluded to missing their pre-pandemic routine and its hectic nature:

> *ANNE: We're used to keeping busy, and it's been hard not being able to do that, if you'd asked us that question [related to daily activities completed together and separately] a year ago we'd have given you a list as long as your arm and we do miss it*

Daily routines appeared to be essential for care partners and individuals living with dementia, they create structure and result in a daily sense of accomplishment when completing tasks. For some participants, the pandemic has substituted their daily routines and filled schedules with large amounts of unstructured time, making it difficult for participants to '*separate the different days'*. The impact of these views and experiences on the wider study relates to the comparison between initial and future activities and routines. Difficulties may arise when exploring the impact that GPS has on the day to day lives of participants Winifred/Peter and Anne/Roger.

A small number of those interviewed suggested that, due to additional health concerns and the point in the dementia journey an individual is at, greater independence cannot be considered. For such participants, they perceived the GPS device would act more as a backup option, enabling them to track the position of the individual living with dementia should they be unable to locate them using other means. Winifred stated:

> *WINIFRED: …But I think that's what we're trying to get across to him [their son] that at the moment we don't have anything, so surely anything is better than nothing, even if we do just use it, just in case. Even if it only ever has to be used once, it is worth it.*

Joy echoed the views of Winifred, commenting on the lack of independent activities Eileen now undertakes and how this alters the role of the device:

> *MF: [On how they feel GPS could benefit them] So in terms of how you think this device will help, it's more of so you know where [Eileen] is if she has got lost.*
>
> *JOY: Yes, I mean she doesn't do much on her own now, I still try to stick to my routines and its difficult with work and the things I want to do, but it's like, like I need to do this and she would support me on it, and the idea of being able to see where she is when I am out and knowing that she's safe will be a big blessing.*

This point of view was also shared by Steve who detailed the need to have a "safety net". Steve felt that Angela was at a stage in her dementia journey whereby the most beneficial feature of this technology was maintaining safety. When asked if they believed that GPS technology could offer a person living with dementia greater freedom, Steve replied:

> *STEVE: …yes early on, But, nowadays no, 'cause I think it has changed for me to just keeping her safe, because we do need a safety net…*

For Steve, the intended use of the GPS has now shifted, he acknowledged how useful this technology may be for Angela at the start of her dementia journey, however their main priority was no longer related to providing Angela with additional freedom or independence:

> *STEVE: …my main priority now is just keeping [Angela] safe.*

Steve continued, speaking of a frustration that GPS technology was not referred to them sooner, as they believed that Angela may have benefited in other ways from such a device:

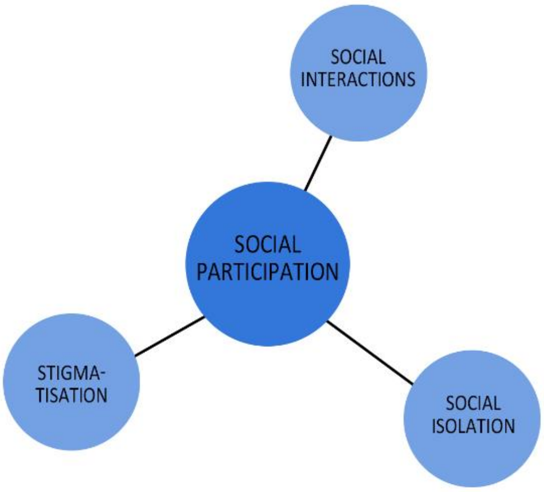
> *STEVE: …because I didn't know anything about these until they told me about your study, I mean I'm sure if I look hard enough now I would be able to, but why isn't someone telling us about this when she's diagnosed? I'm not sure if they were around as much then, when [Angela] did more outside on her own, but nobody told me and I think they could have helped in a different way back then.*

This sub theme has depicted the various ways in which they perceived GPS to be used as a tool to facilitate greater independence, but has also acknowledged the reasons behind participant's motives to not adopt this technology for that reason. Both perspectives are key to evaluate how this technology was used, as dementia is not a condition that affects each individual in the same way, and tailored responses on how to deal with the challenges of dementia are vital.

Summary of Theme 1

During initial interviews participants referred to a number of different motivations for using this technology and where a GPS device may benefit them. The safety of the person living with dementia was considered to be the principal motivation for many participants. It was interesting to note the views of Ken, who discussed how regardless of freedom or independence, their own rationale for adopting GPS was to keep themselves safe, as they acknowledged how this in turn would reduce the worry experienced by their care partner. Motivations were also viewed from the perspective of independence, and where participants perceived GPS to be a welcomed addition to their daily lives, to support and facilitate greater independence. Participants suggested that increased independence may be found following greater confidence in the technology, and for others, as an individual continues upon their dementia journey the purpose of the device may shift towards being used as a backup option or “safety net” (Steve). Independence was also viewed from the perspective of how GPS could help facilitate the managing of participant's daily life, through the development of a routine. Participants discussed the ways in which dementia has impacted their lives and the potential role of GPS to help establish routine and allow for the completion of impromptu tasks. All three sub themes interrelate, with the findings above related to family influences linking to peace of mind and independence, with many members of the care partner's family recommending GPS as a way to relieve anxieties, as many family members were concerned for the wellbeing of the care partner and sought a solution that could establish additional peace of mind. Similarly, findings that show how GPS may lead to additional ‘care partner independence’ coincides with views related to peace of mind and reduction in worry.

THEME 2: Social Participation



Participants discussed their involvement in activities that provide interactions with others in the community and how they foresaw GPS technology as a means to aid social participation. For many participants, being involved in such meaningful activities were considered vital for their wellbeing and provided them with a sense of identity, purposefulness and belonging. Participants discussed the types of social interactions they experienced as well as the impact of social isolation. The sub theme of stigmatisation was also identified as participants discussed wanting technology to blend into their daily life, not be something that highlights a disability and makes them vulnerable. Experiences were also discussed in relation to the COVID-19 pandemic and the year of lockdowns and seclusion from society. Care partners, at times, felt they had greater understanding of how it must feel for a person living with dementia to be isolated, following the amount of time spent shielding and isolating due to coronavirus.

Subtheme: Social Interactions

Overall, participants considered that the GPS device could be used to help those living with dementia engage in more positive social interactions. Participants discussed a wide range of different types of social interactions and how GPS technology could support them. For many participants, hobbies and clubs are very prominent in their social calendars, with weekdays filled with different interests and events. These social engagements are a means to relieve stress, provide identity for the person living with dementia and lead to the creation and maintenance of social relationships.

One participant, Patricia, commented on the social aspect of her husband’s hobby, and how a GPS device could potentially allow her husband, David, to continue conducting this activity independently. Patricia stated that due to their own health conditions, they are now unable to walk for long periods of time. Patricia expressed concern that her mobility problems could ultimately lead to less independence for her husband and discontinuation of a hobby he enjoys. This suggests the guilt that could be experienced by care partners, such as Patricia, when personal issues could impact upon the level of freedom and independence a person living with dementia has. In this scenario, her husband’s favourite pastime could be a risk as he continues upon his dementia journey, however Patricia believes that GPS has the potential to remove this guilt and alleviate her concerns.

> *PATRICIA: [David] is a keen walker, you’ve been doing it for years now haven’t you? And I think something like this [the GPS device] could be a godsend, if it's able to let him keep doing it [hiking]. As I was saying, I just can’t do it with him anymore but it will be hard when he has to stop. As it is like, like when he gets back from a good walk, he’s a different person, if that makes sense, and it is not always about the exercise, cause I know it keeps him good and fit, its more the people, the group he does it with, many of them have been there 30-odd years now.*

Patricia notices a difference in the behaviour of David after returning from this activity and believes it’s more about the social aspect of the event, rather than the exercise opportunity. When Patricia says *“it will be hard when he has to stop”* she may be referring to the difficulties she may face from preventing David from undertaking this social activity and the impact it will have on the wellbeing and relationship of David and Patricia. Another interviewee, Liz, commented:

> *LIZ: Well before all this [Ken] was doing the ‘men in sheds’ group, I think that bit of camaraderie was really good for him … I’ve never stopped him going but it is something I’ve tried to avoid clashing with, so I guess that if this [the GPS device] works it would definitely help us.*

In this example, Liz is referring to being unable to schedule their own activities during Ken’s event, and GPS technology may help them organise more activities individually. Issues related to social events “clashing” were raised by another care partner participant, Steve, who was considering the impact of GPS technology on social participation retrospectively:

> *STEVE: I think it is the same for most carers, you never want to stop the person you love do something, or tell them that they can’t do it. For me, I tried to put that off until the last possible moment, but if I had something like this [the GPS device] then yeah, I do think that [Angela] would have been able to carry on doing a lot of things….*
>
> *STEVE: [Continuing] … then [at the time] I had to juggle work around taking her to certain classes and things, like I know that she wanted to carry on with her art classes, but it was always on a Thursday afternoon and I’d sometimes be working then. A bit of kit like this [GPS device] would have certainly let us do both. And it is a shame, because she had a lot of friends at those classes.*

Steve recognised the importance of social interactions at groups, but ultimately, he had to balance work alongside care. In Steve’s case, he acknowledged that GPS technology may have helped Angela engage in meaningful activities and maintain social relationships with those around them, for a longer period had this technology been known to them at an earlier stage of Angela’s dementia journey.

One care dyad discussed their attendance of non-dementia related social groups and activities and the impact they have:

> *KEN: For me, a lot of these groups, not just the dementia ones, give me something to do. In a way they make me feel like me and make me feel like I’m still a part of it all…*
>
> *LIZ: …I know that you once said that you like going to the dementia groups, but you also found it nice to go somewhere where people didn’t know you had it, and you never had to talk about the dementia side of things… But that’s like I was saying when we first found this [the study], something like this would mean I didn’t have to always be there and people wouldn’t know that you had it at all*

For Ken, these groups provide him with a sense of identity and belonging, ensuring that he feels included in society and able to continue doing what he loves. Liz discussed how important GPS devices could potentially be, to help keep him attending such groups and allow him to attend alone. Liz also states the importance (for Ken) of attending a group where other attendees were not aware of Ken's condition, the inference may be that Ken may face judgment or prejudice due to his condition if his diagnosis was disclosed. Ken responds to Liz by referencing their fear of experiencing social isolation or exclusion, and the role GPS could potentially have in preventing that:

> KEN: *I know for me its early days, but I wouldn't ever want to feel like I don't fit in, because I am still all here and hopefully these things [GPS devices] can mean that I can still do whatever I like...*

Ken's comments summarise the impact that feelings of not fitting in can have on an individual and how, through the use of GPS technology, people living with dementia can address them.

Subtheme: Social Isolation

The topic of social isolation was explored and discussed in two interviews and from diverging perspectives. During one interview, the concept of loneliness was reported by the person living with dementia who perceived this technology as a potential means to alleviate social isolation experienced following a diagnosis of dementia:

> *KEN: …some avoid doing things with you just because you have dementia. I think something like this could help.*

Ken discusses how some people within society hold the negative view that people living with dementia are less able to do things. Ken believes that GPS may help convince individuals in society that a diagnosis of dementia doesn't change who a person is and that *"just because you have dementia"* is not a valid excuse for avoiding conducting activities with someone. Joy also refers to how other people perceive the condition and where GPS may help change opinions:

> *JOY: At the beginning I think people understand a bit more, like when you can't go to something, but after a while you stopped getting asked. And it does get lonely when it is just us. I think it's difficult to look back because of lockdowns and such, but I think the past year has shown everyone what it can be like for people like us … We'll have to see but I do think this kind of thing [GPS device] could stop a lot of it, especially for us carers.*

Joy talks of their experience regarding social isolation, they felt that they get to a point whereby care partners stop being asked to engage in certain social events due to caring for someone living with dementia. By this, Joy may be suggesting that some people presume that the care partner is unable to attend alone, and that they are not invited due to their commitment of caring for the person living with dementia. Joy may also be referring to the stigma surrounding dementia, which is explored in more depth in the next sub theme. Joy envisages that these GPS devices may help care partners appear more flexible and may result in the care partner being invited to social engagements by others. Importantly, Joy also suggests that the pandemic, and the restrictions that had been put in place regarding social contact, may make people acutely aware of the challenges facing some members of society, in terms of social isolation and reduced social interactions. Similarities can be seen between the views of Joy and those expressed by Ken, with both explaining how the diagnosis of dementia prevents or deters people from engaging in activities with them.

Subtheme: Stigma

The sub theme of stigma was found when participants discussed how this technology needs to be discrete and prevent attention being drawn to the wearer's condition. Four participants considered the characteristics of the GPS device and how they may prevent stigma. Bernie found this technology *"very neat"* adding *"nobody is going to know that she has a disability or anything".* Similarly, Roger spoke of not wanting someone to know that they are living with dementia and how they feared some devices may draw attention to the condition:

> *ROGER: I would never have worn that cause then everyone would know somethings wrong with me…*

Roger expressed fears of being treated differently if people were aware of his condition and how poorly designed products could highlight his diagnosis. Anne also referred to her previous knowledge of GPS technology and alternative GPS devices that they have seen:

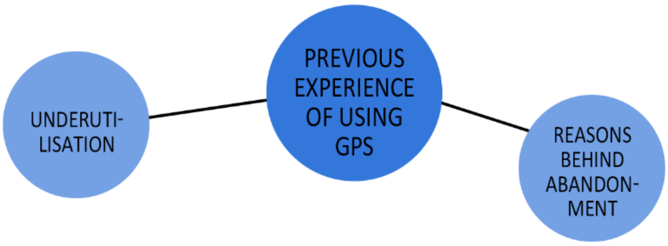
> *ANNE: I saw one that was like a big watch, it looked odd and out of place… ...they want something that's more discrete and I think these [the device used in this study] are perfect.*

These views surrounding the size, shape and type of GPS device align with similar opinions expressed by participants during phase 1. People living with dementia have also expressed a fear of being perceived as vulnerable, with something highlighting their condition to the rest of society, causing them to stand out. As discussed by Roger, this could occur by wearing a device that the person living with dementia feels looks out of place or highlights their condition can result in abandonment of this technology.

Summary of Theme 2

During initial interviews, participants discussed the wide range of ways people living with dementia engage in social participation and where they feel they may benefit from GPS to encourage such interactions. This theme also discusses the stigma individuals living with dementia may face, and how they felt technology, such as GPS, if unsuitable and unsubtle, could add to such stigma and result in discontinuance of this technology. People living with dementia did not want a device that would advertise their condition and make them appear vulnerable. When discussing their social interactions and where GPS could assist them, Ken and Liz discussed their desires to avoid disclosing Ken's diagnosis, out fears of experiencing social isolation or exclusion due to the condition. Care partners acknowledge the importance of social participation and the link between maintaining good social relationships and the wellbeing of the individual living with dementia. Care partners also feared for the time when such engagements may have to be reduced and hoped that GPS may be the answer to extending the individual's involvement in such meaningful activities that provide vital interaction with others.

THEME 3: Previous experience of GPS technology



Some participants (5 out of the 9 dyads) of phase 2 had previous knowledge of GPS technology prior to taking part in this study. From these 5 care dyads, 3 of them had previous experience of using GPS technology in their everyday lives. When prompted further to discuss their previous experience of using this technology, participants discussed what caused their discontinuance as well as describing the benefits they believed the technology could provide, however were yet to encounter.

Subtheme: Reasons behind abandonment of technology

Upon discovery of previous experience in using GPS technology, I probed to uncover explanations as to why participants abandoned this technology. Rationales for discontinuing use of their original GPS devices appeared to come under one of the following headings:

Loss of confidence in the technology

One care dyad reported that, following the purchase of a GPS device, 24 months prior to the commencement of this study, they had been unimpressed with the device and began to quickly lose confidence and trust in it.

> *JOY: Yes, we did actually have one at one point, it wasn't very good and we had a hard time with it...*

Joy found that the result of a loss of trust and confidence was increased panic regarding Eileen's whereabouts.

> *JOY: …We just kept having problems, sometimes it was just off track to where she was, and sometimes the battery went flat, and I didn't know where she was. All this just led to me panicking more…*

These experiences voiced by Joy relate to the sub theme of peace of mind discussed earlier in this chapter. Joy acknowledged that one of the main motivations for initially purchasing the technology was to gain additional peace of mind and reduce the feelings of stress and anxiety that occur when not knowing where her sister was. She had been unable to gain such benefits due to the technical problems she encountered during use and the end result was, in fact, an increase in panic and worry. Joy discussed how the device she previously had went *"off track to where she was"*, similar experiences of device inaccuracy were also raised by Liz, who previously used a mobile phone-based system of GPS tracking. Liz felt the device "*wasn't the most accurate, which was a problem really…"* going on to discuss the worry that inaccurate positional reports caused.

Limitations of GPS devices

Joy pointed towards the limitations of the GPS device that they were using as a potential reason behind why they stopped using it. Joy commented on how the device alone was not enough to guarantee the safety of their sister.

> *JOY: …and that's when you need other things not just a tracker, 'cause the tracker will only let you know that she's safe at home, not safe in the home. This is when I said look [Eileen], you need to come and stay with me.*

Joy also found limitations relating to the battery life of the device as well as the cost, in terms of internet data, of operating the tracking features when outside of the house. Limitations were also noted in relation to how the device was recharged, Joy at the time was not living with Eileen and could not predict when the device would need recharging.

> *JOY: Charging the last one was probably the biggest issue, more than anything, because when you use these devices, you just don't know when you will need it, I couldn't predict when she was going to leave and she couldn't charge it herself. We also needed Internet connection on my own phone, I know to some people it might not be an issue, but having the internet on the phone on all the time can be expensive. When I was at home it was quite accurate to where she was at the time but then if I got in the car and went to find her, it used up all the Internet on it...*

These experiences related to battery life coincide with findings discussed in chapter 4, with participants of phase 1 requesting a device with a sufficient battery capacity to work alongside a person's schedule. Joy also spoke of the cost surrounding using a device in terms of mobile data and the cost of internet access. In addition to problems surrounding accuracy and battery life, Joy felt that their original GPS device, in the form of a wristwatch, was unsuitable for Eileen:

> *JOY: Then the other thing was it was just too bulky for her, she never wanted to put it on. That's one of the reasons why I checked with you first because she wouldn't wear it, we gave up on it after that.*

At many stages throughout discussions with care dyads, the importance of considering the usability of devices arose. This technology needs to be appropriate for the person wearing the device, it is therefore essential that the person living with dementia is consulted regarding what device would be suitable for them. Similar to discussions made in the earlier sub theme of stigmatisation, a person living with dementia may not wear something that is considered “bulky”, resulting in abandonment.

Additional Concerns

Liz spoke of one of the reasons behind discontinuing the use of GPS tracking via a mobile phone: she was concerned that Ken may accidentally leave the phone behind, resulting in Liz being unable to locate him, this causing Liz to panic and worry:

> *LIZ: … and we had the problem of leaving the phone places although I do that as well don't know that is entirely down to the dementia [laughs]…*

The second issue was related to vulnerability, and how this method of GPS tracking presented a danger of Ken being a potential target of crime. This links back to previous discussions in theme 1 surrounding stigma. Liz acknowledged that using a smartphone for this purpose meant that the individual living with dementia carrying a high value item, and that posed an additional concern.

> *LIZ: … yeah well, we had a little problem with the phone it wasn't just the accuracy because it was my old phone we were a bit worried that you may leave it somewhere like I was saying before or maybe that as he’s already more vulnerable because of his condition, this could make him even more vulnerable because he had the phone on him. It is horrible to think about but some people might take advantage of him because of the dementia and try to take the phone.*

This experience, voiced by Liz, further links back to earlier discussions surrounding peace of mind and the reduction of worry. It could be questioned how a piece of technology serves to reduce worry, if the mere act of carrying the technology creates feelings of anxiety for the care partner. Liz believes in the benefits that the technology could afford them, and this prior experience has acted as a motivator to try GPS for a second time.

Lack of technical support or training

One participant, Bernie, had been pointed in the direction of GPS products by a dementia charity. Upon ordering a device online, labelled for use by individuals living with dementia, Bernie found the device difficult to setup, with the instructions difficult to read:

> *BERNIE: It [the device] was just too complicated, it was a tiny little thing but with so many buttons on it, that apparently all did different things. What I wanted was someone to show me how it all worked, and I said about this in a group*

> *which is when they told me about what you're doing. I think they make these things too complicated for just anyone to use them. I opened the box, and it was a little book in the smallest possible writing, and just thought no this is no good. The other thing was that there's so many of them out there that nobody seemed to know this particular one that I'd picked up...*

For Bernie, he found that the technical support, by way of physical instruction manual, was not in an appropriate or understandable format, this is despite purchasing a device aimed at dementia care. Bernie also found that due to the vast amount of choice available in these devices, it was difficult to find technical support for the particular device he purchased. It is unsure what device Bernie previously had, but the phrase *"I think they make these things too complicated for just anyone to use them",* suggests a barrier to literacy facing care dyads.

Subtheme: Underutilisation

Where participants had prior experience in using GPS devices, they were asked what went well when using them. Several participants reported initial success in using the technology however they soon faced obstacles to maximise the potential use of the technology, particularly when it came to the battery life of the device and issues of digital literacy.

Joy acknowledged that she failed to maximise the potential her old GPS device had, however expressed that these failings were not due to her own understanding of the technology. The problems Joy faced were due to the battery capacity of the technology, with the device only lasting for short periods of time, which ultimately restricted the usage of the product.

> *JOY: …If this new one manages to solve all of them problems, then these are really important for people, because they can be the answer to a lot of things. I sound like I keep going on about it, but if the battery lasted longer, it would have meant that I was more comfortable to leave [Eileen] for longer, so she would have had a lot more freedom.*

Joy reported that, should the device have had a better battery life, Eileen could have experienced increased freedom and independence. This shows that Joy foresaw how useful the device could be, however due to limitations in the technology, underutilisation occurred, resulting in the device only being used in certain situations. These views voiced by Joy coincide with earlier discussions regarding freedom and independence, however Joy also cited feeling uncomfortable when using the old device, suggesting the previous device she had was unable to instil feelings of calm and peace of mind.

All three dyads with previous experience in using GPS devices spoke of their desire to revisit this technology, acknowledging that GPS could be an important addition to their lives, if utilised correctly. Participants understood what benefits they could gain from this technology, however had yet to fully experience them. For Joy, she inferred that recent developments in the technology may have solved the problems she experienced, she also reported that she didn't have alternative solutions available:

> *JOY: …I mean the way I have always seen it is that, that was just one idea, and at the time I was grateful to have even that because what's the alternative? You don't have anything. We have to be grateful that these kind of things do exist, and I'm sure they are always getting better. Now that we live together, I have less need for some of them, but the trackers were always something I thought to myself 'this is exactly what I need when I am out and at work'...*

Another participant referenced the opportunity to learn how to use this technology as a reason behind revisiting these devices. In this theme, Bernie had previously discussed difficulties he faced attempting to learn the technology he had purchased, also noting the fear of getting complicated technology wrong without sufficient training:

> *BERNIE: When someone first described this [GPS technology] to me, I said it was a great idea, but they have to make them easy to use, for people like me. There's no point us getting this life-saving equipment if we don't know how to use it. It has to be simple. When I buy a washer, I buy one with the least number of buttons so there's less for me to mess up.*

And finally, Liz reported that the different method of using GPS was an incentive behind giving the technology a second chance, however, she did report potential reservations going forward:

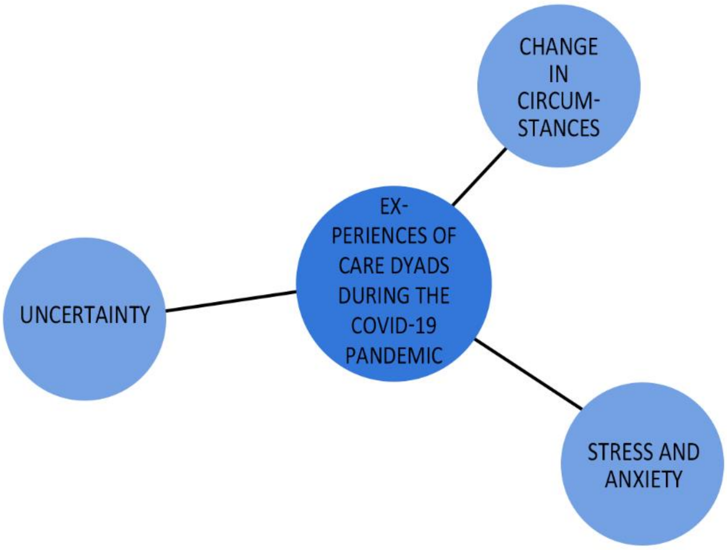
> *LIZ: I think these [GPS devices] are better than using the phone, I think less can go wrong and I guess they are built for this and this alone, but we would be quite sceptical in case the same thing happens again [referring to lack of GPS positioning accuracy].*

Indeed, it must be noted that scepticism was also reported from the perspective of a care dyad without prior experience of using GPS, suggesting care partners will take additional precautions whilst they get to grips with this technology. For example, Winifred stated *"…I think before we do start using this [GPS device] on his own, I'll be* *having to keep an eye out…”*. It could be considered only natural that, given the initial increased risk in facilitating more freedom when using this technology, in addition to the lack of experience when using this technology, initial reservations are present.

Summary of Theme 3

To summarise, this theme encompasses participants’ previous views and experiences of using GPS technology. Participants who did report previous experience of GPS spoke of their disappointments when using it, including poor accuracy and battery life. Many of the problems highlighted by participants when describing their lived experiences of using this technology were cited as the reason behind their discontinuance of the technology. For some participants, these prior experiences had resulted in reservations going forward as the technology had caused care partners increased stress and anxiety due to technical problems experienced during use. This is despite one of the main reported benefits of using GPS to be the peace of mind it can provide care partners. However, for all participants who had prior experience of using GPS, they were still motivated to revisit this technology, despite setbacks experienced. The main reason behind these motivations lay in their belief in how beneficial the technology could be for them.

THEME 4: Experiences of care dyads during the COVID-19 pandemic



Data collection was conducted amidst the outbreak of the COVID-19 pandemic, this undoubtedly impacted upon the recent experiences of participants, however also presented an opportunity to explore how restrictions from the pandemic impacted their lives and if GPS could have assisted them during this time. During the initial interview stage, the United Kingdom was in a state of national lockdown, with restrictions on activities that could be conducted by the general public, and a stay-at-home order issued nationwide. This theme is particularly important within the wider context of this research, since the purpose of the initial interviews was to gather a sense of the day to day activities of participants and where they feel GPS may be a welcomed addition to their lives. Participants described how the pandemic had resulted in a change in the circumstances they now find themselves in, reporting some positive, but mostly negative aspects. Participants also commented on the uncertaintaity brought about by the pandemic and newfound stresses and anxieties, detailing how, in the current environment, they were unsure what place GPS technology may have in their daily lives.

Subtheme: Change in circumstances

Many participants reported that COVID-19 had caused a severe loss of confidence, in particular participant's ability to engage in safe walking as well as activities of daily living. This was mainly due to a reduction in opportunities to go outside independently, with care partners unsure as to how safe a person living with dementia may be when restrictions are lifted. These views were particularly relevant as the literature describes the benefits of GPS in relation to safe and independent walking. When asked what activities they complete on a daily basis, both together and separately, many participants had similar replies:

> *ANNE: Well, I guess with everything that's been happening over the last year or so, not a lot [both laughing]*
>
> *LIZ: Well, we are spending quite a lot of time home recently, aren't we? [laughs]*
>
> *Pauline: Not that much at the moment, we're all stuck like this aren't we?*
> *[In reply to Pauline] Eric: Yes, everyone is in a similar boat.*

The implications here are that difficulties may arise when drawing comparisons on the impact of GPS on the lives of participants. For many, the 12 months prior to the commencement of this study consisted of a lack of activities, other than essential trips, many participants did not leave home and found themselves "stuck" inside. For a study investigating the impact of GPS on the daily lives of participants, the lack of mobility and meaningful activities alone during this time undoubtedly causes issues. If care dyads do not spend time apart, the benefits of using GPS are severely reduced, as the main reported motivations for the uptake of this technology, as reported in the first theme, are independence and peace of mind. If a care dyad spends all their time together, there are no opportunities to experience increased independence for the person living with dementia, or indeed, the care partner.

For one care dyad, COVID-19 had severely impacted upon the mobility of the individual living with dementia, with care partners reporting a decline in mobility as a result of shielding, closure of day centres and lost exercise opportunities.

> *STEVE: [On day centres] …we went to one every week where they'd help [Angela] with some exercise, I mean they didn't do that much, just you know sat down but they had a set routine and I think [Angela] really missed that, you might not think it at the time, but I think it does really help.*

The implications of this, on the wider study, may be a change as to when the GPS devices are used, for example, participants may be less likely to use GPS to conduct activities such as safe walking.

> *JOY: [on exercise and walking] I try to do a bit with [Eileen] and I do try to take her out…*
> *MF: Do you think you'll use the [GPS] device to help with that?*
> *JOY: probably not for that reason but it will help elsewhere.*

Joy discussed how they (Joy and Eileen) had attempted to continue exercise routines during lockdowns, however, they questioned whether the GPS devices may benefit them in relation to exercise and walking. Joy states that the device *"will help elsewhere"*, therefore acknowledging that benefits are still there to be gained, however due to the decline in Eileen's mobility during the pandemic, the purpose of the device has changed from one to promote independence and safe walking, towards one to help locate Eileen should she leave home without Joy's knowledge and become lost or disorientated.

Two care partners discussed how COVID-19 had increased their level of technical knowledge. Eric and Winifred discussed how this would enable them to use technology such as the GPS device, which they did not think they would have been able to, pre-pandemic.

> *ERIC: I'm getting a lot better with my phone, but it is not out of choice [laughs] one of those things that I know I need to use, that sort of encourages me to do it. It has been like that a lot in the last 12 months though, a lot of the things I've had to force myself to use, you know with COVID.*

These findings showed how some participants adapted to digital technology during the COVID-19 pandemic. Eric and Winifred understood the power of digital technology to help keep them socially connected.

> *WINIFRED: … over these lockdowns we got very good at using the skype to see everyone, which was a lifesaver in a way because had it not been for that, we didn't know it at the time, but we wouldn't have been able to see everyone for a long time…*

Both participants commented on how obtaining this knowledge was not their initial preference and was the result of COVID-19 restrictions on face-to-face contact with family and friends. Participants spoke of sense of pride and satisfaction of gaining this knowledge and now being able to use certain technology. It could be argued that Eric and Winifred may face reduced difficulties when it comes to using the GPS technology in this study, largely due to their newfound technical knowledge and skill. Further implications may be that such care partners have greater confidence when using this GPS technology, contradicting earlier indications made in this analysis of initial hesitations when using the GPS device due to lack of confidence and familiarisation of the technology. One participant, Patricia, alluded to a form of acceptance towards the new circumstances they find themselves living in, describing it as "the new normal":

> *PATRICIA: …we now text and we use Facebook to keep in touch with the family and see what the grandchildren are up to... it's almost the new normal now isn't it, it will be strange to go back to the way it was.*

Patricia acknowledged that COVID-19 had impacted upon their social connectedness in terms of closure of groups and social distancing, however they appeared to look for the positives in their change of situation and how they have been able to stay connected through new methods. These views shared by Patricia follow the pattern described above of how some participants used the pandemic to their advantage and developed their proficiency of using technology. The implication of this for the use of GPS is that they are now able to reapply these newfound technical skills and felt comfortable expanding their technical knowledge to cover the use of GPS.

Subtheme: Stress and Anxiety

Individuals living with dementia and their care partners reported increased levels of stress and anxiety as a result of the pandemic. Participants disclosed the new challenges that they may face when asked about their current activities or future plans. Care partners spoke of changes in behaviour as a result of the enforced lockdowns and stay at home orders, with individuals living with dementia recalling their frustration and agitation and being unable to leave their home.

> *PETER: It was difficult not being able to go out whenever, it is not nice, you start to feel like you're held captive and you struggle…*

It could be argued that GPS technology could be able to relieve these feelings of frustration and being confined to the home. Such distresses impacted upon the wellbeing of their care partners, who described how GPS could alleviate difficulties like these in the future.

> *ERIC: I do feel for all carers who have been doing this during this time, because it is so, so tough. I think it is harder for those people who don't live in a big house, you know with big gardens and space to have a break or have some time to yourself. When you live in a smaller bungalow like us, you get to feeling like you are living on top of each other… I wonder if this [Referring to the GPS device] could have helped us then.*

Eric makes reference to the size of the space that is available to them, questioning whether GPS could have assisted them, or people in a similar situation as themselves, during the pandemic. The literature has revealed how important personal space was for people during COVID-19, citing the mental health challenges that arose during the pandemic for those who did not have access to suitable indoor, as well as their own outdoor, space. Eric suggests that those living in larger dwellings would have experienced greater levels of comfort and in the context of dementia may have experienced more respite from care as they are able to "*have a break or have some time to yourself"* (Eric).

> *STEVE: It did get uncomfortable at times, I've always said that its the dementia and its not her, but I'd be lying if I said it didn't take its toll on me, cause at times it did.*

One care partner discussed difficulties in relation to preventing the individual living with dementia from leaving the home, as well as challenges experienced when living together during lockdown. Steve again discussed feelings of discomfort during the pandemic, however he did not comment on how GPS could have eased such feelings. For Winifred, additional stress was caused by the repetition of the Government's COVID-19 rules and regulations to the person living with dementia.

> *WINIFRED: I could tell that he just wanted to get out the house, some days I kept having to explain that he wasn't allowed.*

The types of support that is available to people living with dementia and their care partners during the pandemic was discussed, with care partners detailing how COVID-19 has impacted upon the assistance they have received. The closure, and delayed reopening, of dementia support services was particularly damaging for participants. What Winifred discusses could become a daily occurrence in a post-COVID era, with explanations having to be given to a person living with dementia as to why it may not be safe for them to go out alone. This is where GPS could help Winifred and Peter, enabling Peter to continue going out independently when he wishes.

Subtheme: Uncertainty

Uncertainty was felt by individuals living with dementia and their care partners during the COVID-19 pandemic. This uncertainty was related to their future plans, and where they felt they may benefit from GPS in relation to future activities. Participants also discussed the ambiguity felt towards what they were able to do during lockdown. One participant remarked:

> *STEVE: One of the reasons I think we haven't been able to do much is because we haven't known what we were allowed to do. I know people without dementia who said the same thing, then you think to yourself 'well what are people who do have dementia meant to think'. I know [Angela] didn't understand most of it, but who was there to check if she did? None of it was clear. And it definitely put me more stress on me, you know, not knowing what we could or couldn't do.*

Uncertainty also stemmed from care partners not knowing how the individual living with dementia may react when using the device out in the community. Winifred cited concerns that Peter may forget social distancing restrictions when out independently, with his sociable nature making him likely to interact with others. Winifred states the new worries that care partners may have to deal with when it comes to using GPS devices during the pandemic:

> *WINIFRED: My real worry is that [Peter] will forget all the things that we've kept doing to protect ourselves and when he goes out, I think, it's almost like they'll just go and sit on a bench next to someone or get too close, and forget all about social distancing. But I think before we do start using this [GPS device] on his own, I'll be having to keep an eye out. Cause you are very friendly aren't you [referring to Peter], … you will just go and talk to people, cause you like a chat.*
>
> *PETER: [In response to Winifred] I'll be fine, you'll just have to be reminding me, won't you?.*

These suggestions of "new worries" align with discussions made under the sub theme of peace of mind, with Winifred discussing that even when using GPS, anxieties for the care partner will still exist, in different forms. On the subject of uncertainty, Steve suggested that government advice failed to consider people living with dementia and the essential service that dementia groups provide, especially in relation to social interactions and inclusion.

> *STEVE: Who knows what we'll be able to do, or when, the groups have said the same thing. They can't open until they have a better picture of what's allowed to happen and it's always changing, isn't it? I just don't think they understand how vital some of these things are to certain people, for a lot of the people we used to go with, they are the only people they might see that week.*

There was also a reported sense of uncertainty when participants considered how life will be when the pandemic restrictions relax. Joy discussed the role the GPS device may have in assisting them in day-to-day life when things return to how they were before the pandemic.

> *JOY: I can see it being a big help when we start going back to normal*

For Joy, GPS could help to manage uncertainty in a post-COVID-19 era, providing care dyads with an additional tool to help facilitate independence and improve peace of mind.

Summary of Theme 4

This theme has explored the impact that the pandemic has had on participants, and the implications of COVID-19 on the wider research study. Potential obstacles that dyads may face, due to the pandemic, were described whilst considering the extent to which GPS could support them. Many of the subthemes examined here coincide with topics discussed earlier in this analysis, with participants describing the impact from a social perspective, how the pandemic had resulted in newfound stresses and anxieties, as well as the uncertainties facing participants. This theme described how COVID-19 had impacted upon the mobility of some participants and the subsequent implications regarding how GPS devices are used within this study. This theme additionally discusses experiences of feeling confined due to the pandemic, such views link to the first theme, in terms of GPS enabling greater independence and increased freedom for the person living with dementia. The views and experiences of participants given in this theme also draws links between findings discussed in the first theme surrounding care partner worries and participant's motivations for adopting GPS. This is an important theme that has been identified from initial interviews with care dyads as it contextualises the research and examines the challenges and lived experiences of living with dementia and caring for someone with the condition during a global pandemic.

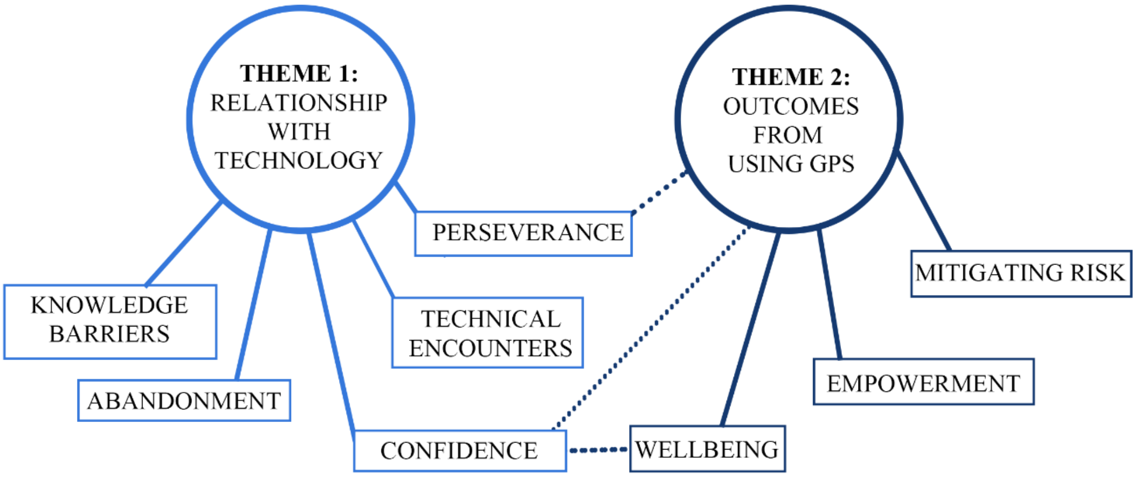
Summary of themes found in initial interviews

In the first section of this chapter, I have explored the key themes that have been identified following the analysis of initial interviews with participants. Themes encompassed how beneficial participants perceived this GPS technology to be and their motivations for deciding to utilise this technology as well as any potential concerns or reservations they may hold. To my surprise, participant's previous experience of using GPS technology was uncovered to be an overarching theme, with three care dyads having prior practice of using the technology and gave their reasons behind discontinuing its use. As this research was conducted amidst the backdrop of the COVID-19 pandemic, the impact of this was also discussed and what the implications on this wider study may be. All four of these identified themes interlink, with some care dyads discussing how their motivations for using GPS stem from the increased opportunity of independence for the person living with dementia. Views on independence align with the theme of social particpation, whereby people living with dementia can experience greater social interaction through the use of GPS, simultaenously reducing social isolation. However, in order for GPS to help faciliate social relations and increase engagement for people living with dementia in society, the technology needs to be destigmatising and appropriate for the person living with dementia. Failure to consider the suitability and usability of devices would result in discontinueance. This analysis has found peace of mind to be situated as the cog that joins and connects these themes together. As aforementioned, the purpose of the initial interviews was to explore the thoughts of care dyads prior to a period of using the device and the next chapter will analyse the data collected from follow up interviews with participants after this three-month period. The next section in this chapter, 5.3, will present the findings from follow-up interview with care dyads.

5.3 ANALYSIS OF FOLLOW-UP INTERVIEWS

This section of the chapter will explore the themes that have been identified from follow-up interviews with participants following a 3-month period of using the selected GPS device. Through using the process of thematic analysis, detailed above, for both the focus group and initial interviews with participants, two key themes were found. The thematic map shown in figure 24 below illustrates how these two themes interrelate. The purpose here was to depict the story that permeated through discussions with care dyads when voicing their lived experiences of using this technology. It was found that discussions by care dyads fell into one of two main themes; the first being the care dyads relationship with technology and the second being the outcomes experienced from using GPS. For some care dyads, this was their first experience of using GPS and they reported little technical knowledge prior to embarking on the 3-month period of use (as seen in theme 3 of section 5.2). Others considered themselves more technologically advanced however still reported upon how the positives and negatives of their relationship with technology impacted upon how GPS was used in their daily lives.

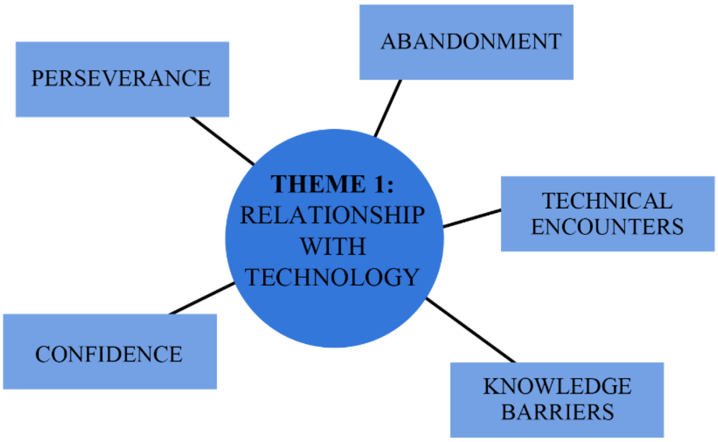
Figure 26: Thematic map of the themes for follow-up interviews



As seen in figure 24, sub themes in this analysis interlink. Theme 1 is concerned with investigating how issues such as confidence and perseverance contribute to a care dyads relationship with technology, as well as the occurrence of technological abandonment and the factors that can cause discontinuance. This theme also considers the existence of knowledge barriers, caused by gaps in technical literacy. Finally, the sub theme of ‘technical encounters’ discusses both positive and negative experiences gained during the period of use

The second theme, ‘outcomes from using GPS’, explores the benefits that can be gained by using GPS, including how the technology can be used as a method of support to promote wellbeing for both the person living with dementia and their care partners. During step 3 of Braun and Clarke’s (2006) framework for thematic analysis, when collating codes and coded data into potential themes, it became apparent that GPS can be used in the fulfilment of a person’s psycho-social needs. So, by drawing parallels to Kitwood’s (1997) model of Psycho-Social needs, Sabat’s (2001) self-hood and Bartlett and O’Connor’s (2007, 2010) ‘social citizenship’, this sub theme looks into how GPS was used to provide feelings of comfort, identity, occupation, inclusion, and attachment. Within this theme, the process of empowerment also arises, depicting the ways GPS promotes autonomy and self-determination in people living with dementia. Finally, this theme further considers the role GPS in mitigating risk. This acknowledges the various uses of this technology and how participants at different stages of their dementia journey may require alternate approaches to risk management. Distinctions are therefore made to show how GPS was used by some to facilitate safe walking and by others, who perhaps had reduced mobility or were further along their dementia journey, as a safety net.

THEME 1: Relationship with technology



The opening theme contains the views and experiences of participants in relation to the technology itself and how certain factors influenced a participant's relationship with technology. This theme also contains the insights from one care dyad who opted not to complete the 3-month period of using the device, and the rationale behind their decision. The theme is comprised of the following sub themes: confidence in technology use, persistence with technology, knowledge barrier, technical encounters as well as technological abandonment of GPS.

Sub theme: Confidence

Confidence in technology use was, for some participants, an important factor in determining the frequency and the duration of use. Care partners often spoke of "getting to grips with" (Patricia) the technology and that as they gained confidence in their own ability to be able to use the GPS devices and gained greater trust in the technology functioning as intended, increased use followed. This was best summed up by one participant, Anne:

> *ANNE: …I think as I got the hang of it, we started to use it more, it is all new to me too so I was a bit wary. After a while we found that [Roger] could go further and further because we knew that he was safe…*

After I prompted further as to how Anne overcame this wariness towards the reliability of the device, she replied:

> *ANNE: … well we started off that [Roger] went to our daughters, she is only a 10 minute walk away, normally she'd ring to say he was there but this time I just looked on the phone and I could see, she knew when he was setting off so she would have called me anyway if he wasn't there in 15 or 20 minutes or so*

> *[pause] we took it from there really (…) Another time he took it with him when he went on a much shorter walk and it was fine, after doing this a couple of times I felt more comfortable about it all and that was that really.*

For Anne, becoming familiar with the technology was vital as it meant that once confidence was gained, Roger had the freedom to use the device and travel further afield without causing discomfort to their care partner. Another participant, Patricia had a different experience regarding confidence in this technology, however eventually reached the same result.

> *PATRICIA: [On issues with the device] It was my fault really can't say it was an issue, but once I had not charged the device for long enough and I thought that it would last, when it said 10 percent left, I started to panic a little that it wouldn't last until he got home. [pause] That knocked me a bit and I didn't know how long it could last for. I figured we do shorter goes at it so that I could get the gist (…) if you put it on [charge] overnight, it lasts the whole day. Eventually I got to grips with it and it we now use it for everything, no matter where he [David] goes, we've found it really good*

Again, Patricia discussed how they tested the device over a shorter distance, building up to using the device regularly and whenever they needed it. However, for Patricia this was prompted by a negative experience in relation to the device's battery capacity, and the worry that the battery would not last for a long enough period for the person living with dementia to return home. Like Anne, Patricia eventually "got to grips" with the technology which resulted in an increase in frequency and longevity of use.

For another care dyad, Joy, confidence in this technology was initially low due to previous negative experiences of using a different GPS device. Recalling their initial interview, Joy had found issues related to the accuracy as well as the battery capacity of the device. During their follow-up interview, I asked them if this had impacted how they went about using this new GPS device to begin with:

> *JOY: At first, I was very careful, with the last one the battery went all of a sudden and I was worried that the same could happen with this one. What I did was I'd charge it up and take it with us whenever we went anywhere, that way I would know if it was working and that we were where it said we were. After a while, I was happy that it was up to scratch and then I started leaving it with [Eileen] when I went out, checking in now and then, obviously we weren't using it for the same reason that a lot of others could….*

This cautious approach taken by Joy was important as their previous experience of using GPS technology had resulted in an increase in worry for the care partner, despite one of the main reported incentives of this technology being to reduce care partner anxiety. This suggests that whilst benefits are there to be gained in relation to wellbeing, (in particular, reducing care partner stress) previous negative experiences had damaged Joy's relationship with technology and was a cause for worry. Joy continued:

> *JOY: …at the moment, as it is, I haven't found any of the same issues I had with the last one and I'd definitely be recommending this sort of stuff, because if it works, it is life-changing*

Joy did state in their initial interview that they had not been entirely put off using this technology due to their previous negative experience and noted that *"We have to be grateful that these kind of things do exist, and I'm sure they are always getting better" (Joy, Initial Interview)*. Joy did, however, recognise that *"even one problem"*, coupled with an increased lack of trust and confidence in this technology, could result in these devices *"being left in the drawer, which is shame because they really can make a difference"* (Joy, Follow-up interview).

On the other hand, it was interesting to note that for one participant, Gloria, and her mother, Janice, through increased confidence and a better relationship with this technology, Gloria and Janice were able to spend less time using the device as they trusted the device to work as expected. Gloria reported:

> *GLORIA: once we got mum all set up with it, and we were happy that it was working okay, we didn't have to look, we knew that it would just tell us if something was amiss.*

This comment suggests that, whilst the technology continued to be used, in the background and alongside the daily life of Janice, Gloria's trust in the technology alerting them to potential hazards or dangers meant that they were no longer dependent on the consistent use of the live positioning feature. Similar points of view regarding a lack of confidence in the technology working as expected were also discussed during initial interviews and were a reason behind Winifred's son being against the uptake of the technology. This sub theme suggests that confidence in using technology is essential in order to fully maximise its use and access all benefits of GPS. Cautious approaches were taken due to unfamiliarity with the technology, as well as previous negative experiences. Nonetheless, through perseverance (detailed below), the refining of digital skills and trust in the technology working as expected, benefits were found.

Sub theme: Perseverance

The sub theme of perseverance was identified as participants discussed their experiences of continuing with the devices despite a lack of technical knowledge, as well as sticking with the technology when it may have not performed as expected.

One care dyad, Patricia and David, discussed how they struggled with the mobile application side of the technology but were determined to continue using the device as they believed this technology would benefit them greatly:

> *PATRICIA: I'd only recently started to get on with the facebook, so this one was all new to me, but I knew I had to sit down and read all the bumf, because I wanted [David] to do what he could on his own, without me constantly nagging*
>
> *MF: [Laugh] And how did you find that?*
>
> *PATRICIA: [Addressing David] We got there in the end, didn't we?*
>
> *David: Well, you did [Laugh]*
>
> *PATRICIA: It took me a bit (…) I don't think I'd have got it without all the pictures, and me being me, I had to do it on the gadget whilst looking at all the steps*

On reflection, Patricia and David found the funny side to the struggles they experienced with their relationship with technology. Patricia persisted in learning about this technology and how to use it, studying the information available to them (in the form of the user guide) because they recognised the benefits to be gained from this device. This dialogue between Patricia and David shows how they used humour to mask embarrassment of not being able to initially use this technology, and ultimately, they overcame these barriers of knowledge. Persistence was also inferred by another participant, Steve, who stated:

> *STEVE: I did get annoyed with it because I didn't understand why it wasn't sending the warning when [Angela] pressed the button (…) I didn't think it was working right and wanted to give up with it, and I probably might have, but I found where I was going wrong, like I was saying about not having it ticked, and after that it worked perfectly (…) Looking back I'm so glad I did, its helped so much and I knew it would.*

Steve spoke of how his initial reaction was to abandon this technology when it failed to work as expected, however they had the perseverance to continue trying, learning what was going wrong with the device and overcome the barrier they faced. For Steve, they experienced feelings of annoyance and frustration when the device was not working correctly, something also voiced by participants of the focus group. Steve acknowledged that their issue was caused by human error with Steve accidentally turning off SOS button alerts. Both examples show how care partners were motivated by their desires for the person living with dementia to have more freedom and independence and this led to continuing getting to grips with this technology, in spite of the difficulties they had to overcome.

Sub theme: Knowledge barriers

This sub theme discusses the extent of a digital literacy barrier that may have prevented participants accessing certain features and could ultimately prevent use of GPS technology. The phrase digital literacy is used here to refer to having the practical skills in using technology to access, manage and create information, with barriers being the obstacles facing individuals to obtain such skills. One care partner discussed that, despite the user guide and videos that were available, she still felt she lacked the technical skills to use this device to its maximum potential and, in turn, she believed she missed out on certain benefits:

> *WINIFRED: I got a lot better with it as time went on, but I never managed to learn bits, like you told us about setting [geo-fences] home and the doctors, that would have been handy (…) I got settled with what I did know and then its thinking to yourself 'are you going to mess that up by doing this' and that takes over*

Experiences voiced here by Winifred closely align to theories of underutilisation, whereby a user of technology may be prevented from accessing features or functions. In Winifred's case, this appears to have been caused by a lack of self-efficacy in her own technical ability. Winifred states she *"got settled with what I did know"* and expressed a worry that she was going to undo progress she had made in learning how to use the technology by trying to advance her skills. Underutilisation was also a subtheme found during analysis of initial interviews regarding their previous experience of using GPS. This shows that despite this new version of the technology, that has presented overall positive experiences, technology underutilisation is still an issue

A similar statement was made by another care partner, Anne, who spoke of how a lack of confidence in her own ability to learn new digital skills slowed down the uptake in this technology and may have prevented her from using this device to its full potential:

> *ANNE: it took me a while to get started (…) I didn't want to get it wrong, and I wanted our daughter to show us how so that I knew I was doing it right. That's the thing, because it is so important that it is done right (…) I didn't trust myself to do it on my own.*

Both views given by Winifred and Anne also closely align with discussions made in the sub theme of confidence, with lack of confidence in their own ability creating a barrier to use. Similarly, both experiences show the worry caused by attempting to further their technical knowledge, worry that may have had an adverse effect on their wellbeing during this period of use.

Analysis of both the focus group consultation phase and the data from the initial interviews showed how important family support was to overcome knowledge barriers, with people living with dementia and their care partners giving examples of how family members offered technical support and advice to care dyads. This family support was, for some, essential in helping them overcome potential barriers of technical literacy. For Bernie and Barbara, they didn't have such options available to them and this was suggested as a possible reason for why they did not experience all possible benefits from using this technology:

> *MF: Yeah, I know a lot of people in this study have had extra help from the family, just kind of showing them what to do in person, face-to-face …*
> *BERNIE: … that would be a big help, our children live quite far nowadays, we do see them on the holidays and such but cause of the virus and not being able to see one another we don't have that. I did say I might take it to the group [dementia support group] but we are only just going back now.*

Restrictions due to COVID-19 may have also impacted their decision to use this technology, since COVID-19 had prevented face-to-face family contact as well as attendance of the dementia support groups they attend.

Sub theme: Technical encounters

Technical problems were encountered by participants during the 3-month period of use, which for some impacted upon their relationship with the technology being used. Two participants spoke of experiencing false alarms that were generated when they were using the geo-fencing feature. In both examples, care partners received alerts to inform them that the person living with dementia had left (or returned to) the established geo-zone. Whilst this was acknowledged by most participants as an inconvenience (as they knew the person living with dementia had not left the set perimeter), one care partner remarked:

> *LIZ: It would sometimes just say that dad [Ken] had left when they hadn't, we couldn't understand it but we were worried that the rest of the family would also get the alert and then when one day it was real then they might think 'oh its just playing up again'. We actually stopped using that as we thought it was handier just to see where dad [Ken] was instead.*

Liz discussed how the false alarms that they experienced when using the geo-fence feature resulted in turning-off that function so as not to cause worry for other family members who had access to the tracking information. This again shows an example of technical underutilisation, whereby a user was required to disable a potentially important feature due to worries surrounding its use. Feelings of worry were also expressed by Liz, including fears that if her father was in danger, due to erroneous reports of an emergency, alerts would be ignored. This is a lived experience that demonstrates Liz's concerns for Ken's safety, and the decision to disable this important feature was done to protect Ken. Concerns were also expressed about the size of the radius of the geo-fence and how it resulted in a false alarm for another interviewee, who stated:

> *GLORIA: We had an issue with the fences, and we had set one to the hospital because [Janice] once just took herself there because she didn't know what was wrong, so I set the fence to the hospital and one day I got the alert. What had actually happened was she was at the car boot sale across the road, and it must have picked up the signal and said that she was in the hospital area. It caused a bit of panic, but it just took a couple of phone calls to see what had actually happened*

Gloria refers to a sense of panic caused by the malfunction of the geo-fence, with herself and family members presuming that Janice had taken herself or been taken to the hospital without their knowledge. This resulted in phone calls from concerned family members who also had access to the tracking data and subsequent alerts. Gloria spoke of how this panic was resolved, through clarification with family members as to how the issue occurred and the disabling of a potentially important feature. It was also interesting to note Gloria's use of the technical jargon when discussing the issues that they experienced.

False alarms were reported with the ‘SOS key pressed’ feature, which provides the user with an alert should the SOS button be pressed by the person living with dementia:

> *ANNE: It didn’t worry me because I was with him, but it did have our daughter ringing me in a panic asking about [Roger] cause she’d seen it come up on her phone. We just don’t know if he had pressed it because it was attached on his belt, I guess it could have just gone off on its own*

False alarms can cause unnecessary stress and anxiety for some and in the case of Anne, it is unknown if this was a device issue or if it was caused by human error and could have resulted in the disabling of an important feature so as not to cause undue worry for others. These negative experiences shared by Liz, Gloria and Anne again show potential adverse effects to wellbeing from the perspective of the care partner.

Another important finding was participant’s views and experiences on the issue of battery life. This finding was consistent with those discussed in depth during the focus group stage of this research, with chapter 4 (page 138) discussing how participants requested a device that could handle busy day-to-day schedules and require infrequent charging. Ultimately, this device was chosen due to its increased advertised battery life which, given the vast number of features available for this product, appeared to outperform competitors in the battery capacity field. During follow-up interviews, on the subject of battery life, one participant stated:

> *WINIFRED: It is enough, but there’s room for improvement as sometimes it meant we didn’t use it. The other thing is remembering to charge it every day, sometimes I’d forget and [Peter] would go out, I’d say ‘don’t forget to take it’ and when I check on the phone it is saying last seen a day or so ago (…) That [low battery alert] does help, and I know that no matter how long it lasts there’s still me having to put it on charge…*

Winifred alludes to the issue of human error in remembering to charge the device, stating the battery capacity is adequate but could be improved upon. Another participant commented:

> *STEVE: It can be a bit hit or miss, sometimes it lasts longer than other days*

Steve considered the battery capacity of the device to be unpredictable, with it lasting longer on some occasions than others, this may be due to the frequency of tracking, with Steve requesting the geographical location of device at more frequent intervals on some days, causing the battery to drain quicker. This experience was also discussed by Gloria who commented:

> *GLORIA: … you have to set it [tracking to higher intervals] to 30 minutes or so, I then found that it lasts a lot longer. It is fairly decent, but only when its set that high, otherwise it drains too fast. Other than that, it is just remembering to put it on charge every night, or every other night, and that's what we struggled with*

Another participant drew reference to their prior experience of using GPS technology:

> *JOY: [On battery life] It is miles better than the last one we had, that's for sure*

This statement by Joy is an encouraging one, as battery life was one of the main factors that resulted in their abandonment of the technology during their last attempt. Improvements in technology has helped to rebuild Joy's confidence in these devices.

Participants also offered their views, opinions, and insights on aspects of the device that they considered essential and felt were responsible for strengthening their relationship with technology and resulting in continued use. The design of the device itself was a pivotal factor, and was briefly discussed during initial interviews, but following the period of using the device, participants explained why elements such as the size, shape and weight were so important to them. One participant remarked:

> *JOY: It is very neat and not obvious what it is, a lot of what they aim at us lot nowadays is always big buttons and clunky*

Joy discussed how technology aimed at older people may use design considerations such as large buttons or displays, resulting in a product that is bulky and difficult to conceal, for Joy, these devices need to be as discreet as possible, so as not to draw attention to the function of the technology. This point of view was shared by another care dyad:

> *ROGER: we can't have something that gets in our way…*
>
> *ANNE: …we always said that you don't want to wear something that tells people you've got something the matter, and this is great because you can just have it in your pocket*

Anne and Roger may be alluding to the stigma attached to some assistive technology products, with the size of the device suiting their need for a device that is inconspicuous and unobtrusive, further coinciding with statements made by Anne and Roger in their initial interview.

Good functionality of the application for displaying GPS location data was also touched on by participants. Winifred discussed that mobile applications (apps) do not always meet the needs of older people and are usually complex and difficult to navigate, however Winifred praised the design of this application:

> *WINIFRED: …it has got nice sized buttons and it is all very simple, I don't like them when they cram everything together and I can't see what's what.*

A convenient user interface was a quality also remarked on by Liz, who evaluated the user friendliness of the application, commenting on the need for minimal design and avoidance of any irrelevant content on the main section of applications:

> *LIZ: … the map is all we really need to see there, and I like how it is just a map and then a little marker to say where [Ken] is*

Other participants noted the importance of clear instructions on how to use the application, with simple steps to follow and easy navigation through the app:

> *ANNE: if you'd given it me without the booklet, I wouldn't have had the foggiest on where to start [laughs]*

This was echoed by Bernie:

> *BERNIE: the guidebook and photos were very useful, showing me each of the different steps is the only way I can do it nowadays*…

Whilst this was not an expected outcome of follow-up interviews with participants, one care partner discussed a potential feature that could be added to devices that they felt would improve the technology.

> *LIZ: do you think they could have something to tell you when someone has been in one place for a long time? I'm thinking an alarm of some description so if someone had a fall when they had it on them, it would tell you to check on them.*

This point made by Liz may closely align with the concept of safe walking, described below in greater deal, whereby care partners wish to ensure that a person living with dementia can walk independently whilst being steady on their feet. Personal alarms and fall detectors are fairly commonplace technological solutions in healthcare, however they usually work using motion sensors to detect any unexpected fall and downward motions, or alternatively will be pendant devices that can be carried by a user, featuring a button to call for assistance. What Liz was describing is more of a lack of movement alarm, which would utilise GPS technology. Liz may also be alluding to their concerns surrounding the safety of Ken and may want extra precautions to be taken in an attempt to counter the additional risk which occurs through increased freedom and independence.

Sub theme: Abandonment

One care dyad, Eric and Pauline, opted to not use the GPS device provided to them for this study, however still wished to partake in a follow-up interview to discuss the reasons behind their decision. Their rationale forms a sub theme within this analysis where discussions are made regarding their worries and concerns of using this technology, and whether or not such anxieties could be mitigated.

Fear of digital competency

Upon reflection, Eric felt that he did not possess the adequate digital skills to use the device and worried that their own human error or misunderstanding could put Pauline at risk. Eric stated:

> *ERIC: … a lot was I didn't feel happy about it, her life could be in my hands then and how much I could remember, it's like some jobs [inaudible] know when they have a life at stake, and it comes down to them and how good they are at doing what they do (…) I can't remember the buttons and I think it all came down to that…*
>
> *MF: Yeah, I see, do you think it would need to be simpler to make you more comfortable using it?*
>
> *ERIC: I'm not sure [laugh] I think us folk can forget even simple things when it comes to these*

During their initial interview, Eric spoke of how members of their family acted as technical support when it comes to learning how to use technology. I proceeded to ask Eric if family members were on hand to help them overcome these fears related to digital competency:

> *MF: I know originally you said you were going to ask your daughter to come around and show you how it all works, was she able to do that?*
>
> *ERIC: Yes, yes she came around and we sat and went through it all, and she is very good with me, very patient, but I just couldn't catch on with it (…) She said it wasn't any different to this and that, but because of how important it is that I know it all, I was getting worked up about if I do this wrong or I forget to do that, and what happens if I press this, then we said we would leave it for the time being and try again*

> *MF: No, I understand, did you manage to pick it back up or was it something you …*
>
> *ERIC: … I did look at it all again but no, not really.*

Adapted to new way of daily living

In contrast to other participants, Eric discussed how they had become fairly established in their new routine following Pauline’s diagnosis. Eric questioned how often they would get a chance to use the device given that they conduct all activities together, this was noted as one of the reasons they decided against using the technology in this study:

> *ERIC: “well we thought about it and everything we do we do together, we’ve got used to doing that and I know how much this could help people with dementia, but maybe it is just not for us”*

Whilst during the initial interview Eric had foreseen opportunities to conduct tasks individually and independently, they had now concluded that since they had become settled doing everything together, they may not experience the sort of benefits related to freedom and independence that others report.

However, Eric did state:

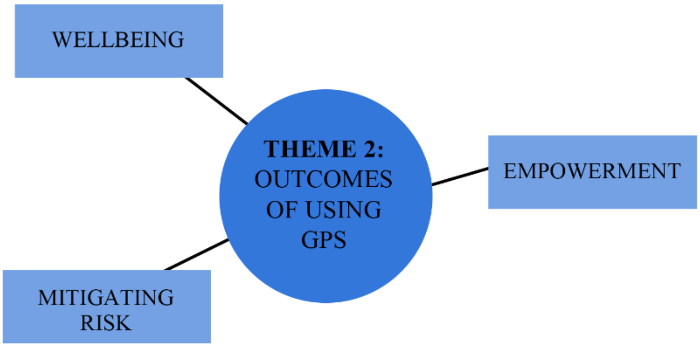
> *ERIC: “although it would be handy if [Pauline] did wonder off on her own, but she’s never really done that”*

This suggests that Eric did still consider the benefits GPS may provide, as a back-up option should Pauline’s behaviours change, and may revisit this in the future. This view of seeing GPS as a back-up option coincides with other participants who recognise the change in role of the device from a tool that could support freedom and independence, to a “safety net” (Steve, initial interview), should Eric not be able to locate Pauline.

Summary of theme

This theme has provided important insights into the relationships care dyads had with this technology. Sub themes have considered the various determinates of use, ranging from confidence in the technology to the persistence and perseverance required to make appropriate use of the devices. The theme has also considered the barriers that participants faced, including the challenges related to digital literacy, as well as the problems with the devices that they encountered along the way, all of which could impact upon a person's relationship with GPS. It was also important to consider the rationale behind one care dyad’s decision to not take up using this technology, as it provided a comparator for the reasons that other participants chose to use these GPS devices. This theme often interrelates with other ideas and concepts found throughout the next theme; outcomes of using GPS. Participants alluded to issues of confidence or disussed negative experiences when using this technology, with these insights linked to adverse effects in terms of a person’s wellbeing. As well as wellbeing, instances of errors and malfunction were also connected to views surrounding safety and risk mitigation, an outcome that is discussed in more detail in the next theme.

THEME 2: Outcomes of using GPS



The following theme has been identified to show the outcomes of using GPS, as experienced by care dyads. Within this theme, discussions centre on the impact GPS has on a person’s wellbeing. The sub theme of wellbeing is discussed by drawing parallels from Kitwood’s (1997) model of Psycho-Social needs, which he argues are essential to maintain a good sense of wellbeing. Kitwood identified 5 fundamental psychological and social human needs, namely: comfort, identity, occupation, inclusion, and attachment. Discussions also considered Sabat’s (2001) selfhood and Bartlett and O’Connor’s (2007: 2010) concept of social citizenship. During analysis, it became clear that the views and experiences of participants, regarding the ways in which GPS technology could assist when caring for and supporting people living with dementia aligned with Kitwood's model of needs. This theme proceeded to focus on how GPS was used to empower individuals living with dementia. A sub theme of 'mitigating risk' is also discussed, this considers the role of GPS in mitigating risk, and how care partners harnessed the technology to control or prevent exposure of a person living with dementia to potential hazards. Methods for mitigating risk deviated among participants. Care partners of individuals at early stages of their dementia journey considered the benefits of GPS to be in facilitating safe walking, enabling a person to retain independence, whilst reducing the stress experienced by care. Other methods included using the device to enhance the safety the individual living with dementia, by alerting a care partner to potential dangers such as a busy road. For care partners of individuals in the more advanced stages of their dementia journey, GPS was viewed as a back-up option and an additional safety tool, to help locate a person should they get lost or disorientated.

Sub theme: Wellbeing

"Wellbeing is about feeling good and functioning well and comprises an individual's experience of their life; and a comparison of life circumstances with social norms and values" (Department of Health, 2014: p.6)

This sub theme will consider benefits in relation to wellbeing from the perspective of the individual living with dementia and the care partner, before discussing mutual benefits or where benefits may contradict one another. Discussions will consider each of the 5 psychological and social human needs, as proposed by Kitwood (1997), beginning with comfort.

Comfort

"This word, in its original sense, carries meanings of tenderness, closeness, the soothing of pain and sorrow, the calming of anxiety, the feeling of security which comes from being close to another." (Kitwood, 1997: p.81)

Participants described how, through using the GPS device, comfort was found through relief and reassurance, with a range of reported benefits of using GPS, in particular, how devices were used to reduce fear and anxiety, provide additional peace of mind and aid in reducing or managing family stress. In terms of using GPS technology to reduce the fear and anxiety experienced by care partners, participants discussed how merely the existence of the GPS device provided reassurance, stating that they felt more "at ease" (Anne), and a greater sense of relief when the person living with dementia was carrying the GPS device. Participants reported that even when the GPS device had not actually been used to track the person they care for, they felt more relaxed knowing that they now had the ability to check the location of the person they care for on demand:

> *PATRICIA: … having the option there, it has been so nice to know that I can see exactly where [David] is if I ever need to*
>
> *ANNE: …it is a weight of my mind*

The comment below illustrates how Joy utilises the device differently but still found comfort in using the technology. Instead of checking the location of Eileen when they are out of the house conducting tasks and activities independently, Joy checks in on the location of Eileen when Eileen is still at home:

> *JOY: it definitely calms me, but it is funny isn't it 'cause I know that she might have gone out without taking it, but if I leave her at home and check-in on it [the application] and I see the dot is still in our house, I get that bit of peace knowing it.*

Joy comments on the comfort gained from using the device but also mentions an underlying worry that Eileen could still leave home without carrying the device with her. Joy also uses the phrase "it is funny isn't it" and goes on to suggest a potential drawback of this technology, in that human error could result in Eileen getting into danger and Joy would presume they were still safe at home. In this, Joy is acknowledging and describing a new worry they have regarding this technology and that whilst GPS is proving peace of mind, problems could still arise, and Joy is aware of that.

Another interviewee alluded to the notion of comfort gained from using GPS when they spoke of the fear that they sometimes experience when Peter is out of the house on their own, so to overcome this they utilise the device to lessen their worry:

> *WINIFRED: if I ever start to panic, I just go on my phone and look, I did it a lot more at the start, but I can't tell you how helpful it has been for me*

Interestingly, Winifred comments on how this process to alleviate their anxiety has reduced overtime as they continue to use the GPS device, implying an increase in trust and confidence in her mind that Peter is safe. This may also coincide with an increase in confidence in the technology itself, as Winifred becomes more familiar with the technology, they do not feel the need to check-in on the location of Peter as often. Confidence in technology use is discussed in more detail in a later theme as discussions are made regarding the impact it has on participants continuing to use these GPS devices.

During initial interviews with participants, care partners perceived that added peace of mind would be one of the overarching benefits of using this technology, and this was confirmed during follow-up conversations. Almost all participants that used the devices (7 out of 8 care dyads) discussed how GPS provided them with a feeling of greater peace of mind that the person living with dementia was safer when carrying a GPS device. Participants referred to a freedom from worry, or at least an increase in calmness, when the individual living with dementia is independently leaving the home:

> *LIZ: When he goes out, I now know that I have something in place, and that in itself gives me so much peace (…) because that has always been the worst since the beginning, just the not knowing where he is and the being helpless if something did happen…*

Liz describes the peace of mind that results from them having a back-up plan available to them should something happen. Liz reported a prior feeling of helplessness and lack of control over the situation should Ken become lost. Liz discussed how GPS has provided them with a solution to their concerns and given them reassurance that should Ken become lost or disoriented, they have a potential tool to help locate him.

In terms of mutual benefits, some participants described how both members of the care dyad had found a shared sense of comfort from using the device. Ken found comfort by considering the impact of the devices on the lives of care partners:

> *KEN: I know that it has helped [Liz] stop worrying about me so much and when she's happy, I'm happy*
>
> *MF: Yeah, so it has worked for both of you and made you both feel better?*
>
> *KEN: Yes*
>
> *LIZ: Yes, it has*

Ken spoke of how they have felt an increase in calmness whilst using the device and attributed this to their care partner's increased feelings of calm, suggesting that *"when she's happy, I'm happy".* In many ways this shows how interdependent the dyads had become, where one person's wellbeing is mirrored in the other person. Feelings of shared comfort whilst using the device were also described by Roger, who stated:

> *ROGER: "I'll do what I can to make it easier and I know that this is, we're muddling through aren't we? [comment directed towards Anne]"*

Roger wants to do all he can to reduce the stress felt by the care partner. Additionally, participants attributed the feeling of relief regarding their situation to a reduction in family stress following the adoption of the GPS device. Some participants spoke of how they had shared this new technology with the wider family, and whilst the initial intention of the research considered the device and mobile application to be used solely by the care dyad, participants chose to include the contact details of multiple users to share found benefits.

This was described by one participant as "ideal" who reported the benefits of multiple family members being able to receive alerts:

> *GLORIA: It has been ideal in many ways, I have been able to add my two brothers to the contacts so they can know what mum's up to, and I think it has helped everyone … I did give them all the details [to login to the app], but I think just receiving any warnings is enough to make them feel better about things…*

One care partner, Anne, discussed how often their adult children had been using the app, and how this may have contributed to a reduction of stress:

> *ANNE: I think our two children have used it more than I have [laughs] they're always calling up, telling me that they were checking where he was because they knew he was going out, so it has helped all of us (…) they have also been good at reminding me to charge it too.*

This was echoed by another care partner, Winifred, who discussed the benefits the entire family have experienced when using the device:

> *WINIFRED: I feel like as a family we're a lot more at ease about it all, we don't have all those worried phone calls every time [Peter] goes off without telling someone*
>
> *MF: Yes, I know in our last interview you discussed that your daughter was convincing your son that it [GPS] was a good thing, do you think he's changed his opinion on it?*
>
> *WINIFRED: he did struggle with it [pause] it's just because he worries about his dad [Peter] but he's come around (…) I think that he saw how less on edge we*

> *all are every time [Peter] goes on his own, but he knew that we can't stop him because he needs that, and we don't know how long he can still do it for*

Referring back to initial interviews with participants, Winifred discussed the views of their son and how they were initially sceptical of the technology and fearful that it may result in undue risk. For Winifred, they faced a dilemma of risk versus reward, however they believed that this technology presented them with an opportunity for Peter to continue undertaking meaningful activities and retain a level of independence that she felt was vital for her husband's wellbeing. Winifred's comment regarding how long Peter can remain independent for adds a poignant reminder of how important it is to live in the present moment and optimise wellbeing for the person living with dementia.

Participants living with dementia described how GPS devices gave them a feeling of security and safety when outside alone. One participant, Peter, commented:

> *PETER: well just having this with me lets me know that I could be found…*

Another participant compared the GPS device that they carried with them to a distress signal that they could activate should they experience feelings of fear or danger. Ken makes this link and refers to their past occupation in the Royal Navy:

> *KEN: … I don't pay it much attention when I'm out but if I need it, I have it [pause] I was, I was saying to [Liz] it is a bit like the flares you get when at sea isn't it*

Conversely, the use of GPS technology can also have negative repercussions in terms of comfort. A small number of those interviewed (3 care partners) suggested that GPS brings with it new worries and anxieties. Some of these experiences have been discussed in the previous theme when negative experiences or issues of confidence and trust were explored. For one participant, Liz, whilst their view of GPS technology overall was positive, they did comment upon their new role in managing the GPS device:

> *LIZ: It does give us another job [laughs] you have to look at it from all sides, because I often forget to plug it in [put the GPS device on charge] and that itself is a worry for me.*

Liz continues to list the benefits they found from using GPS technology, however their statement regarding forgetting to recharge the device and the worry it caused could not be overlooked. Similar inferences were discussed above when Joy described a new worry in terms of the person living with dementia not taking the device with them.

Whilst GPS may result in many fears and anxieties being reduced, care partners may find that GPS brings with it new concerns and challenges, particularly for the care partner, and these may lead to new stresses and almost certainly does give the care partner "another job" to do in terms of managing the technology. This shows that whilst one burden may have been lifted, another has replaced it, with care partners now finding themselves concerned with potential issues related to the technology itself, whether that be the battery life, the accuracy of the device or the increased risk the person living with dementia may come under from increased freedom and independence. Other care partners discussed how GPS has alleviated, but not entirely eliminated their concerns and worries.

> *PATRICIA: I just have to worry a lot less*

Analysing this point of view by Patricia, they described their reduction in worry, by saying; she has to *"worry a lot less"* (Patricia), inferring that worry was a mandatory feeling, and she will always experience some form of worry, however the technology meant that it could be lessened through its use. Parallels can be drawn here with comments made by other participants in both phases of this research, with Ethel expressing similar feelings in phase 1 and Joy stating earlier in this chapter that care partners will always worry about something.

Comfort has described the ways in which GPS can be used to provide all members of a care dyad with feelings of safety and security. Participants living with dementia spoke of how knowing that if they become lost and disorientated when outside alone, they could easily be found, and this was a cause of great comfort to them. Comfort was discussed from the aspect of the care partner and the ways in which GPS devices provided them greater peace of mind and a reduction in anxiety. This also benefitted individuals living with dementia, who, at times described their desires to relieve the burdens that their condition places on the care partner, with views such as "*when she's happy, I'm happy"* (Ken) showing how one person's wellbeing can be mirrored in the other person. For Kitwood (1997), the need for comfort can be fulfilled through providing an individual with practical and emotional support, instilling feelings of calm, warmth, and security.

Identity

“To have an identity is to know who one is, in cognition and in feeling. It means having a sense of continuity with the past; and hence a 'narrative', a story to present to others. It also involves creating some kind of consistency across the different roles and contexts of present life.” (Kitwood, 1997: p.83)

Participants shared details about their life history and described how GPS has enabled them to continue aspects from within it. Roger and Ken, participants living with dementia, spoke of how GPS devices have supported them to continue engaging in activities that they have been doing for a long time, before their diagnosis, activities that provide them with a sense of who they are, in addition to assisting them with opportunities to contribute to society:

> *ROGER: “you were talking about it this morning and we’d use it when we do the poppies”*
>
> *KEN: “I think you [Liz] used it when I go to church?”*

This sense of continuity with the past was also inferred by Roger who recalled his role of collecting daily groceries, commenting on how this has continued with the help of GPS:

> *ROGER: “It is good for me to get out of the house, I try most days, just to the shops, [Anne] said that they’d seen me all the way one day to make sure I got there”*

Speaking on behalf of an individual living with dementia (Peter), Winifred stated:

> *WINIFRED: “…its helped him do a few more things (…) It now doesn’t have to stop him doing the things he has always done on his own”*

By referring to Peter’s past, Winifred spoke of the way in which GPS has been enabling and supporting Peter’s sense of identity in giving them the opportunity to continue living their life the same way they did before diagnosis. Participants also considered identity in terms of being the person that they have always been, as well as acknowledging the person that they are now, with Patricia stating that David understands that they have dementia and not everything will always be possible, but this should not limit the input they have into everyday life.

> *PATRICIA: … [David] knows what he has and some things we can do, some we can’t, it is just about knowing what we can and can’t do, because there are still so many things that he can do.”*

Patricia draws reference to the importance of acknowledging what a person living with dementia can do, shifting the focus towards abilities and refraining from solely viewing limitations of living with dementia. These views expressed by Patricia are central to person-centred ways of viewing dementia, acknowledging the identity of the person, “knowing who one is” and the value they have to give (Kitwood, 1997: p.83).

From the care partner stance, participants reported that GPS devices had the ability to create or maintain a sense of normality within their everyday routines and schedules. The term normality has been used here to describe the usual, typical, or expected ways of conducting activities of daily living that existed prior to an individual’s diagnosis of dementia. Participants commented on how, during the dementia journey, elements of normality may have been lost, with this technology giving them an opportunity to regain or re-establish aspects that had been missed. This is best illustrated in a quote by Anne:

> *ANNE: …because I thought a lot of that was behind us, I’d come to terms with how things had to be but then this [GPS device] came along and it has almost given us the choice again to go back to how it was before, just, you know, going out on his own and that...*

Anne spoke of going “back to how it was before”, suggesting that through the use of GPS, Roger was able to go out unaccompanied again and return to levels of freedom and independence experienced by Roger prior to their diagnosis or perhaps at the beginning of their dementia journey. Whilst it is not as implied, Liz also explains how Ken was able to return to conducting activities that they have done in the past, with the help of GPS:

> *LIZ: He can do more of what he used to do now, well shall we say that we had a bit of a wobbly start [laugh] which I’m not even going to go into, but we’re getting back to it…*

Whilst it is unknown what the obstacle is that Liz was referring to, the remarks suggest that as they have utilised features of GPS within their daily routines, they have been able to return to a sense of normality. Normality was also considered from the aspect of creating a ‘new normal’ for participants, with Patricia stating that, through this technology, they can establish new routines that can benefit both the person living with dementia and the care partner:

> *PATRICIA: thanks to this [the GPS device] I’ve got used to it and I don’t know what I’d do without it.*

This suggests that Patricia has gained familiarity with using this new technology and now struggles to envisage what life would be like without it, this also shows there is a level of dependency on the device.

Many of the views expressed in relation to identity, by both individuals living with dementia and their care partners, are advantageous to both members of the care dyad, in particular how GPS was used to create or maintain a sense of normality within their everyday routines and schedules. There are, however, potential contradictions that could arise, in particular with regards to care partner anxieties as a result of increased independence. Whilst it was not explicitly stated by participants, as freedom and independence increases, the downside for the care partner could be increased worry. Whilst GPS will help to alleviate some of the increased worry, as described by Gloria, it cannot entirely eliminate it:

> *GLORIA: [on GPS reducing worry] there will always be some there, but that's to be expected, the only way to rule that out is to be with them constantly*

Gloria defines this worry as expected and almost inevitable, with Gloria suggesting that the only way to prevent care partner anxiety is through constant supervision of the individual living with dementia. This potential contradiction may also apply to other needs listed in this theme, particularly where needs result in an increase of freedom for the person living with dementia.

In summary, identity has considered the role GPS can play in helping to continue the story that people have to tell, providing individuals the ability to retain levels of independence during their dementia journey and helping to support them in their desire to continue contributing to society. This has also analysed the way in which GPS can provide dyads with the opportunity to regain or re-establish aspects of normality within the daily routines that had been lost following the diagnosis of dementia. For Kitwood, the need for identity is an essential aspect of wellbeing, to provide people living with dementia the ability to *"know who one is, in cognition and in feeling"* (Kitwood, 1997: p.83). The need for identity is likened to a story or narrative, told by the individual, that links to their past, displaying continuity and consistency.

Occupation

"To be occupied means to be involved in the process of life in a way that is personally significant, and which draws on a person's abilities and powers. The opposite is a state

of boredom, apathy and futility" (Kitwood, 1997: p.83)

Participants discussed how the GPS device was used to help a person take part in activities and outings, in particular activities that were meaningful and significant to the person living with dementia. Remaining active was a key desire discussed by participants, including David. During David's initial interview, he spoke of how walking was one of his main interests and how it kept him feeling fulfilled. During the follow-up discussion, David and Patricia stated that GPS had been used to enable them to continue with this interest:

> *PATRICIA: I've made sure [David] has had it with him on his walks, I don't think you even notice it's on your backpack most of the time, do you?*
> *DAVID: No, not really*
> *PATRICIA: But this is what I was saying to one of our friends, for such a small thing, it can make a big difference because it will mean that [David] can carry on with his walks and I don't need to worry so much, I think it is wonderful and more needs to be made of it.*
> *DAVID: Yes, I do like my walks*

Patricia suggests that "*more needs to be made of it"* implying that this technology, which has proved successful for them, requires greater awareness being made regarding the benefits it might hold for people living with dementia and their care partners. Another participant stated that although the activity may, for some, be considered insignificant, for them it was rewarding and resulted in a feeling of accomplishment.

> *ROGER: … it's the little things (…) it's only a little walk but for me it is more than that and I come back feeling like I've done something and it is something I might one day take for granted.*

Roger comments on how they believe certain activities may not always be available to them and cannot be assumed, GPS however could prolong the amount of time spent doing the tasks and activities they enjoy. Roger later spoke of how their "worst days" are when they are not conducting activities that stimulate their mind and coincide with feelings of boredom and frustration. For Roger, such days tended to occur when their care partner, Anne, was out of the home conducting her own tasks, however they have found that GPS has reduced the frequency of such occurrences:

> *ROGER: I have my worst days when I'm at home on my own, doing nothing, but I think it is better…*
> *ANNE: … it's because when I go out, you don't have to wait for me to get*

> *back before we do something…*
> *ROGER: …yes that's what I mean*

One care partner, speaking on behalf of the person living with dementia, similarly recognises the importance of certain activities:

> *PATRICIA: being able to carry on doing this [independent walking] means the world to him and you can see that*

The concept of care partner independence can be used to show how GPS can support care partners in fulfilling their own need of occupation. This concept considers how care partners are able to perform activities of daily living independently when using GPS. Interestingly, this was also present in the initial interviews as care partners perceived this to be a positive impact of GPS.

Participants discussed the ways in which they utilised GPS technology to facilitate more opportunities to conduct separate tasks, and how this impacted upon their daily lives. One participant commented:

> *ANNE: it's been great, being able to get out and about and tick off things on my to-do-list (…) there was a bit of worry to begin with, getting used to it and all, but it has helped enormously*

Anne was one participant who predicted this benefit during initial interviews, recognising how GPS could provide both the individual living with dementia and the care partner with greater freedom. However, Anne stated that getting there took time, mentioning the worry that arose from this newfound independence.

Another care partner, Steve, remarked:

> *STEVE: I've found more hours in the day [laughs]*

This comment by Steve infers that through use of the GPS device, they have been able to get more of their own tasks completed during the day, alluding to time constraints that they may have faced when leaving Angela at home on her own. Increased pressure on the care partner, in relation to time constraints are also referred to by Joy who stated:

> *JOY: …it's maybe hard to tell what from what given everything that's happened [the COVID-19 pandemic] and us just getting back to normal, but I think one of the big things has just been knowing that [Eileen] is okay when, for example, I'm out shopping and that, I feel as though I am not rushing around as much…*

Joy's experience regarding *"not rushing around as much"* may be suggesting that, prior to using GPS technology, they were uncomfortable leaving the person living with dementia on their own for lengthy periods of time, and as a result faced time pressures and associated feelings of worry and anxiety. Through using GPS, they are able to mitigate this stressor as they are able to check the location of Eileen on demand and potentially leave a person living with dementia alone for increased time periods. This is a further example of care partner independence, whereby through using GPS, Joy can conduct her own activities independently, without experiencing feelings of guilt or fear.

Both individuals living with dementia and their care partners discussed the valuable and beneficial ways in which GPS could help facilitate meaningful and significant activities. When considering possible conflicts that could arise as a result of using GPS to satisfy one part of the care dyad's need for occupation, the occurrence of isolation could be discussed. Whilst it was not explicitly reported by people living with dementia, as care partners gain increased feelings of independence and the ability to conduct more activities individually, the person living with dementia could face negative repercussions in terms of increased periods of isolation. For example, taking comments made by Anne *"it's been great, being able to get out and about and tick off things on my to-do-list",* the downside of this for Roger is that Anne is out of the house for longer and they may be left alone at home for extended periods of time. From Anne's perspective, they are experiencing less anxiety when Roger is at home alone, and through using GPS, they can go about their daily activities checking on the whereabouts of Roger on demand. The same could be argued when Steve stated, *"I've found more hours in the day [laughs]"* and inferred reduced time constraints. Whilst people living with dementia did not articulate this as such, as care partners discussed going out independently more often and for longer periods of time, there is an inference that people living with dementia remained at home on their own.

These discussions have shown the potentially vital ways that GPS can support people living with dementia to fulfil the need for occupation and to continue conducting tasks and activities that have meaning for the person living with dementia. Participants living with dementia expressed the feelings of success and achievement that are experienced when conducting certain activities alone with care partners adding how in some circumstances GPS made such possible. Considerations have also been made with regards to the care partners need for occupation, examining views and experiences related to the concept of care partner independence and how GPS was used to enable a care partner to *“get out and about”* (Anne) on their own, without certain time constraints and reduced feelings of worry when leaving an individual living with dementia alone.

Inclusion

“The social nature of human life has another aspect, related to the fact that we evolved as a species designed for life within face-to-face groups. To be part of the group was essential for survival” (Kitwood, 1997: p.83)

Participants discussed the different ways in which they used their GPS devices to experience inclusion, a sense of belonging and acceptance, through meaningful connections with friends, family and the rest of society. The different social groups that participants attend were often referenced, with care partners explaining that GPS technology may enable them to extend their attendance at certain groups throughout their dementia journey. During initial interviews, participants expressed the importance of social interactions at groups, and how some care partners feared the day when they had to prevent the person living with dementia from undertaking certain social activities, citing the impact it may have on wellbeing. Analysis of follow-up interview data showed that GPS was able to lessen such fears, with Patricia stating:

> *PATRICIA: I said to you before that I never want to stop him from attending things and this has helped him keep up with the things he used to do, and I think it will a lot more when everything returns to normal (…) I can’t always go but with this I might not have to stop him just yet …*

One participant living with dementia spoke of the importance of attending these groups for both members of the care dyad, with their care partner expressing what it means to both of them:

> *ROGER: I go without you [Anne] which is good for us both [both laugh]*
>
> *ANNE: I drop him off and I know that I have the tracker to see where he is, but it is so nice to hear him talking about some of the groups and what he got up to and that….*

Care partners often spoke of the ways in which they utilised GPS to support their own need for inclusion, as well as the person living with dementia. During initial interviews, one dyad spoke of the difficulties they faced staying connect to society and how dementia often resulted in feelings of loneliness experienced by both members of the care dyad. Initially, Joy spoke of how they get to a point whereby care partners stop being asked to attend certain social engagements as people presume that caring for someone living with dementia would make them unable to attend, comparing this to comments made by Joy at the follow-up interview shows how GPS has enabled them to be more flexible, and, as such, more sociable:

> *JOY: …well its things like being able to go to the shops on my own, like I said before not I'm not rushing as much.*

In terms of the benefits to be gained from a mutual perspective, one care dyad indicated how GPS can be used to increase social inclusion for both partners in relation to attending social groups independently. Gloria discussed the impact which GPS had, in terms of commitment to certain events, with Gloria working whilst caring for her mother:

> *GLORIA: we were finding that a few of mum's groups fell on days when I was going back into the office, so that's when it was really a godsend because otherwise, she'd have had to miss it…*

Gloria discussed the difficulties that they would have faced in terms of scheduling Janice attending certain social groups when Gloria was at work. By utilising the GPS device, both Gloria and Janice were able to attend their respective events. Gloria found that she was able to arrange travel for her mother to the local group before going into the office to attend work. Whilst at work, Gloria was able to check the location of Janice via the application on her smart phone and go about her work-based activities without worry or anxiety, safe in the knowledge that she could check the location of Janice on demand and be alerted should Janice face difficulties. In addition, Gloria did not have to experience feelings of guilt related to preventing her mother from attending the group. In both scenarios inclusion was experienced, inclusion for Janice through attendance at the social groups, and inclusion for Gloria at work. This is an important finding as it depicts challenges that may only impact certain care dyads, however as the number of working age care partners rises, many may struggle to combine the responsibilities of working and caring for someone living with dementia simultaneously. For many care partners, caring for a person living with dementia could be viewed as a full-time occupation, with many individuals living with the condition needing 24-hour care. In Gloria's instance, they discussed the need to find the right balance between their work commitments and their role as a care partner for Janice, they went on to discuss the challenges that can arise if a balance cannot be met:

> *GLORIA: … with this you just can't spread yourself too thin*

The phrase Gloria used here alludes to difficulties that could arise if you attempt to include yourself in so many activities that the result is not being able to give enough time or attention to any of them. Gloria has utilised the technology to help find this work-care balance, enabling both members of the care dyad to be involved in activities simultaneously.

These discussions show how GPS technology has been used by participants to increase opportunities for people living with dementia to conduct activities that instil a sense of belonging and acceptance, keeping them connected with society. Participants offered examples of how GPS has been used to support attendance of groups and social events independently. Additionally, care partners own need for inclusion has also been highlighted, and how they used GPS to support this. Finally, an example of how a care dyad used GPS to manage caring and working concurrently was given to show the mutual advantages of using this technology to support inclusion.

Attachment

"Ours is a highly social species, and this is clearly shown in the forming of specific bonds or attachments … Life is overshadowed by new uncertainties and anxieties, and some of the good memories from past secure attachments may be lost." (Kitwood, 1997: p.82)

Whilst some of the extracts above may also fall into the category of attachment, as participants described how GPS was used to provide continuity with a person's past, the instance described below shows how GPS was used to create more opportunities for the person living with dementia to feel closer to others. Liz describes how they used the device to facilitate social interactions for the person living with dementia with other family members:

> *LIZ: I showed my brother and his wife the app and the tracker and they were very impressed with it (…) they've always been a bit funny about having dad [Ken] stay with them, but I showed them how to use it, and I think it made them feel a lot more at ease about it. We'll see.*

In this situation, Liz described how, due to the GPS device, her father living with dementia was able to spend time with other members of the family. It is assumed that without this technology, this would not have been possible due to the concerns and worries held by family members of Liz with regards caring for someone living with dementia in their own home.

One care partner, Bernie, discussed how he has used the device to help keep Barbara living at home, in the community and most importantly to keep them living together. Bernie spoke of being realistic in terms of the help and support that is available to them whilst they live at home together but stressed that he wanted to keep his wife at home with him for as long as it was possible to do so. Bernie goes on to talk about his fears on what would happen if Barbara was no longer able to live at home:

> *BERNIE: It will happen one day, I know that and we talked (…) anything that can keep her here with me for longer, because when you go into a home that's almost that (…) a friend of ours told me something similar.*

Bernie discussed their perceived difficulties and how they had, together, considered the possibility that Barbara may need the support of a residential care home in the future. Bernie spoke of a bleak outlook on transitioning into residential care and part of what he discussed could fall into a number of the needs explored above. These views may be alluding to the loss of identity and occupation *"when you go into a home" (Bernie)*, as Bernie states "that's almost that" as if he is acknowledging limited expectations for the future. However, this statement by Bernie has been placed under attachment as it is believed that the main concern Bernie has is that Barbara will no longer feel connected to someone or something, and they will both lose their attachment to one another. Links can be also be drawn here with the need for comfort, explored above in relation to care partner wellbeing, and how the added reassurance provided by this technology in turn fostered attachment for the person living with dementia. Kitwood spoke of the need for individuals to feel connected to someone or something, forming relationships that can act as *"a kind of safety net (...) when the world is full of uncertainty"* (Kitwood, 1997, p. 19). Such words were echoed by one participant (Steve) during initial interviews when they voiced the perceived benefits they felt were there to be gained from using this technology.

Sub theme: Empowerment

The evidence presented in this sub theme suggests that one of the outcomes from using GPS technology is empowerment of the person living with dementia. The term ‘empowerment’ is used here to refer to opportunities for people living with dementia to exercise greater choice and control in their lives. In addition to aiding in the fulfilment of the above psychological needs, GPS can also help to empower people living with dementia through facilitating interactions between the person living with dementia and their environment. The literature review situated in chapter 2 considered Sabat’s (2001) theory of selfhood and malignant positioning as well as Bartlett and O'Connor’s (2007) concept of social citizenship.

Throughout interviews with care dyads, for those who utilised GPS to promote independence and autonomy for the person living with dementia, examples can be seen of how GPS has provided them a sense of control, affording them the ability to make their own decisions. Regarding having a sense of choice, one participant stated:

> *Ken: I’m grateful to still be able to do what I want and [Liz] was telling me that this here [GPS] will mean I’m doing that without causing a fuss for other people to deal with.*

Ken may be acknowledging that, at times, increased control over decision making can result in increased worry for care partners and family members, and states that the benefit of GPS is that it can result in an increase in a sense of control without the *“fuss for other people to deal with”* that comes attached.

Whilst this is covered in more detail in chapter 6 (aim .6), many of the views and insights offered by people living with dementia here align with Sabat’s (2001) arguments around social positioning. When using GPS, the outcome for people living dementia can be the removal of ‘micro-management’, where people living with dementia are closely observed, controlled and reminded of what they can and cannot do. This research has considered many situations where GPS has enabled people living with the condition to continue to ‘do what they want’ and challenge the view that people living with dementia are ‘less able’ following their diagnosis. This sub theme draws many parallels with the earlier theme of wellbeing, with inclusion and identity being the obvious comparators.

Whilst not directly applicable to the outcomes of using GPS, on the topic of being listened to and involved in decision making processes that empower people living with dementia, one care partner commented upon the valuable positive affect that partaking in this research has had on the person living with dementia. Liz remarked:

> *LIZ: …it is also about being part of this sort of thing [research] and with the groups, he's got a lot from it too, but this is what dad's always been about, helping others…*

Liz notes the feelings of reward and satisfaction experienced by Ken upon helping others and conducting tasks that may help to make a difference in the lives of other people. Liz continues, speaking about their altruistic motives and the benefits that have been gained:

> *LIZ: [Continuing] … dad didn't want to talk about it at the beginning, it frightened him [the diagnosis of dementia], but now we go to the groups and talk about it, help raise awareness and fundraise, and we enjoy doing it together, we get a lot out of its, its a win-win' isn't it, dad? [laughs].*

These views conveyed by Liz also link to the sub themes of empowerment and wellbeing. Liz described the direction and purpose that is gained through the opportunity to be involved in research that may benefit others. In the text above, Liz mentions prior feelings of fear experienced by Ken upon receiving a diagnosis of dementia. However, through being empowered and through involvement in research projects like this, where Ken can provide their opinions and experiences, as well as through dementia support groups and fundraising opportunities, Ken is able to fulfil the needs of occupation, inclusion and identity. Liz suggested that this drive for selflessness linked to their past and *"is what dad's always been about, helping others".* They also speak of how they have gained a lot from using this technology, describing it as a 'win-win', with benefits gained on all sides.

Sub theme: The role of GPS in mitigating risk

The final sub theme discusses the role GPS has in mitigating risk. Care partners harnessed the technology to prevent exposure of a person living with dementia to potential hazards in different ways. The outcome of using GPS for some revolved around conducting safe walking. Such activities enabled a person to retain freedom and independence, whilst simultaneously reducing care partner anxiety. This was predominately used by care partners of individuals at early stages of their dementia journey. For care partners of individuals in the later stages of their dementia journey, GPS was used as a back-up option, a ‘safety net’ to help locate a person should they get lost or disorientated, only if they needed it. Each of these alternative outcomes are discussed below.

Four care dyads utilised GPS to support safe walking for people living with dementia. The term ‘safe walking’ is used here to refer to the ability of an individual to walk independently whilst being steady on their feet. Both initial and follow-up interviews found the need for people living with dementia to keep fit and exercise, citing walking as an enjoyable commonplace activity that was deemed vital for the person’s wellbeing. One participant discussed another aspect of safe walking to bear in mind, in particular, assessing the risk and potential dangers the person living with dementia may face when wayfinding outside independently.

> *GLORIA: We live near quite a busy road, so I marked the road as an area [geo-fence] so that mum can’t get too close without it letting us know*

In this example, Gloria is mitigating the risks and dangers Janice faces when safe walking. Gloria created an alert to keep themselves and family members informed should Janice get in close proximity to hazards in the environment, such as roads and traffic. Gloria also alluded to an issue they have with safe walking, and how GPS has been used to help them overcome their doubts and concerns:

> *GLORIA: one thing we do talk about is that we wouldn’t have known that mum can’t do it until she has a fall or starts to wander off (…) I think that’s the beauty of this, we can know more now – otherwise we’d have to either wait on something going wrong or follow her around*

In this example, Gloria states that they will not know when, or if, Janice’s ability to conduct safe walking changes; they are almost relying on a problem occurring. The risk facing the individual living with dementia must therefore constantly be reassessed. This is a cause of anxiety for Gloria and family members, but through the use of GPS, they have a potential solution to their worries. Gloria states that the GPS device has replaced alternative answers of either accepting the risk that one day Janice might encounter a problem, or constantly following Janice in order to mitigate the risk. Janice did not offer her insights into this, however, Ken, a participant living with dementia, did offer his perspective on the issue of risk:

> *KEN: my daughter [Liz] explained to me that this thing here [GPS device] keeps me safe and that's good for me, I don't understand how but that's not important (…) I'll make sure I have it with me just in case*

Ken acknowledges the importance of the GPS device in terms of mitigating the risk when they are out and may be touching on the ethical debates made in the literature regarding safety vs privacy and autonomy. Ken takes the view that they don't understand the technology in question but do know that it is there for their safety and will ensure that they keep the device with them when conducting daily activities independently.

Safe walking may also consider the impact of orientation and involve the individual living with dementia being aware of where they are and be able to navigate from place to place. Whilst the person living with dementia is responsible for selecting the route, care partners spoke of how they assisted in monitoring the chosen route and checking in with the GPS device. In doing this they were able to make sure that the chosen route is heading towards the desired destination and the person living with dementia is still on the correct path. One care partner, Patricia, discussed how they used the device to facilitate this:

> *PATRICIA: I check to make sure that [David] is where he's meant to be and hasn't wondered off course, it is only a 10-minute walk [to the shops].*

Patricia is aware of the route David normally takes and the time it takes to complete such a walk, as such, Patricia utilises GPS when her husband is taking longer than usual and ensures that he is still on track to reach his destination.

Whilst for some, the use of GPS was a means to facilitate safe walking and greater independence, other participants referenced the ways in which they utilised GPS as a safety net, to ensure the person living with dementia is safe or could be easily found should they leave home unexpectedly. The main difference between this and the aforementioned safe walking is the emphasis on 'unexpectedly'. Some care partners spoke of how the person they care for may leave the house without warning and put themselves in danger. Care partners Joy and Steve discussed how, due to deterioration in the mobility of the person they care for, the main use of the devices over the three-month period was as a back-up option, to provide the care partner with a method to monitor the location of the person living with dementia. Some participants detailed the lack of independent activities the person living with dementia undertook but spoke of the benefits that they still gained from using the GPS device.

> *JOY: [On how they used the device] mainly just in case she decides to go off on her own (…) although she hasn't in a long time it is good to have.*

From the outset, Steve foresaw this technology to act as a *"safety net"* (Steve, Initial Interview) due to the stage of the dementia journey Angela was now in. Steve confirmed that this was indeed how the device was used:

> *STEVE: I've explained it to people as just a little extra that we have, should the worst happen.*

Bernie also spoke of how they utilised the device as a back-up option, to provide additional safety. Bernie referred to the speed at which they could located Barbara should they become lost or disorientated:

> *BERNIE: …as it was, we was fine, but having that feeling, just knowing that we could find her quickly.*

It is unsure whether Bernie is referring to emergency services being able to locate a person living with dementia quicker, or a care partner, but in both situations, Bernie is describing how GPS can be used to reduce the risk of being unable to quickly find a person living with dementia.

Participants often referred to GPS devices using phrases such as *"a life-saver"* (Joy), a *"godsend"* (Gloria) and a *"guardian angel"* (Bernie, Initial Interview). Metaphorically describing GPS technology as being similar to divine intervention shows the amount of trust participants may have in the device's capabilities to protect a person living with dementia. By drawing comparisons to the act of lifesaving, Joy is describing how GPS can be used as a tool to protect or preserve life, in a similar way that Ken describes the act of locating a person using GPS as *"a bit like the flares you get when at sea"* on page 202. In both examples, GPS is likened to search and rescue, the act of searching for and providing aid to people who may be in distress or imminent danger.

Participants also considered the alternative solutions that could help mitigate risk should they choose not to use GPS technology. Joy discussed the use of GPS in comparison to the locking of doors and potentially hiding keys:

> *JOY: … it has meant that I haven't had to, for example, hide the keys when I go out, cause if [Eileen] does go out, it will tell me when (…) of course I still have to go to some lengths, but this is helping keep her safe*

When prompted on the "lengths" Joy is referring to, they added:

> *JOY: …erm well I used to disconnect the car battery for example, because she didn’t always know that she can’t drive anymore. That’s an extreme example but what I mean is that if I had this a few years ago, I wouldn’t have had to do that, because it would alert me wouldn’t it?*

Such examples show the potential benefits of using GPS, both in terms of reducing exposures to risk and increasing independence and autonomy for people living with dementia. Joy spoke of their reluctancy to curtail the freedom of the person living with dementia and the difficulty of confining the person they care for, however, for them, the paramount consideration must be the safety of the individual. In the case of Joy, GPS has lessened the need to impose such restrictions, using the technology to provide safety and greater freedom, Joy also reflects on how this technology could have helped in the past and where an earlier intervention of GPS would have further reduced risks for the person living with dementia.

Summary of theme

This theme has sought to illustrate how participants have used GPS technology during this study, and what the outcomes of using the device have been. The first subtheme of wellbeing considered the psychological and social needs of the individual living with dementia and the care partner and how GPS was used to support wellbeing. The subtheme was broken down into feelings of comfort, identity, occupation, inclusion, and attachment, all of which interrelate.

The theme of empowerment described how GPS can provide people living with dementia the power to control more aspects of their life, including decisions and actions, with the hope that GPS could enable a person to live their life as they want to, for as long as possible. The subtheme also discussed the need for the person's abilities to be recognised before considering the challenges or limitations they may face due to their diagnosis, focusing on what is possible, or could be made possible with the help of GPS technology, instead of a person’s limitations. This theme also considered the various aspects of risk, from discussions made regarding safe walking and minimising the risk of a person getting into danger when walking independently, to the use of GPS as a backup plan – providing care dyads with a ‘safety net’ should the person living with dementia become lost or disorientated. The subtheme also explored comparisons that participants drew regarding GPS being a “lifesaving” intervention that can locate individuals in a similar way to search and rescue, providing protection, safety and security to an individual. It must be stated that GPS does not prevent people from taking risks, perhaps the opposite in fact, as the nature of this technology promotes greater freedom at the cost of increased risk. However, devices can mitigate these risks, from using features such as geo-fencing to map out routes a person may take, providing proximity alerts to hazards in the environment, such as roads and traffic, to movement alerts enabling the use of GPS as a backup option to alert a care partner should a person living with dementia leave an area unaccompanied. This theme also sought to provide a comparison with alternative solutions to reduce risk for the person living with dementia. Prior to using GPS, care partners described the lack of other safety-related solutions available to them and therefore they reported often feeling like they relied on restricting the movement of people living with dementia. Many of the discussions made in this theme coincide with conversations that take place elsewhere in this analysis. Safety was a major motivator for care dyads in the decision to uptake GPS devices, with an increase in safety simultaneously impacting upon participant wellbeing, including comfort, inclusion, and empowerment. Without safety-related assurances, confidence and trust in this technology would undoubtedly falter, perhaps leading to abandonment of this technology. Ultimately, using a quote by Steve *"… mind you, she (Angela) has to be safe"*, without assessing safety, none of the perceived benefits in using this technology could have been accessed, and as for the majority of participants, their primary concern will remain safety.

It is also worth considering the contexts within which care dyads operate and how this may have impacted upon the types of benefits they reported in terms of wellbeing. The majority (6/9) of care dyads included in this phase of the study were spouses, with two parent-adult child dyads taking part and the final care dyad consisting of siblings. In both instances of a parent-adult child dyad, the adult children prioritised the need for inclusion, utilising the technology to help keep their parents connected with society, whilst also considering their own commitments and how this technology can assist them. Spousal care dyads appeared to have placed a greater focus on fulfilling the need for occupation, as well as attachment. Spouses discussed the ways GPS can help facilitate the role their partner has to play in society, whether that be a daily walk to the shops for essential groceries, or the completion of activities of daily living alone.

It appeared that spousal relationships have greater knowledge of what is required in order to instil a sense of purpose, how to fully utilise one’s abilities, and where GPS can assist. Parent-adult child care dyads were also much more concerned with the ethical repercussions of using this technology, and that may have impacted upon the level of use. On the whole, spousal care dyads did not appear to be concerned with ethical issues that may arise from using this technology, instead, they focused on the benefits that can be gained.

5.4 Summary of Chapter

This chapter has outlined the thematic analysis of both initial interviews with care dyads and the follow-up interviews with participants which took place after a 3-month period of using the selected GPS device.

Analysis of initial interviews with care dyads identified four key themes. The first theme details a care dyad’s motivations for utilising this technology and contains the benefits they perceived GPS to have for them, as well as their concerns or reservations. The second theme considers social participations, care dyads existing social interactions and their lived experiences regarding social isolation and where they foresaw GPS to be an addition to help facilitate social engagement for a person living with dementia. Participant’s previous experience of using GPS technology was also identified as a key theme, that explores a care dyad’s prior practice of using the technology and provided their reasons behind abandoning the device. The final theme investigates the impact of the COVID-19 pandemic and the role participants believed GPS could have played during this time of crises as well as in a post-COVID-19 era.

The two key themes that were identified following analysis of follow-up interview data examined participant’s relationship with technology, as well as the outcomes of using GPS in their daily lives. The first of these themes focused on participant’s confidence in this technology, considering how trust in the devices was built or earnt and how it could potentially be lost. This theme also explored care dyad’s perseverance in learning how to use this technology and the motivations that helped drive them to success in being able to operate this technology. Analysis also found the barriers that participants encountered along the way and how they could impact upon a person's relationship with GPS. It was also important to consider how technological abandonment occurs and how negative experiences of using this technology can result in discontinuance. The second of these themes considers the outcomes of using GPS and contains the subthemes of wellbeing, empowerment, and the mitigation of risk. The subtheme of wellbeing discusses a person's psycho-social needs and how GPS was used by participants to support the fulfilment of such needs for both members of the care dyad. When examining how GPS could impact wellbeing, it was important to consider the ways in which one person's gain with respect to wellbeing was another person's loss, with this theme containing these possible contradictions in addition to mutual benefits. The subtheme of empowerment addresses how GPS provides some people living with dementia with a sense of control and greater choice, especially when it comes to making their own decisions. The final subtheme was concerned with how participants utilised GPS to mitigate risk, considering the various approaches that were taken whilst using the technology to manage risk.

From the outset, this thesis has acknowledged that the needs of an individual and their care partner may fluctuate and change as they progress upon their dementia journey. As discussed during the analysis of the focus group and initial interviews, the role of a GPS device may modify and shift during this journey from a tool to increase freedom and independence, towards a tool with the ability to keep someone safe at home. For such reasons, this technology needs to be multi-purpose, and able to adapt to the user. Both the focus group data and interview data considered the importance of battery capacity and how a long battery life was required to promote increased independence, with inadequate duration restricting how and when devices are used. Participants from both phases also emphasised the need for this technology to be simple, limiting what is required for the person living with dementia in order to make it easier for them to learn how to use the devices. Analysis of both phases found that failures to consider simplicity and the ease at which this technology can be adopted can cause user frustration and lead to a person abandoning this technology. Chapters 4 and 5 have also considered the effect of digital literacy and the barriers that prevent usage of technology. The next chapter will discuss the findings from both data collection periods and situate them within the existing body of literature, as well as highlight original contributions these findings make to the field.

CHAPTER SIX

DISCUSSION

CHAPTER SIX: DISCUSSION

6.1 Introduction

This study has explored the lived experiences of people diagnosed with dementia and their care partners. The purpose was to achieve a greater understanding of the main factors that influence the uptake and continued use of GPS technology, whilst also investigating the perceived benefits and limitations of using GPS. In addressing the research question, this study was divided into two distinct phases. Phase one featured a focus group consultation with those who have direct experience of dementia; people living with dementia, care partners and former care partners. Participants were presented with a range of 'off-the-shelf' GPS devices and invited to discuss the characteristics and functionality of devices and asked to provide their views and insights on what factors they found the most important and whether any of the devices presented to them would be suitable for them. Findings from this phase were then taken to develop phase 2, the main research study. Nine care dyads (eighteen participants) participated in phase 2, a three-month period of using a device selected by participants of phase 1, with interviews with care dyads taking place before and after this period of use. The findings from both phases 1 and 2 suggest that off-the-shelf GPS is a viable option for use by people living with dementia and their care partners, offering a range of benefits that help the care dyad, both individually, and, as one.

This chapter will examine and discuss these findings in relation to the research question posed at the outset of the study, as well as the projects aims and objectives. It will situate the analysis of chapters 4 and 5 within the wider academic literature, showing where findings differ, echo and build upon evidence in the field, to provide insights into how off-the-shelf GPS technology was used by care dyads.

Research Question: 'What are the perceptions and experiences of using 'off-the-shelf' GPS technology for people living with dementia and their care partners?'

Each of the following aims and objectives, posed in chapter 1 of this thesis, will now be discussed in turn, drawing on the findings of this study. As a reminder, this study aimed:

1. To evaluate the user experience and acceptability of a range of GPS tracking devices, analysing factors that care partners and individuals living with dementia find the most important and characteristics that may be missing from certain products.
2. To explore the benefits that may be gained through using GPS technology, particularly in relation to freedom, independence, and safety.
3. To identify concerns that individuals living with dementia and their care partners may have in relation to the reliability and usability of GPS technology, and how this could impact use.
4. To ensure that the views of people living with dementia and their care partners are taken on board and used to shape the project, utilising their wealth of knowledge and exploring the lived experiences of dementia.
5. To explore how the views and perceptions of the technology may change, through the use of participant interviews before and after a period of use.
6. To explore how GPS can impact upon the wellbeing of a person living with dementia and their care partner.
7. To explore the lived experiences of the COVID-19 pandemic from the perspective of care dyads and consider if GPS could have assisted them during this time.
8. To explore the ethical concerns that care dyads may have regarding the use of GPS technology.

1. To evaluate the user experience and acceptability of a range of GPS tracking devices, analysing factors that care partners and individuals living with dementia find the most important and characteristics that may be missing from certain products.

This is the first study to have consulted people living with dementia and care partners on off-the-shelf GPS technology before utilising these views and experiences to shape the study. This research used a device which was selected by people with first-hand experience of dementia and assessed the lived experiences of using this technology in the daily lives of care dyads. Earlier studies into the use of GPS technologies for people living with dementia date back to 2007, (Kearns et al., 2007; Rasquin et al.,

2007) where devices were viewed as a ‘a treatment for wandering’, to manage what was viewed as a symptom of dementia in the community and in long-term care settings. Since then, focus has shifted towards the view that GPS can be used as a method for care intervention, to promote living well with the condition, with later studies interested in the attitudinal (Liu et al., 2017), ethical (Landau et al., 2009) and privacy (Wan et al., 2014) related considerations that need to be made when adopting GPS (Dale, 2010). Whilst such considerations are vital to understand why people use this technology, as suggested by Dale (2010), it is also important to explore the practical experiences of this technology, in particular, gathering the views and opinions of those with direct, first-hand experience of dementia on how this technology should be designed. This research contends that people living with dementia and care partners need to be involved in research design and the selection of technology to ensure that it is fit for purpose and appropriate for the required use.

In line with findings drawn by McCabe and Innes (2013), this study sought to highlight the importance of seeking the views and opinions of people living with dementia themselves regarding how devices should be designed. Participants involved in this research offered useful and practical considerations that must be taken into account when designing or selecting GPS technology to be used within their everyday lives. An initial objective of this project was to identify concerns that individuals living with dementia and their care partners have in relation to the reliability and usability of GPS technology. Findings from the consultation focus group and interviews directly corroborate the findings of a great deal of the previous work, in particular when it comes to the battery capacity of GPS devices.

Battery Life

This study found that battery life continues to be a main concern for care dyads. Participants of this study suggested that, whilst the battery life of the device used in the main research project was sufficient, there was still room for improvement. Participants shared their concerns that inadequate battery life could result individuals living with dementia restricting their movements out of fear that they could be left stranded, without this important lifeline to let others know their whereabouts. Participants of this study prioritised the battery life of the device over other potential features, stating that a long battery life was vital as it serves to promote independence, rather than restrict one's actions.

McShane and Skelt (2009) reported that battery capacity was a limitation of this technology, with participants describing the battery life of the device used in their study as inconsistent and presenting additional risk. Similar findings were also presented by Liu et al (2017), with this study concluding that battery life was a major concern for users. For Bantry-White et al (2010: p.157), the battery of the device was considered "dangerous", inadequate by 9 out of 10 of their participants and "not 100% reliable". Despite the advances in this technology since some of these studies were conducted over a decade ago, findings showed that battery life remains an area for improvement in these devices. Discussions in the focus group build upon evidence in the literature, going beyond issues of risk and the dangers of limited battery, to suggest that inadequate battery life could essentially result in reduced freedom for a person living with dementia. Participants warned that activities and independence could be curtailed due to insufficient battery capacity. Participants of phase 1 argued that it was vital that the battery of the GPS devices could last an entire 24 hours and went on to suggest that even this may be inadequate should a person take the device with them on holiday or when staying away from home.

Findings from this doctoral research have also shown how participants sought to increase the battery-life of the product through changing device settings, with two care partners reporting that they increased the time-interval between positioning reports to ensure that the device had adequate battery. This was an interesting finding as it highlighted the priority placed on battery life, whereby users were willing to receive fewer alerts to prolong the duration the GPS device was able to be used for. This compromise, whereby a user is willing to reduce functionality to gain a better experience of using the technology, is an insight into the lived experience of care dyads using GPS that is yet to be documented by the wider literature. This is explored in more depth below when discussing findings in relation to aim 3.

Device design

Findings also explored other practical considerations taken into account by individuals living with dementia and their care partners prior to selecting a GPS device. The overall size and weight were important factors for participants, with concerns shared relating to devices being large or bulky, with the aim being to reduce the attention given to the product. Participants voiced concerns that bulkier devices could draw attention to them, alluding to issues of stigma, creating a visible sign of their disability and the disclosure of their condition. These findings resonated with other research in the literature, the Yang and Kel's (2017) study reported on participants' desires to have discrete devices, with similar views outlined by participants of a focus group conducted by McCabe and Innes (2013). A study by Williamson et al (2017) found stigma as a factor related to the use of wearable GPS technology, with the size of the device contributing to the amount of stigma experienced by people living with dementia. Robinson et al (2009) concluded that device design should focus on reducing the size, weight and visibility of GPS devices carried by people living with dementia, to limit stigma, with this study concurring with these findings. This study found that participants were concerned with other people's perceptions of them and the fear that a noticeable device would in some way identify them as being different.

These findings are consistent with McCabe and Innes (2013) who discussed participants not wanting a visible device that could make an individual living with dementia vulnerable to stigma and prejudice. My study goes on to consider how device design and the visibility of wearable GPS technology could result in increased vulnerability caused by carrying expensive technology upon the person. 2 participants (on page 162) voiced concerns that carrying a high value item could make the person living with dementia a potential target of crime. This resonates with findings from the aforementioned McCabe and Innes (2013) study, which concluded that a device should be inconspicuous to reduce vulnerability, citing the risk of carrying a visible device that could make someone a target of crime, for someone to pull off and steal. Whilst my study did draw findings relating to stigma and vulnerability, with participants discussing a fear of being identified as different or demarcated by their condition, no evidence was found in relation to concerns regarding the associated use of GPS tracking technology in law enforcement, as reported by McKinstry and Sheikh (2013) and Landau et al (2009).

2 participants of this study also felt that bulkier devices, such as one of the wristwatches presented to participants of the focus group, appeared 'childish',

concurring with findings from Williamson et al (2017). On the other hand, participants of phase 1 were in agreement that devices should not be too small, as they did not want to misplace them. It appears there is a happy-medium when it comes to the size of the device, with the product that was taken forward to the main research study, which was considered by the focus group consultation participants to be desirable, being the middle product between the two extremes given here. These results further support the idea that people living with dementia need to be consulted when it comes to designing and selecting technology that they will be the wearer of.

Cost

This is the first study to have examined the cost of GPS devices within dementia care and sought a more affordable option through considering the use of off-the-shelf products. From the outset, this research aimed to address the rising costs facing people living with dementia and their care partners, and the existence of access gaps when it comes to technology. This research found that, for some, purchasing technology whilst on a low budget is not possible, regardless of the benefits that may be gained.

Findings from phase one showed participants to be concerned that the cost of this technology may prevent it from being accessed by all, with cost a motivating factor coming into force when selecting a device. The findings of this study also indicated that cost is important when discussing how needs may change over time, with chapter 4 (page 124) reporting that participants would avoid purchasing a type of device that may become obsolete if it cannot adapt and they may not take a financial risk on expensive technology if they are unsure how cost-effective it may be. These findings respond to a call from previous research that highlighted a gap in the literature when it comes to the cost-effectiveness of GPS, with off-the-shelf GPS proving to be a cost-effective option for care dyads. The findings reported in this thesis also shed new light on how the marketing of devices aimed at dementia care could be seen as being exploitative of a vulnerable group, whereby people are targeted with more expensive devices, believing that these may be ‘safer’ than alternatives. This thesis has questioned the reasoning behind the price differential between ‘dementia branded’ and off-the-shelf technology. On page 129, phase 1 participants commented on how they rely on being recommended technology and told that it is suitable for them. Participants may therefore be influenced by clever marketing strategies that position a product for use by people living with dementia and care partners. This is an example of the technology adoption life cycle (from section 2.2.4), and the associated marketing and pricing strategies in practice. Early majority consumers are offered off-the-shelf technology through low-cost, high-volume channels with the product advertised for general-purpose. For late majority consumers, niche positioning as a 'dementia friendly product' result in leveraged value propositions to maximise the amount of profit to be gained. This thesis is the first to question the ethical nature of these marketing and pricing techniques for an assistive technology product that could be *"life-changing"* (Joy, Follow-up interview) for people living with dementia and their care partners. These findings therefore may also be of use in other fields where alternative off-the-shelf technological options are available.

Simplicity

The need for simple technology was identified by participants throughout both phases of this research. Participants argued for devices to be simple and easy to use in order to have *"less things that can go wrong"* (Jane, focus group) and "*less for me to mess up"* (Bernie, initial interview). These findings coincide with evidence in the literature with Holzinger et al (2011) exploring how simplicity of technology for older people enhances performance and use. Similarly, Liu et al (2017) and Chen and Leung (2012) both report on how ease of use, in terms of how to operate a device, will define its success in terms of adoption. Elsewhere in the literature, Neubauer et al (2021) concluded that devices should be as minimally complex as possible, so the person with dementia remembers how they work. Findings from the consultation session of this study (page 127) build upon these results obtained by Neubauer et al (2021), with Jane, a participant living with dementia, discussing the annoyance and discouragement felt when failing to understand or remember how technology works. Interestingly, Scherer (2017) discusses device oversimplification and how, for some older adults using assistive technology, this can be just as frustrating to use as complex technology. Similarities can be drawn here with a comment made by during phase two (page 193), with one participant suggesting *"…a lot of what they aim at us lot nowadays is always big buttons and clunky"* (Joy, Initial interview).

2. To explore the benefits that may be gained through using GPS technology, particularly in relation to freedom, independence and safety.

A core objective of this research was to explore the benefits of using GPS technology, by the care dyad, with a focus on examining the amount of freedom, independence and safety that this technology may be able to provide. One of the narratives within the literature discusses the importance of freedom, independence and safety in relation to the use of GPS, it is therefore not surprising that my study echoes this.

Freedom and Independence

Existing literature offers different perspectives on the notions of freedom and independence, ranging from them being a key benefit of using GPS (Bartlett and Brannelly, 2019) to suggesting that the technology is not utilised fully to give people with dementia more freedom and independence (McShane and Skelt, 2009). Other studies suggest independence is perhaps a by-product from the use of GPS, with primary concerns being that of safety and the reduction of anxiety for the care partner (Bantry-White et al., 2010). Findings from this study reflect these different perspectives on independence. This research highlights the following key finding in that **GPS technology can enable greater independence for both the person living with dementia and their care partner.**

Findings from this study are consistent with evidence found in the literature, reviewed in section 2.5 of this thesis, that demonstrates how GPS is used to support independent living. For 4 of the care dyads from phase 2, increased independence was facilitated through longer periods of time spent outside alone, completion of ADLs alone and having an active role in everyday decision making. Participants often discussed their hobbies and interests and how GPS could support the continuation of certain activities as they continue upon their dementia journey, activities that would not be possible without a certain level of independence. For one care dyad, due to a decline in the outdoor mobility of the care partner, the individual living with dementia faced a restriction in terms of independence and in particular the amount of exercise they could undertake through walking. The care partner described their feelings of guilt and fear of their own health problems impacting upon the wellbeing of the person they care for. In this example the care partner acknowledged how important freedom, independence and especially the activity of walking is for the individual living with dementia. Through the use of GPS technology, the individual living with dementia has been able to continue conducting activities that require independence and the care partner has been relieved of the feelings of guilt and anxiety that once burdened them. This was an interesting finding and whilst it supports evidence from previous observations (Bantry-White and Montgomery, 2014), it comes from the perspective that the constraints noted were due to the declining physical health of the care partner, and not the individual living with dementia.

Care partner independence

Alongside the independence experienced by individuals living with dementia, this study builds upon existing literature by describing the concept of care partner independence and how this is facilitated through the use of GPS. The term ‘care partner independence’ was adopted in this study to describe how care partners found that the technology gave them greater freedom to conduct activities that are not directly associated with the responsibilities of their care-giving role. This study drew on the work of Clark and Bond (2000) to conceptualise the term ‘care partner independence’. The literature often discusses concepts related to the use of GPS to facilitate respite from caring for an individual living with dementia (Landau and Werner, 2012; Liu et al., 2017), however, the idea of ‘care partner independence’ described here goes further than that. Rather than being a means of providing short-term relief, this study has shown that GPS can enable care partners to experience independence without the feelings of worry, guilt and anxiety. This was demonstrated by 4 participants in phase 2 of this study (Anne, Eric, Steve and Bernie). For these four care partners, GPS had the power to enable them to complete their own activities alone. Findings from phase 2 (page 208) also suggested that GPS had reduced the time constraints that they may have faced when leaving a person living with dementia at home on their own. Whilst not related to the use of GPS, other studies in the field of dementia have analysed the link between greater “carer independence (e.g., activities and time not spent on caring duties)” and better quality of life of the care partner (Contreras et al., 2021: p.2; Clark and Bond, 2000). This study is the first to highlight the relationship that exists between the use of GPS, care partner independence and care partner wellbeing, with GPS technology acting as an agent to support these two benefits.

GPS to help establish routines

This study also explored the role GPS plays in helping care dyads establish routines in their everyday lives. One aspect of daily routines that is understudied in the literature pertains to informal care partners who work a full-time or part-time job alongside caring for a person living with dementia. This current research was able to explore the lived experiences of one care partner, Gloria (page 211), who described the struggles she experienced in balancing work and caring for an individual living with dementia and the impact when these responsibilities conflict. GPS was introduced to enable the care partner and the individual living with dementia to both fulfil their commitments, for example allowing the care partner to attend work and the person living with dementia attend a support group. The result was reduced care partner stress and guilt whilst simultaneously supporting the individual living with dementia to attend activities that can positively impact their wellbeing. Similar findings were reported on page 165 when a participant discusses how valuable this technology could have been when he was working alongside caring for a person living with dementia. Although studies (Øderud et al., 2015; Gibson et al., 2015) have previously explored how GPS can assist in establishing routines, findings in relation to working-age care partners balancing their responsibilities of work and care, through using GPS, have not previously been described.

Consistent with wider literature in the field of dementia, reviewed in section 2.2.5, care partners participating in phase 2 of this study discussed how establishing routines was essential when caring for individuals living with dementia. Whilst not related to the use of GPS within dementia care, findings related to the need for routine and familiarity reflect those of Porock et al (2015) who also found that maintaining routine and familiarity can help enable people living with dementia to continue to lead normal lives for as long as possible. For participants of this study, GPS provided care partners with a tool to manage their daily schedules and routines without time constraints and with the addition of greater flexibility.

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GPS to help keep a person living in the place of their choosing

Participants in both phases of this study commented on how GPS can help keep a person living in the community for as long as possible, through increased independence, the mitigation of risks associated with dementia and a reduction in care partner anxiety. The majority of participants (8 out of the 9 dyads) reported that they would continue to use these devices following the conclusion of this study as they believed in the benefits of using this technology and saw GPS as a solution to prolong community dwelling for as long as possible into their dementia journey. One participant (Bernie) discussed GPS as one of their final options before they would have to consider admittance into a residential setting for the person he cares for.

Dementia is the most common cause of admission to residential care (Luppa et al., 2010) and participants of this study recognised that this is often due to concerns surrounding safety and a person living with dementia no longer being able to live independently. This research has been consistent with the wider literature in highlighting how GPS can give people living with dementia the opportunity to remain independent in their own home, within the community, and ultimately delay the transition into residential care. In the Øderud et al (2015) study, care partners discussed the potential ability of GPS to postpone transfer to institutional care, whilst McKinstry and Sheikh (2013) considered the use of GPS to help individuals remain living at home, to avoid the difficulties in securing and affording long-term care. For McKinstry and Sheikh (2013: p.288), decisions to transfer people living with dementia from community dwelling to long-term residential care are taken due to the impact of "wandering", defined as "leaving home without informing a carer, thereby increasing the risk of accidental injury", with GPS providing a solution to this. Whilst this study disagrees with the term "wandering", it draws similar findings to those reported by McKinstry and Sheikh (2013), with care partners discussing the unexpectedness associated with the condition and how a solution is required to alert them when the person they care for leaves the house without warning and puts themselves in danger. For many of the care partners interviewed in phase 2, without such a solution, the person living with dementia cannot safely remain living in the community unsupervised.

This research has found GPS can contribute to enabling people to remain living in the community, through aspects of independence and safety, however, this study did not report findings related to the motivation of cost, as reported by Meiland et al (2017), who discussed how elements of support, such as GPS, can promote independence to keep a person at home for a longer time and perhaps result in financial savings by delaying entry into residential care. Similar conclusions are offered by Milne et al (2014) who discuss the cost of providing care services and how GPS may result in resource savings in terms of long-term care, as well as services to locate missing people. Even though statements related to cost, as featured in Meiland et al (2017) and Milne et al (2014), may also be true for participants of this study, concerns voiced by care partners tended to centre around safety, wellbeing and the mitigation of risk and did not consider the financial burden of long-term care.

Safety, Mitigation of risk and safe walking

The literature often identified safety as the main value of using a GPS device within dementia care, with safety concerns taking precedence over other reported benefits (Williamson et al., 2017). This study demonstrated the major benefits of using GPS in relation to safety, through risk mitigation and the concept of safe walking.

This research has demonstrated that **GPS can be used as a safety net, to mitigate risk and act as a secondary intervention to care partner supervision**. Participants utilised GPS as a safety net, to ensure that the person living with dementia is safe or could be easily found should they leave the home unexpectedly. The phrase ‘safety net’ was first used by participant Steve, a care partner who felt that the person they care for was at a stage in their dementia journey whereby the most beneficial feature of this technology was maintaining safety. This term was then inferred by other participants when describing their priorities in terms of using GPS, with safety being their paramount concern. A safety net is somewhat synonymous with a back-up option, with participants describing how use of this technology may only arise in an emergency and when other options available to them have been exhausted. Within the literature, Holbø et al (2013) also considered the role of GPS as a ‘safety net’, however their description differs to what is described in this research. For Holbø et al (2013), they discuss GPS as a safety net when discussing a person’s desire for control over their own life whilst living with dementia, exploring how technology can promote self-management and provide a person living with dementia an option to contact their care partner on their own initiative when required. In Holbø et al (2013) the use of GPS technology is reserved for potential emergency situations. Elsewhere in the literature, McShane and Skelt (2009) also describe the use of GPS by some care dyads as a backup. In contrast to findings drawn in this research, GPS was considered a standby option as other assistive technology interventions may already in place. Similar findings are reported by Bantry-White et al (2010) who discussed how care partners preferred to use tracking as a back-up to other strategies of management, citing door sensors as well as care partner supervision as the front-line interventions used. Findings from this study do not consider GPS as a secondary technological intervention, as no participants reported using alternative assistive technology devices. However, findings are consistent with both McShane and Skelt (2009) and Bantry-White et al (2010), in reporting how GPS can be used as a backup to care partner supervision. Many of the studies cited here are now over 10 years old, but this research has shown that there is still an important place for the use of GPS for people living with dementia and their care partners.

The literature reviews undertaken for this thesis, documented in 2.5.2, found that a large body of evidence focuses on the use of GPS to aid the concept of safe walking. Findings from this research project also broadly support the work of other studies in this area, linking the use of GPS to the concept of safe walking with a key finding of this research being **GPS can be used to promote and support safe walking for people living with dementia.** The origins of the term ‘safe walking’ trace back to Marshall and Allen (2006) who challenged the notion of wandering, arguing that walking by people living with dementia should be neither feared nor discouraged. The term ‘wandering’ is still used in contemporary literature, however it is felt that this term implies a sense of purposelessness and is therefore dismissive of the activity and infers negative connotations. This study prefers the phrase ‘safe walking’ and agrees with Marshall and Allen’s (2006) argument that walking is a positive activity, that holds significant potential and benefits and is meaningful for the person living with dementia.

This study confirms similar findings to those discussed by McCabe and Innes (2013) and Bartlett and Brannelly (2020) in relation to safe walking, with participants of my study initially describing their current techniques for safe walking, before moving on to discuss where GPS may benefit them to achieve safe walking. This study explored participants' experiences, following the period of use, examining if the perceived benefits were met. For many participants, expectations of the technology were met in relation to safe walking, with care partners utilising GPS to alert them should the person they care for get in close proximity to hazards in the environment, such as roads and traffic. Evidence from this study differed to that collected by Bartlett and Brannelly (2020) in that, participants of this study, with a diagnosis of dementia, did not report making use of the devices personally to gather locational information, instead, 'tracking' was conducted solely by the care partner.

This study showed how care partners utilised the GPS device to monitor individuals living with dementia, giving them more opportunities to conduct safe walking and help both the care partner and the individual living with dementia overcome doubts and concerns. One participant (Gloria) shared a concern that interlinked findings related to safe walking with the concept of there being no 'one size fits all' approach to dementia. Gloria discussed her concerns that a care partner does not know when, or if, a person's ability to conduct safe walking changes and they become almost reliant on a problem occurring, with this being a source of anxiety and stress for the care partner. GPS was viewed as a potential alleviator of some of these worries, and whilst the solution is not perfect and does not provide a resolution to the danger of falls and problems related to mobility, it gives the care partner an insight and a method to monitor the geographical position of the person living with dementia. 3 participants metaphorically linked using GPS technology to acts of divine intervention, describing its use as a "godsend" (Gloria, Follow-up Interview), "a life-saver" (Joy, Follow-up Interview), and a "guardian angel" (Bernie, Initial Interview). These findings show the significance of exploring the lived experiences of using technology and the importance that care partners attach to this technology. It is also worth considering how dementia is being framed in these insights by Gloria, Joy and Bernie. Whilst accounts denote the positive impact of GPS, these views are situated in a discourse of dementia being dangerous and allowing someone living with dementia to go out and about alone is something to be restricted.

Consistent with the literature, this research found that participants cited walking as a vital activity for the wellbeing of the individual living with dementia, with care partners expressing a fear of one day having to restrict a person’s movements and prevent them from carrying out safe walking. Findings match those observed in earlier studies, such as Brannelly and Bartlett (2020), in reporting how mobility, and the ability to conduct safe walking, is an integral aspect of wellbeing. Brannelly and Bartlett (2020) contradicted those who questioned the necessity of mobility and referred to safe walking as ‘wandering’ or walking aimlessly without purpose. Similar findings were shown here, with participants relaying the importance of being able to retain their mobility and how GPS will support them to do so. Whilst some may see the unnecessary dangers associated with it, for a person living with dementia, walking is about more than the functional act of getting from A to B. Participants here described their experiences associated with the activity of walking, and the value and power walking has to instil feelings of accomplishment, inclusion in society and relieve frustration and agitation. Previous studies have demonstrated similar findings, for example in Milne et al (2014: p.5), on the subject of safe walking, one care partner remarked “there’s a risk but it’s worth taking”, walking was important and should be continued, if possible, with GPS providing the means to achieve it safely. This study had the unique perspective of being undertaken during a global pandemic, where people’s freedom, across the UK, were restricted due to government-enforced stay at home orders and to prevent the spread of COVID-19. During discussions with participants, the importance of safe walking was often discussed as walking was seen as an activity vital for wellbeing. Findings from this study, in light of COVID-19, show how essential the activity of walking is for people living with dementia, and many care partners were able to relate to how damaging restricting a person’s movements could be. Care dyads also highlighted how instrumental technology such as GPS would have been during periods of lockdown to help facilitate safe walking when the activity could only be undertaken alone.

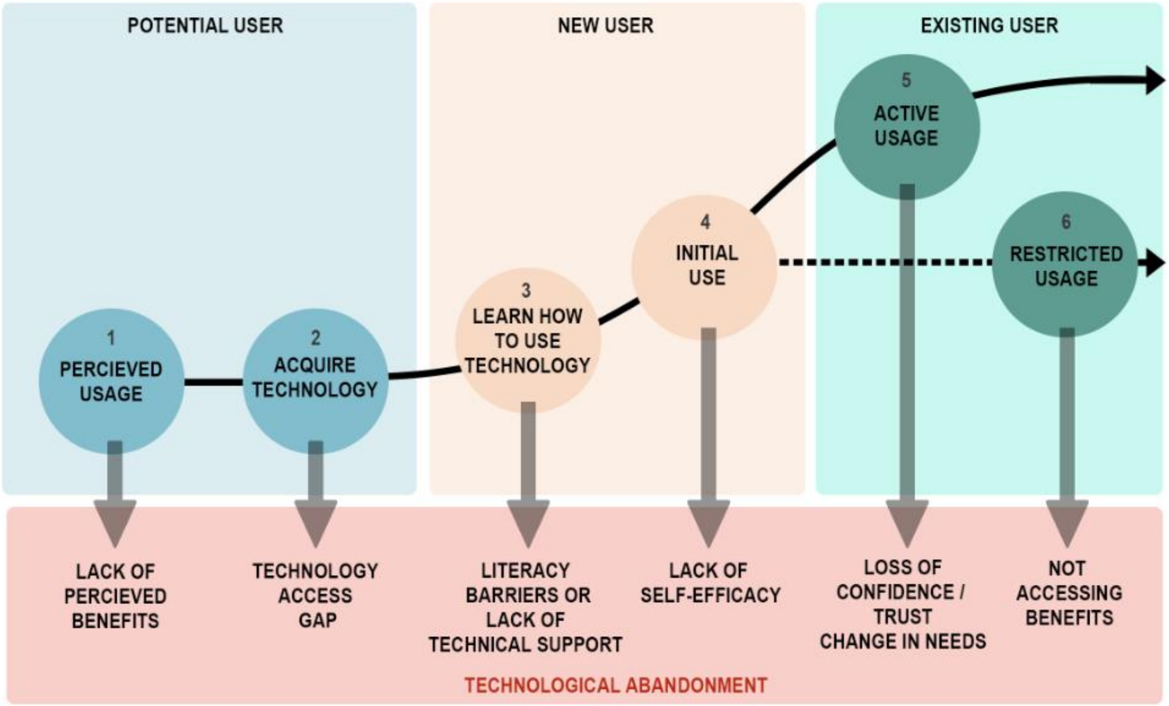
3. Identify concerns that individuals living with dementia and their care partners may have in relation to the reliability and usability of GPS technology and how this could impact use

Both the systematic review and the wider review of the literature, situated in chapter 2 of this thesis, present existing evidence related to the usability of GPS technology and how usability can impact upon experiences of using GPS. Usability is defined here, by the International Standardisation Organisation (ISO 25010), as *“the degree to which a product or system can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use”.* Findings from both phases of this study build upon evidence found in the literature in relation to appropriateness, learnability, operability, user error protection and accessibility, and how such characteristics can impact upon the use of this technology.

Whilst initial aims sought lived experiences related to the reliability and usability of GPS, findings from phases 1 and 2 in fact showed care dyad attitudes towards what factors may result in technology abandonment or discontinuance of using this technology. Evidence shows that the solution of GPS may not always work as desired, with participants detailing how if their expectations and needs were unmet, discontinuance would occur. This thesis has demonstrated how **certain factors can result in the abandonment of this technology or can influence how GPS devices are used**

Many of the findings highlighted in this thesis, in relation to usage of technology and the factors that contribute to abandonment, are original contributions to the field. Although previous studies have considered the extent of technological abandonment, in relation to general assistive technology (Williamson et al., 2017; Petrie et al., 2018), this is the first study to present a range of different encounters with GPS technology by care dyads and how they can cause discontinuance. This thesis found examples in both phases, ranging from complete abandonment of GPS to a deliberate reduction in functionality, as participants describe their journey of adopting and using GPS. Findings presented here merge together different fields, incorporating relevant literature from wider technology usage as well as sources found in the fields of dementia and ageing. The following chart (figure 25) has been developed to depict the usage of GPS by care dyads, potential influences of technological abandonment and where such discontinuances may occur.

Figure 27: Usage flowchart - journey of adopting and using GPS



1. *Perceived Usage*

Part one of this flow chart represents ‘perceived usage’ and is situated within the wider section known as ‘potential user’. Prior to making any decisions about acquiring technology, users consider the benefits that are to be gained from using such devices. This stage of the process was made clear in both phases of this research, with participants providing views, opinions and examples of lived experiences to detail the ways that this technology may be beneficial to them. This is where the first instance of a drop-off towards technological abandonment may occur and could be seen through the example of Eric and Pauline. In section 5.2, this study was able to uncover the reasoning behind one care dyad’s (Eric and Pauline) decision not to adopt the GPS technology provided to them (page 184). Such rationale is important as it provides an alternative perspective. Given that all participants received the same GPS device, guidance and information, it was interesting to hear the accounts of two individuals who, upon reflection, found it was not in their interest to use this technology. They viewed this technology, upon reflection, as unnecessary in their current situation, acknowledging how GPS may help people living with dementia, but concluded that *“it’s just not for us”* (Eric, Follow-up Interview).

Participant’s Eric and Pauline also discussed a sense of acceptance through adapting to their new way of daily living, an interesting insight that may often be overlooked due to the nature of assistive technology. Whilst many consider GPS technology as a vital intervention, playing a pivotal role to support wellbeing, freedom and independence, Eric and Pauline described how they had come to terms with the challenges a diagnosis of dementia may bring them and found no use for technologies that seek to increase independence. This can also be seen in discussions held during the consultation focus group, where participants spoke of their reluctance to invest in this technology, particularly ‘dementia branded’ products that were seen as expensive, without understanding the full extent of the benefits offered.

2. *Acquiring Technology*

The second step in this flow diagram considers the act of acquiring the technology, and the influences or factors at this stage of the process that could result in abandonment or rejection of technology. Participants of phase one of this study discussed difficulties in acquiring technology, in particular the selection process attached to purchasing assistive technology. For participants, this issue of choice overload arose when researching assistive technology products such as GPS devices, causing confusion as to what to purchase, and, ultimately resulted in postponing the acquisition of this technology. Participants felt that they lacked the knowledge required to use the technology in their decision-making process. Whilst relevant literature has discussed issues of GPS technology adoption, acceptance and diffusion (Liu et al., 2017; Chen and Leung, 2012), there is little evidence regarding issues of GPS avoidance and rejection.

Another reason behind non-usage and abandonment of potentially vital technological solutions in the area of acquiring GPS is caused by the technology access gap. The literature reviews undertaken for this study commented on the large body of evidence on the digital divide and the gaps that exist between populations that have access to technologies, and those that have restricted or no access. Whilst this was not an issue for participants of the main research study, as the technology was provided to them, access gaps were discussed by participants of the consultation focus group (page 135). Ease of device procurement, or obtaining the device, is considered by Phillips and Zhao (1993) as one of the four predictors of device abandonment.

3. *Learning how to use technology*

The third stage of this process occurs following the procurement of the technology, when a new user is required to learn how to use the device. Throughout this study, participants alluded to digital literacy barriers when it came to learning how to use new technology, with participants questioning their ability to learn the skills required to utilise technology such as GPS, and how failures to overcome such barriers would lead to non-use. Eric and Pauline discussed their fear of digital competency (page 184) with Eric feeling that he did not possess the requisite digital skills to use this technology, worrying that human error or technical misunderstandings could put Pauline at risk. In section 2.5.5, the literature review considered factors of accessibility and the impact of digital skills access gaps when it comes to using assistive technology such as GPS, however, there is little information published relating to the fears of digital competency, as discussed by participant's Eric and Pauline, fears that resulted in non-adoption of this technology.

Participants also discussed what is required to help them overcome such barriers. For some (Anne and Liz), digital literacy was enhanced through one-to-one technical support and training, often conducted by a family member who they considered to be patient and would take their time to go through each function of a device. Others (Patricia) discussed the need for clear, simple and comprehensive guidance, through a physical user guide with step-by-step instructions. Throughout the second phase of this research, Participants pointed towards the user guide and the online technical support that was offered as vital resources, that ensured the successful deployment of GPS.

It is encouraging to compare these findings with those in Williamson et al (2017) who also discuss the need for appropriate support, education and training to use this technology in order to avoid technological abandonment. Similarly, a study by Holthe et al (2020) reports upon potential barriers to implement assistive technologies, with limited knowledge and training on how to use technology resulting in unsuccessful use. Findings related to a care dyads motivation to adopt GPS depicts the importance the care dyad's wider family play in the decision-making process to adopt and use technology. Participants spoke of family members introducing them to GPS technology, as well as acting as a support resource, in some cases giving them the technical knowledge and ability to use GPS devices. It is believed that these findings, showing the influence of family members and the role they have regarding awareness and technical support for GPS, are new to the field and would also be of interest to wider literature involving technology adoption.

4. *Initial use*

Following learning how to use the technology, the user embarks upon initial use of the device. During this stage, confidence and trust in this technology is low as the user begins to familiarise themselves with the capabilities of devices. This was clearly noted during phase two of this study, with participants describing their lived experiences of using GPS and the apprehensions they had going into the 3-month period of use. One care dyad reported that trust and confidence in this technology was low going into initial use of the device, proceeding forward with scepticism and reservations, due to the issues previously experienced that resulted in abandoning GPS (page 165). For this care dyad, they proceeded through the initial usage stage with more caution than others and reported that a negative experience at this stage would have resulted in abandonment for the second time.

During this stage, technological self-efficacy and perseverance were found to be key to successfully implement this technology. Technological self-efficacy is described here as a person's perceived ability to use a product successfully (Ellen et al., 1991). Findings from this study considered participant's perseverance with the technology, particularly when faced with obstacles related to a lack of technical knowledge. Two care dyads (Patricia/David and Steve/Angela) discussed the struggles they faced in learning how to use the device but described their persistence to better their understanding of how to use this the technology, brought on by their personal belief in the benefits of the product.

It was also interesting to note in phase 2 (Sub theme: Knowledge barriers, page 179) how care partners expressed a lack of self-belief in their technical ability and how this impacted upon their experiences of using the devices. These findings show the lack of self-belief and trust in a person's technical abilities and how this caused them to miss out on certain functionality of the technology. Previous research into the use of technology by care partners has explored care partner self-efficacy and its role in minimising burden, increasing perseverance, improving resilience, and influencing perceived difficulty or burden of a task (McHugh et al., 2012; Gonyea, 2005; Megges et al., 2017). However, there are a lack of studies examining the impact of care partner self-belief and how fears of digital competency influence utilisation of GPS technology, or assistive technology in general.

5. *Active use*

Following the initial use stage, findings showed that usage could take one of two different paths, influenced by confidence, trust, self-belief, technical support and the ability for the technology to adapt to a change in contexts or needs. The first path is that of active use, where a user builds upon their existing knowledge and digital skills, improving their use of the technology and making full use of all functions. This was reported by 4 of the 9 care dyads

During this stage, factors that could result in discontinuance included instances where confidence or trust in the technology faltered, perhaps through inaccuracies, errors or false alarms. Several participants in phase 2 reported the occurrences of such problems. Findings related to the occurrence of errors and false alarms when using GPS and the impact such malfunctions can have on the confidence and trust held in these devices are in agreement with those obtained by Dahl and Holbø (2012) and Megges et al (2017). Both studies found that inaccuracies and false alarms, particularly with respect to geo-fences, were a cause of great annoyance for care partners and such occurrences gradually resulted in a loss of confidence in the technology. However, the findings from this study showed how one care dyad (Liz and Ken), due to the unnecessary stress and anxiety caused by false alarms, opted to disable the notification feature to avoid undue worry for herself and other family members who had access to the location data and warnings. This is significant as it depicts the lived experience of the care partner, and how their perception of the technology shifted from use to a gradual loss of trust, to stress and anxiety brought about by a combination of errors, to a change in attitude that saw them disable the feature to protect family members from the same experience. In this instance the care dyad changed paths in order to restrict how the device was utilised.

During the stage of active use, findings also showed that a shift in user needs and requirements, and a failure to adapt to such changes, represent another factor that can cause abandonment of this technology. From the outset, this thesis has recognised that needs and requirements change as an individual progresses on their dementia journey. Analysis from the focus group and interviews showed how the role of a GPS device may change and shift during this journey from a tool to increase freedom and independence, towards a means to keep someone safe at home. Devices need to be flexible and be able to adapt to changes in circumstances and contexts in order to avoid discontinuance. Findings related to changing needs and adapting to the dementia journey are discussed in greater detail below.

6. Restricted use

Findings show that the second path, that of restricted use, occurs when the user changes or limits the way they interact or use the system to continue use, and prevent technological abandonment. This may be caused by a negative experience (as seen in the example of Liz and Ken detailed above), or due to a lack of technical knowledge or support, which simultaneously effects confidence in the digital skills they possess to fully utilise the product. This step may also be known as technology underutilisation and is defined here as to use technology less than fully or below its potential use, therefore failing to access all possible benefits of a product.

Whilst literature around technology use within dementia care frequently considers the impact of technology acceptance (Liu et al., 2017; Kramer, 2014; Holthe et al., 2018; Liu et al., 2018; Miguel Cruz et al., 2021), there is a lack of research regarding technology underutilisation and the factors that contribute to it. Within the wider field of assistive technology literature, Scherer (2017) comments upon similar gaps in research, arguing that despite the growth and advancement of technology and the instantaneous rise of literature devoted to adoption, acceptance and diffusion of assistive technology products, there is a lack evidence on technology avoidance and rejection, and even less on technology underutilisation, overutilisation and overreliance.

Findings from this study showed that participants underutilised devices, potentially missing out on key benefits due to a sense of fear related to human error or a lack of support (Subtheme: Underutilisation, page 163). These findings show an area of the digital divide that could be explored in more detail. Whilst in this situation, the divide was not concerned with economic status or access, it does, however, illustrate the gap between those who benefit and those who do not, and how this is influenced by an absence of digital skills and a lack of face-to-face contact to help individuals learn and utilise the technologies they do have access to. This is an important finding as it shows that the digital divide cannot necessarily be bridged merely by supplying equipment or delivering access, efforts must be taken to show individuals how to make use of the technology, through providing various methods of technical support.

4. To ensure that the views of people living with dementia and their care partners are taken on board and used to shape the project, utilising their wealth of knowledge, and exploring the lived experiences of dementia

The design of this study was unique in its attempt to ensure the views of people living with dementia shaped the research. Those with direct experience of living with the condition were consulted in phase 1, with their views, insights and experiences informing phase 2. Previous studies have often conducted research ‘about’ people living with dementia, or by proxy to explore what people with dementia might have thought or chosen, this research goes a step further to directly involve them in selection and use.

This thesis, alongside a plethora of existing evidence, illustrates the need to involve people living with dementia in research. In wider dementia literature, the involvement of individuals who are ‘experts through experience’ in research has improved considerably over the past decade (Clarke et al., 2018; Scottish Dementia Working Group, 2014), with a notable shift occurring in dementia studies changing the approach from ‘research on’ to ‘research with’ people living with dementia (Morbey et al., 2019). In the past, people living with the condition were often excluded from participating in research due to perceived difficulties in gaining consent, evaluating capacity and communication, this is despite the invaluable knowledge they bring to discussions (Brooks et al., 2017). Now that co-production in dementia research is becoming more commonplace within research, it recognises the valuable contribution that people living with dementia can make to the research process (Bethell et al., 2018; Bowker et al., 2020). However, for studies involving the use of GPS, or assistive technology in general, it must be stated that improvements could still be made regarding the extent people living with dementia are involved and consulted, with the literature still dominated with views, attitudes and experiences given in proxy form supplied by care partners.

Through involving people living with dementia and their care partners, as well as former care partners, in this research, findings build upon those discussed in earlier observations showing that **there is no 'one-size-fits-all' approach to the use of GPS devices in the daily lives of the care dyad. GPS technology needs to be adaptable, flexible, and tailored to individual needs, preferences and contexts.** Whilst the device used in phase 2 was selected with the input of people living with dementia in phase 1, it was still not appropriate for every care dyad taking part in phase 2, with participants explaining why this was the case and what they did to rectify problems they experienced. In chapter 5 section 3, participants discussed how they adapted the devices to suit their specific needs and preferences. By providing each care dyad with the same device, this study was able to compare different lived experiences of using the technology, and how care dyads made the technology work for them. This malleability of technology to support use is discussed in greater detail in chapter 7 (section 7.2.4) when this thesis documents the original contributions this research has made to the technology focused world.

It is encouraging to compare findings related to the need for adaptable technology with studies reviewed in chapter 2. The literature review reports, in section 2.7 (page 67), on the importance when developing this technology, for devices to be flexible and be able to adapt to meet different needs and lifestyles. Similarly, in both phases of this research, participants living with dementia and care partners discussed the need for technology that accommodates the uniqueness of a person, that encompasses personality, knowledge, behaviours, attitudes, life experiences and overall ways of living. Participants of phase 1 discussed how efforts must be taken to enable technology to accommodate all characteristics of a person and that technology cannot hinder how a person wishes to live their life, for example through inadequate battery life or lack of functionality. In line with literature reviewed on page 66, this study found that failure to be responsive to the needs of the person could result in abandonment. These findings support the need for developers and designers of GPS technology to understand that dementia impacts upon every individual in different ways and that the needs of an individual living with dementia may change as they progress upon their dementia journey. Findings in both phases confirm the need for person-centred technological solutions, to recognise that *“When you’ve met one person with dementia, you’ve met one person with dementia”* (Alzheimer’s Society, 2019: p.10), and that technology requires tailoring to the person living with dementia and their care partner, for use in a way that benefits them best. Findings from this study also build upon early observations in the field, including those reported by Kearns et al (2007) who discussed the need for flexible systems that are able to accommodate change over time.

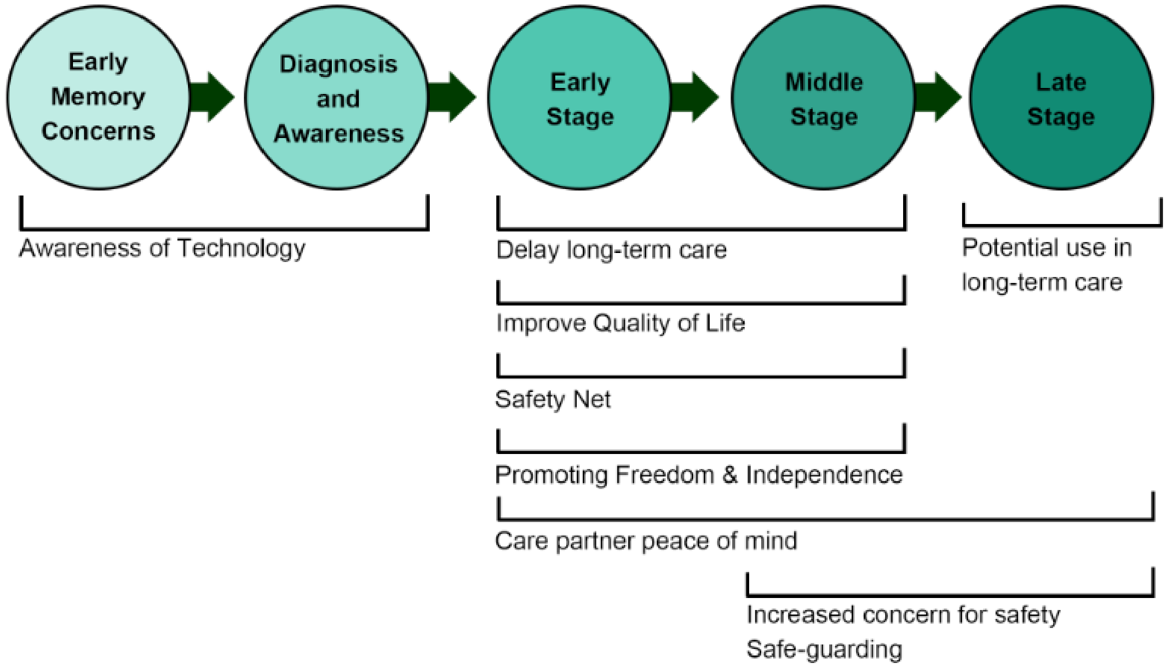
5. To explore how the views, perceptions and experiences of the technology may change, through the use of participant interviews before and after a period of use.

Participants of this research study often described how features of existing GPS devices may be relevant to them at different stages of their dementia journey, and that as they continue upon this journey together, needs and expectations of this technology will change. This coincides with other findings in this study that consider how GPS can be used to support wellbeing, reduce stress and anxiety and factors that influence how the technology is used.

In chapter 2 of this thesis, a figure was provided (figure 4, page 27) to show the Alzheimer’s Society’s attempt at mapping the dementia journey. Figure 4 has been adapted using findings from chapters 4 and 5 to show where **GPS technology may be of assistance during a person’s dementia journey**.

In section 2.1.1, I discussed how viewing the dementia journey as linear is problematic, as a person’s skills and abilities may fluctuate and change at different times. However, just like figure 4 presented earlier in this thesis, I am using Figure 26 only as a guide, intended to show how the role of GPS may change over time, and where it may be of use to a care dyad. As I have argued above, it is important to recognise that every person’s dementia journey is different.

Figure 28: The role of GPS in the dementia journey



Adapted from: Alzheimer's Society (2020) The progression and stages of dementia and Alzheimer's Society (2022) Mapping the Dementia Diagnosis Journey to Improve Self-Guided Support

The timing of GPS technology, as an intervention to support a person living with dementia and their care partner, to assist in everyday living is key. Findings from this study show that the care dyad needs to be aware of the existence of this technology following concerns about a person's memory and into the diagnosis stage. This is also reflected in the wider assistive technology literature with Lorenz et al (2017) reporting that low levels of utilisation of technology is caused by a lack of awareness of the options available to care dyads. In phase 2 of this study (page 153), one participant expressed their frustration that they were not made aware of this technology when it could have benefitted the social health of the person living with dementia. Care partners asked, "*why isn't someone telling us about this when [the person living with dementia] diagnosed*" (Steve, Initial interviews), asking to be made aware of technological options available to them at an appropriate time. This finding must be interpreted with caution because it is also remarked upon in the literature that care dyads become inundated with information at diagnosis (Giebel et al., 2021).

For participants at an early point in their dementia journey, this technology represented a means for continued freedom and independence, whilst simultaneously supplying care partners with a 'safety net' to provide peace of mind and reduced anxiety. Figure 26 above points to the benefits of using GPS in terms of delaying long-term care, and where this may be gained during the dementia journey, these benefits have been stated and discussed alongside existing evidence stated earlier in this chapter. Participants who were considered to be at the ‘early stage’ in their dementia journey discussed how GPS had enabled inclusion in everyday activities in their community, from attendance of support groups to conducting hobbies and interests independently. Care partners of individuals living with dementia who may be considered ‘middle or late stage’ described a different focus, that being solely to track the individual living with dementia and keep them safe when constant care partner supervision is not possible.

These findings corroborate the findings of previous work in discussing the changing role of this technology reviewed in section 2.5.9. Like Neubauer et al (2021) and Bantry-White and Montgomery (2010) discuss, findings from this study support the idea that the purpose of a GPS device may change from a means to facilitate safe walking, towards mitigating risk, with the main goal being to keep a person living at home in the community. Findings from this study differ from those reported by Lorenz (2017) in section 2.5.9, regarding the short period of usefulness of technology within dementia care and the unwillingness for care partners to engage with learning new technology that could become redundant. Findings presented in chapters 4 and 5 showed care partner’s desire to try any solutions available to them, acknowledging how GPS may be repurposed during the dementia journey but will still hold value.

Figure 26 also includes ‘potential use in long-term care’, whilst this study did not investigate the use of GPS within institutional care facilities, findings from similar studies that did investigate such use have been utilised here to show how the role of the technology may change. Wan et al (2014) and Dahl and Holbo (2012) use GPS technology in long-term care settings, reporting the faster recovery of missing individuals living with dementia as a key benefit in both studies that included participants in the middle or late stage of their dementia journey. To further understandings, more research is required regarding the long-term use of GPS by a care dyad, a point that will be made in due course in the recommendations section of this thesis (section 7.2).

6. Explore how GPS can impact upon the wellbeing of a person living with dementia and their care partner

This study took a unique approach of aligning participants views and experiences regarding GPS with the work of Kitwood (1997), Sabat (2001) and Bartlett and O'Connor (2007, 2010) to show the outcomes of using GPS in terms of supporting wellbeing, maintaining personhood and empowering people living with dementia. The findings from this study indicate that **GPS technology can be used to support the wellbeing of the person living with dementia and their care partner, enabling them to satisfy multiple Psycho-Social needs**. Findings from follow-up interviews were discussed in chapter 5 using Kitwood's model of Psycho-Social needs, to show how GPS can support the fulfilment of the 5 fundamental psychological and social human needs of comfort, identity, occupation, inclusion, and attachment (Kitwood, 1997).

Comfort

The term comfort was adopted from the work of Kitwood (1997) to describe how GPS can help provide feelings of safety and security and calm a person's fears and anxieties. Comfort was found, for participants living with dementia and care partners, through the practical and emotional support GPS offers them, through instilling feelings of calm, warmth, and security. For individuals living with dementia the feelings of security and safety were compared to a distress signal on board a boat, that they could activate should they experience feelings of fear or danger (page 189). For care partners, this comfort was closely aligned with feelings of peace of mind and relief and reassurance that they had a solution, should they be unable to locate the person they care for. A large body of the literature focuses on how GPS can increase peace of mind for care partners, this is documented in section 2.5.6 (page 65). Findings from my study echo this existing evidence, with additional peace of mind identified by care partners and individuals living with dementia as a key benefit of using GPS technology, and for many underpinned their desire to use this technology. Analysis showed that comfort can be mutually experienced by both members of the care dyad, with the comfort experienced by a care partner providing comfort to the person living with dementia. Roger reported wanting to do all he could to reduce the stress felt by their care partner (Anne) and relieve some of the burden their condition places on her (page

190). The desire of a person living with dementia to relieve the burden placed on a care partner is also discussed in the literature in section 2.6.

The technology in phase 2 was also shared with wider family members, to share the benefit of increased comfort and the feelings of calm and security that this GPS was seen to provide. Family members were given access to the mobile application that relays the geographical position of the device. In the case of Winifred's experience of using the device, not only did it have the power to increase wellbeing for Peter (the person she cares for) in terms of the ability to continue conducting meaningful activities alone, but added comfort was experienced by herself and the rest of the family. This is a seemingly unique insight into the lived experiences of using GPS in dementia care, whereby once the care partner was familiar with using the technology, benefits were shared with the wider family so that additional comfort, mainly gained through peace of mind, was experienced by all, eliminating confusion, panic and worry.

Identity

In chapter 5, a quote by Kitwood (1997) is used to describe the need for identity, where he discusses how a person living with dementia requires a connection to their past, to help continue the narrative of their life. The need for identity was likened to a story that links history with present day, to display continuity and consistency. Participants shared details about their past, aspects of their life that they enjoyed prior to diagnosis and how GPS has helped enable them to continue parts of it. Individuals living with dementia and care partners discussed a range of activities they enjoyed and where GPS was used to help such activities continue. Activities ranged from conducting charity work to running daily errands to the shops, with care partners and individuals living with dementia expressing how continuity is vital. This finding is in accordance with previous research that has pointed towards individuals living with dementia expressing connection to place, the significance of everyday practices both past and present, and how they can express and restore identity (Brannelly and Bartlett, 2020). Linking GPS technology to a person's need for identity shows the importance of tailoring assistive technology, to ensure that the device matches a person's unique character, their lifestyle and suitably reflects a person's identity. This coincides with discussions made previously in this chapter in aim 4 regarding the need for personalised technology.

Personal identity was also discussed in section 2.11 upon reviewing the work of Sabat (2001; 2002). During this section, the 3 selves are discussed in terms of how the behaviour of others in society can damage and cause a loss of self for a person living with dementia, in the way they are viewed and treated. Importantly, this thesis considers how we need to challenge negative stereotyping and the negative positioning of people living with dementia, by continuing to recognise the abilities they have retained, rather than focusing on that which they cannot do. Findings from this study support the need for a person's social identity to be respected and GPS technology could contribute to the empowerment of people living with dementia, to continue activities that were important to them.

Occupation

Kitwood (1997) argues for the need for occupation and that a person's abilities and powers need to be recognised and utilised. Findings related to occupation were discussed from the perspective of using GPS to enable the completion of meaningful activities, that provide purpose and utilise the abilities of individuals. For others in society, the need for occupation may be overlooked, as participants living with dementia described activities that may be viewed as insignificant to others, but for them held great value and were of great importance. This finding resonates with Miranda-Castillo et al (2013: p.7) finding that the most frequent unmet need of people living with dementia was in the area of daytime activities, with individuals missing out on conducting meaningful activities and expressed a "need to continue doing the things they used to do and being useful for others".

Theme 2 of section 5.2 describes the necessity for people living with dementia, and care partners to keep socially connected, attending groups and events both individually and with their care partners. This reflects findings in the literature, particularly how providing opportunities to stay occupied, conducting tasks that utilise a person's skills and abilities, can enable continued engagement in life (Genoe and Dupuis, 2012). Care partners also described the importance of meaningful activities for the person they care for, explaining how failures to fulfil this need for occupation can result in changes in behaviour, resulting in the person living with dementia experiencing frustration, boredom, and agitation. This was noticeable for care partners during the COVID-19 pandemic, with section 5.2 (theme 4) discussing the challenges of participants living with dementia not always understanding current guidelines and having to remain indoors for long periods of time. Kitwood (1997: p.75) discusses the impact upon a person living with dementia when the "external environment" fails to recognise the need for occupation, where the result can be a person retreating into a 'bubble' as their self-esteem "drains away". In phase 2 of this study, when Roger discusses his "worst days" and how they come about due to a lack of occupation (page 196), these views align with Kitwood's (1997) understanding that failure to meet the need for occupation can result in feelings of boredom, apathy and futility. The views of care partners across both phases support Kitwood's (1997) view that the more that is known about a person's past, and how they gain feelings of fulfilment and enjoyment, the more likely it is to satisfy the need for occupation. Care partners discuss their fears at one day having to restrict what the person living with dementia can do, and how GPS was able to prolong taking part in certain activities and outings. Aligning this research with the work of Bartlett and O'Connor's (2007;2010) social citizenship, GPS was also shown to support an individual living with dementia to be an active agent in their life, retain feelings of purpose and aid in conducting activities that are meaningful to them, independently, whilst also facilitating choice and control.

Inclusion

Kitwood (1997: p.83) argues that people living with dementia need to feel *"part of the group"* and reports on how the social life of those living with the condition tends to "dwindle away" as they progress on their dementia journey. The need for inclusion was documented by participants in both phases. This study demonstrated in section 5.3 (theme 2) the ways GPS was used to help support the need for inclusion, enabling people living with dementia and care partners to feel a sense of belonging and acceptance. Participants discussed using GPS to assist with undertaking social activities and attending events, in particular the attendance of dementia support groups, that all participants were members of. These findings align with other similar findings in the field in terms of how GPS can encourage social inclusion and participation. The use of GPS to promote inclusion in communities was explored in the second part of the literature review in section 2.5, with this study echoing the findings of studies that discuss how GPS, along with other e-services, can enable greater social inclusion and participation in community.

Inclusion was also considered from the perspective of being included in research, with participants discussing their motivations for getting involved in research studies and the importance of ensuring people living with dementia are able to contribute to the advancement of scientific knowledge. These findings are in agreement with those obtained by Brannelly and Bartlett (2020) and Bartlett and O'Connor (2007;2010) who discuss the role of active citizenship and the significance of enabling the contribution of people living with dementia to help challenge the belief held by some that dementia equates to passivity and exclusion. Referring to the definition of social citizenship offered by Bartlett and O'Connor (2010: p.37) and proposed earlier in this thesis on page 74, a person living with dementia is entitled to *"have opportunities to grow and participate in life to the fullest extent possible"*. Findings from chapter 5 show how GPS can help to facilitate such opportunities.

Attachment

Kitwood (1997: p.82) commented on how we are a highly social species and constantly look to form bonds and attachments, these attachments provide us with reassurances in a "world full of uncertainty". Findings in section 5.3 showed how GPS was used to help create more opportunities for the person living with dementia to experience attachment, to feel closer to others, in particular with friends and family members. Some of these findings align with those reported by Miranda-Castillo et al (2013), who highlighted the need for meaningful relationships and how they impact upon the general wellbeing of the person living with dementia. However, no previous literature has been found that has explored the role of GPS in helping to facilitate attachment and such meaningful relationships. This thesis shows an example on page 201 of how a care dyad was able to use this technology to create more opportunities for the person living with dementia to feel closer to other family members. In this example, Liz, a care partner for her father, Ken, shared the technology with her wider family who had previously been apprehensive about having Ken stay with them, Liz explained that she "*showed them how to use it and I think it made them feel a lot more at ease about* *[having Ken round to stay]".*

7. To explore the lived experiences of the COVID-19 pandemic from the perspective of care dyads and consider if GPS could have assisted them during this time.

This research has been the first attempt to examine the impact of the COVID-19 pandemic and the role GPS could play during such a time of crisis. Whilst this was not an original aim of this study, due to the declaration of COVID-19 as a pandemic by the World Health Organisation (2020), this study had to swiftly respond to a number of changes and COVID-19 related challenges. COVID-19 severely impacted the design of this research, but it also provided a unique opportunity to gather data related to the challenges individuals living with dementia and their care partners faced. This aim was added to explore if GPS could have supported people living with dementia and their care partners through the COVID-19 pandemic and associated restrictions on movement.

Conducting this research amidst the backdrop of a global pandemic gave unique insights into changes in behaviour due to enforced lockdowns, quarantining and stay at home orders. In section 5.2, individuals living with dementia and care partners recalled their frustration and agitation at being unable to leave their home and where GPS technology could be able to relieve these feelings of frustration and confinement. Care partners expressed that they would have had more options available to them if they had a GPS device during this time, in particular when individuals were only permitted to leave home for essential exercise and activities such as grocery shopping, alone.

The current study also found that, as a result of the COVID-19 pandemic and restrictions on face-to-face contact, some care dyads reported an increase in their level of technical knowledge. This increase provided them with the opportunity and time to overcome barriers of digital literacy. On page 168, participants of phase 2 discussed how they experienced very little face-to-face contact with the wider community during the pandemic, with some turning to technology to help them engage with the rest of society. Eric stated that learning to use technology came "*not out of choice" (Eric, initial interview)*, with Eric having to force himself to close the digital divide that he experienced, to learn new digital skills that enabled them to benefit from technologies. Similar experiences were discussed by others, with newfound technical skills quickly becoming vital to their health and wellbeing during the pandemic. For two care dyads these new digital skills gave them the confidence to enrol in this research study and gain benefits related to GPS. There are also similarities between the attitudes expressed by participants in this study, in terms of using technology to ensuring social connectedness during the pandemic, and those described by Cooper et al (2021).

These findings are also in agreement with those obtained by Gedde et al (2021) who also report an increase in access to and interest in technology such as mobile phones following the outbreak of the COVID-19 pandemic. However, Gedde et al (2021) reported that few participants expressed interest in using assistive technology such as GPS during the pandemic. Findings from my study disagree with those obtained by Gedde et al (2021), with some participants discussing how such interventions would have been invaluable during the pandemic.

In terms of the impact of the COVID-19 pandemic on people living with dementia, similar findings reported in this thesis in relation to anxiety, depression and isolation were discussed by Giebel et al (2021). The study by Giebel et al (2021) was one of the first to investigate the availability of social support services during the pandemic and concluded that social support services need to be able to adapt in times of crisis, to continue to provide support for people living with dementia and their care partners. Goodman-Casanova et al (2020) found participants expressed feelings of fear, frustration, boredom and confinement during the pandemic, with walking found to be the most common leisure activity undertaken to help mitigate the restrictive measures enforced during COVID-19. This is corroborated by findings in phase 2, with participants discussing how activities involving walking were essential for participants living with dementia during the pandemic. Care partners acknowledged the necessity of such activities but also voiced the worry and anxiety that arose from enabling such activities to take place.

Findings also showed best practices in relation to how to conduct research during a time of crisis. This study swiftly responded to challenges such as restrictions on face-to-face contact, which from the outset was seen as an essential method to delivering adequate training for care dyads. Similarly, face-to-face presentations were initially viewed as the best way to recruit participants living with dementia and their care partners to the study. Through the creation of a custom-built website and online learning tool, challenges were overcome, and the study utilised remote methods to recruit, train and support participants during a time of crisis. To implement these changes to the study, I made use of my knowledge and background in computer science. However, I ensured that the material I produced was appropriate and accessible for the intended user group through consultations with care dyads and made any necessary revisions based on their feedback. This unique contribution to knowledge, and the role the website played in supporting care dyads, to help with retention of participants and their understanding of the technology, is discussed further in chapter 7, section 2.

8. To explore the ethical concerns that care dyads may have regarding the use of GPS technology.

Whilst this study sought to explore the ethical concerns surrounding the use of GPS following interviews with participants, it was found that there was little concern with regards the ethics of tracking a person living with dementia from both members of the care dyad. Section 2.3.6 of the literature review discusses ethical issues surrounding the use of GPS technology reported by other authors, including concerns regarding privacy, autonomy, consent, control, trust, and security. A figure (figure 7) is offered on page 44 to depict the socio-ethical framework of location-based services (such as GPS), as proposed by Michael et al (2008). However, findings from this study suggested that care dyads were more focused on issues of safety, rather than ethical concerns surrounding privacy, autonomy and the topic of surveillance.

Boxes 1 and 2 in section 3.4.2 shows the type of questions put forward in phase 2 interviews. Participants were asked about their concerns and worries about this technology, and their views on surveillance and tracking technology. Findings differed from those obtained by Dobson and Fisher (2005) and Niemeijer et al (2015), with no participant living with dementia, in either phase of this study, voicing concerns that their privacy may be breached through the use of GPS. One participant (Ken, page 146) questioned why someone may bother to infringe on his privacy as he felt he was not doing anything of interest to someone else. Where care partners provided their worries and concerns surrounding GPS, focal points were on issues of battery life, human error and false alarms, rather than worries that are ethical in nature. A possible explanation for this may be that because these issues are addressed at different ontologial plains, this list of practical concerns are ones that take place in the 'here and now' and can be practially addressed. Contrastingly, ethical issues surrounding, for example atonomy and consent, may be reflected on and considered at a different level of reality. Participants were encouraged to reflect on the ethical implications of GPS (as seen in section 3.4.2) however, participants appeared to be more interested in how this technology could help them rather than any ethical questions arising. Similar findings were reported by McCabe and Innes (2013) who noted that participants in their study were more interested in the potential benefits of GPS devices over ethical issues.

6.2 Summary of chapter

This chapter discussed the meaning, importance, and relevance of findings from this study and positions them in relation to existing literature in the field. This chapter demonstrated the impact of using off-the-shelf GPS technology on the daily lives of people living with dementia and their care partners. Findings build on existing evidence related to how GPS can be of benefit to the care dyad, to facilitate greater freedom and independence whilst simultaneously providing safety and mitigating risk. Findings contribute to understandings that dementia is a condition that impacts everyone differently and that special considerations need to be made that take into account individual contexts and needs, to ensure that technology is flexible, adaptable and tailored. Discussions also considered the influences that result in non-adoption and discontinuance of this technology, showing limitations of GPS, as well as the barriers that exist to prevent access to what has been described as “*life-changing*” (Joy, Follow-up interview) and *“life-saving”* (Bernie, initial interview) technology. During these discussions, unique insights were made into the usage of GPS technology and the factors that can amount to technology underutilisation, that saw participants restrict their use of GPS to basic functionality due to concerns surrounding confidence and trust in the technology, fear of human error and issues surrounding appropriate training and support. This research went on to deliver new insights into the impact of the COVID-19 pandemic on people living with dementia and their care partners are then proposed and insights into whether GPS technology could have assisted living during government enforced lockdowns and stay-at-home orders. My findings resonate with other academic literature in demonstrating how GPS can enhance social inclusion, participation and engagement but emphasises that the timing of this technological intervention is key. Through discussions within the context of the dementia journey, this research has shown that awareness of technology is needed at the earliest point, to allow the care dyad to gain the benefits of GPS at the right and appropriate time. The benefit of support for wellbeing is discussed using Kitwood’s (1997) model of Psycho-Social needs. This demonstrated how GPS can support the fulfilment of the 5 fundamental psychological and social human needs of comfort, identity, occupation, inclusion, and attachment for both the individual living with dementia and their care partner. This project offers useful insights into the lived experience in relation to the ethical considerations of using this technology, with participants of this study prioritising safety and the practical considerations of using GPS than they are to the ethical issues involved in its use. The next and final chapter in this thesis will summarise this project and the unique contributions to knowledge that this thesis has made, in terms of research, policy and practice.

CHAPTER SEVEN

RECOMMENDATIONS AND CONCLUSIONS

CHAPTER SEVEN: RECOMMENDATIONS AND CONCLUSIONS

The final chapter in this thesis will provide a summary of the project, outlining the contributions to knowledge that this research makes, in addition to debating the strengths and limitations of this study. The chapter concludes by discussing the recommendations that can be made for future research, policy, and practice of using GPS in dementia care.

7.1 Introduction

This is the first study to explore the lived experiences of people living with dementia and their care partners on their use of off-the-shelf GPS technology. This study involved and consulted with people living with dementia throughout. The aim was not to conduct research 'about them' or through the use of a proxy to explore what people with dementia might have thought or done, this research actively sought to ensure that their voice was heard, understood, and had an impact. This project was designed and undertaken to gather diverse perspectives on a range of off-the-shelf devices before putting a device selected by members of a consultation focus group into use by individuals living with dementia and their care partners. The off-the-shelf GPS product, selected by participants of the consultation focus group, retailed at £19.99, with a monthly fee of £2. One of the major findings from this study was that off-the-shelf GPS technology is viable and cost-effective for use in the daily lives of people living with dementia and their care partners.

This project was devised following an investigation into GPS technology that is available for people living with dementia and their care partners. Investigations uncovered an industry of GPS products aimed at dementia care, as well as older adults in general, with products retailing from upwards of £110 with ongoing monthly costs amounting to £9.95 (TechSilver, 2022). I questioned this high cost, which seemed excessive and disproportionate, given the increasing availability of the technology and its integrated use within society, from smartphones to driverless cars, tracking pets and belongings. After further research I found off-the-shelf GPS devices are available from as little as £10.00 and carry similar, if not identical, technical specifications to those that retail under the label of ‘dementia care’. ‘Off-the-shelf’ technology was selected due to its availability, accessibility and predominately its cost. This study was developed to consider how suitable these off-the-shelf GPS devices would be for people living with dementia and their care partners.

The first chapter of this thesis introduced the study and contextualised it, providing a broad background the topic of dementia and assistive technology, before placing the study within the context of existing research. Chapter two presented the review of the literature available to date, divided into two parts. The first considered a broad review of the literature pertaining to assistive technology within dementia care, GPS as well as existing government dementia policy, with the purpose of providing contextual information. The second part of chapter two discussed the systematic review that took place for this study, investigating the benefits of using GPS technology for those living with dementia. The key benefits reported in the literature related to increased freedom and independence for individuals living with dementia, as well as peace of mind for care partners. Chapter two concluded by bridging the results of the literature review and the project's research design, focusing on the concept of person-centred care. The third chapter of this thesis provided a detailed account of the design of this research, and the research methodologies that underpinned this study, detailing the aims, objectives and research question that this study sought to answer.

Chapters four, five and six set out the findings of this research and situated them within relevant literature. Chapter four presented phase one of this study and the thematic analysis of the consultation focus group. The consultation session explored the views and opinions of people living with dementia and care partners on a range of off-the-shelf GPS devices, enquiring into their suitability and appropriateness. 5 themes were identified in this chapter and were subsequently used to shape phase two. Chapter five presented the second phase of this study, introducing the 18 participants that took part in the main research study which involved care dyads using the device deemed most suitable by those who took part in phase 1 over a 3-month period. The chapter discusses data analysis from two interviews with participants; the first taking place before this 3-month period and the second following up with care dyads to explore the lived experiences of using this technology. The sixth chapter of this study brought the research together, discussing findings in relation to the aims set out in the design of this research and situating them within the broader literature. This final chapter of this thesis summarises the research and highlights the novel contributions this research makes to the field.

7.2 Contributions to knowledge

This section of the chapter presents the key contributions to knowledge that this study makes for research, policy and practice within the field.

7.2.1 Contributions and recommendations to research

Inclusion of people living with dementia

My study was the first to directly consult people living with dementia and care partners on off-the-shelf GPS technology, ensuring these voices were heard, understood and influenced the design of the subsequent phase of research.

This study lays the foundations for future research that consults and is co-produced with people living with dementia on the appropriateness of GPS technology, before using these views, opinions and experiences to shape the main research study. This study began by consulting people living with dementia, as well as current and former care partners, known as the ‘Salford Dementia Associate Panel’, based at the Salford Institute for Dementia, University of Salford (Manchester, UK). This consultation focus group put forward examples of off-the-shelf GPS technology to participants who have direct, first-hand experience of dementia, as well as experience of the research process. The ‘dementia associates’ were founded in 2014 and have been involved in advising on different aspects of research and engagement (Bowker et al., 2020; Innes et al., 2021). The group was formed with an aim of raising awareness of dementia and contributing to improving the lives of those living with the condition (Bowker et al., 2020).

This consultation session sought to enable people living with dementia, care partners and former care partners to guide the research that followed. Many of the studies reviewed in the literature review (section 2.5) opted to select a form of GPS and provide participants with the technology for a set period of time. This research was designed on the basis that those with direct experience of the dementia would select this technology themselves. Assistance was provided, based on my knowledge of technology (and inclusion criteria based on reviews of the literature), to narrow down the 147 GPS-enabled devices found from a rigorous review of online marketplaces to a manageable size. This study has gone some way towards enhancing our understanding of how a suitable device is selected by people living with dementia and care partners, what factors they hold most important to them, what device characteristics they prefer and what they feel is missing. These insights will be of interest to designers and developers of this technology, with the hope being that the technology sector will seek to increase representation of people living with dementia and care partners in order to improve suitability and appropriateness.

Conducting research in a time of crisis

My study has been the first to examine the perceptions and use of GPS technology during a health pandemic and the resulting associated challenges public health measures brought about for those living with dementia. This thesis also offers an innovative approach to conducting research during a time of crisis through the ways the study adapted, transformed, and overcame challenges brought about during the COVID-19 pandemic.

For the vast majority, the pandemic impacted essential aspects of human life, resulting in economic and social disruption across the world. Conducting this research during a global crisis has offered unprecedented insights into the challenges facing people living with dementia and their care partners. Within dementia care, COVID-19 and preventative measures forced restrictions on social contact and resulted in limiting or terminating access to vital support services.

Alzheimer’s Disease International stated in 2020, *“People with dementia are being disproportionately impacted by this pandemic and are in danger of being forgotten”* (ADI, 2020). It is therefore vital that during times of crisis, such as during a health pandemic, the voices of those with direct experience of the condition are heard, and that research is adapted to enable their valuable contribution to research be made. The methodology designed for this study was subsequently changed to meet the everchanging restrictions and regulations involving social contact, to ensure that suitable support mechanisms were in place for all participants. Face-to-face research and training, from the outset were viewed as a requirement due to the perceived difficulties in distance-delivered research and technical support for this user group, however, changes made to this study can be considered successful.

A custom-built website and online learning tool were developed to aid participants in understanding how the technology used in this study works, featuring downloadable user guides, relevant project information and step-by-step instructional videos for device functionality. Online technical support was provided through a live chat function, that connected participants with myself upon demand. Similarly, one-to-one remote assistance was available through a contact form, over the phone or via email. Participants were also given the ability to interact with myself and other users through an online forum. In terms of data collection, initially this study sought to interview care dyads face-to-face, however due to enforced social distancing practices, this research was successfully conducted remotely. Interviews took place over the phone with the technology and physical information (user guide, participant information sheet, consent form etc) supplied to participants via post. A dedicated area on the custom-build website was also used to promote the study and encourage users to sign-up to take part in the study, here. users could browse required documentation (the participant information sheet and consent form) and enter their contact details. It was found that the website was a useful tool in terms of participant recruitment, with it being easily shared across social media platforms by charities I had contacted to promote the study and also shared via email. This provided a means of accessing all required information concerning the study, in one place. This approach would also prove valuable in a post-COVID era.

Wider lessons can be shared in terms of how to conduct research and support participants in times of crisis, especially when it comes to the involvement of this particular user group. When it was decided that this project would incorporate remote and distance-delivered features, extra considerations were made to the characteristics of the user group. For instance, the user guide was developed in partnership with older adults, to ensure the wording and descriptions given were appropriate and understandable. The custom-build website and online training tool were developed to incorporate user-friendly design and changes were made based on feedback from early participants to maximise suitability and usability.

The findings reported here also shed new light on the age-based digital divide and how the COVID-19 pandemic has impacted upon it. During the pandemic, digital measures were sought to overcome the negative effects of the crisis, in particular, interventions to tackle loneliness and social isolation. Social connection was facilitated virtually through phone calls, web-based video calls (including Zoom, Skype and Facetime). Participants in this research study discussed the use of email and online messaging (through Facebook Messenger and SMS texting) to help them stay connected to others. However, many spoke of their lack of digital skills, and their inability to make use this technology prior to the pandemic. The presenting situation then forced individuals to engage with social media, and computer programs, which they had previously not utilised, but became essential for social connection. Participants spoke about how learning new digital abilities came "not out of choice" (Eric, Initial Interview), but rather due to the circumstances they had found themselves in. For Eric, he was aware of the technology and knew he needed to learn how to use it, but he had always delayed learning new digital skills until the choice was taken away from him.

The cost of assistive technology

From the outset, this thesis sought to address the rising costs facing people living with dementia and their care partners, through exploring the use of off-the-shelf GPS technology. Studies in the past have often explored costs in relation to services and how GPS may reduce the cost of care or emergency services locating people living with dementia. However, this thesis has put the focus on the care dyad, concentrating on the cost of GPS assistive technology and how devices targeted at dementia care are, at times, excessive and disproportionate, and can prevent access to "*life-changing"* (Joy, follow-up interview) technology. This is the first study to have provided a cost-effective solution to the problem of access to this technology, through exploring the viability of using off-the-shelf GPS technology in the daily lives of people living with dementia and their care partners.

Off-the-shelf devices are available at a low-cost in terms of the acquisition price (maximum of £30), as well as operating expenses (the majority of devices require a monthly fee to access services). Given the rising costs associated with dementia care in the UK, estimated at an average cost of £32,250 per person per year (Alzheimer's Society, 2019a), and high rates of older people living in poverty (Age UK, 2020), low-cost technological solutions must be considered. This study has demonstrated that off-the-shelf GPS devices positively impact upon the lives of people living with dementia, their care partners, and wider family members. Benefits are gained through GPS being able to facilitate independence, provide peace of mind and promoting wellbeing. These findings align with other studies that utilise targeted (or ‘dementia branded’) devices, solely aimed at individuals living with dementia and their care partners, suggesting that the only difference between the two types of products is cost. This new understanding that off-the-shelf GPS appears comparable to targeted/’branded’ devices in reporting benefits such as independence, added peace of mind and social inclusion should help to improve accessibility to this assistive technology.

This study acknowledges that affordability is subjective, as it is an assessment of a person’s economic status and will differ on an individual basis. However, findings from this research, in particular the consultation session, suggests potential users would be more likely to “take a chance” (Ethel, focus group) on purchasing low-cost assistive technology as there is less financial risk than purchasing a device for upwards of £100. This concept of financial risk for people living with dementia, with regards purchasing and adopting GPS assistive technology, is one that the literature to date has so far failed to consider. Given the aforementioned rising costs facing people living with dementia and their families, many may be financially unable to commit to purchasing ‘dementia branded’ products without knowing how effective they may be. People living with dementia and their care partners may delay investing in potentially life-changing technology for this reason. Therefore, it is essential that off-the-shelf devices, and indeed the benefits of using them, are given wider publicity. These findings may be of interest to previous studies which have issued calls for research that consider the cost-effectiveness of GPS technology within dementia care. For Ethel, a participant in the consultation session, the cost of the device was important *“especially when you just don’t know how much you might use it”* (Ethel, Focus group). Whilst studies often investigate cost from the aspect of reductions in the need for emergency services (for example search and rescue, or the police locating a person living with dementia) there is a paucity of evidence related to cost from the point of view of the individual, in particular the cost of the device itself.

Dementia specific studies, not solely focused on GPS but within the field of assistive technology, have considered the use of off-the-shelf technologies, reporting that they often fail (Kintsch and DePaula, 2005; Armstrong et al., 2010). For Armstrong et al (2010), this is due to an inability for people who purchased off-the-shelf technologies to integrate them into daily living and everyday lives. Armstrong et al (2010) therefore found that utilising off-the-shelf technology is not cost-effective from the perspective of the individual. However, the findings of the current study do not support this previous research. This thesis shows that off-the-shelf GPS technology is a viable, cost-effective alternative to targeted/'dementia branded' products, reporting the same benefits. A possible explanation for this might be that such studies are now over a decade old, and from a socio-technical change perspective, technology has advanced considerably and is now more widely adopted. However, it may also be a result of this study's research design, and due to the technical support, that was given to participants throughout the study.

7.4.3 Recommendations for future research

A review of the literature found a lack of longitudinal research that examine how a care dyad's interaction with GPS technology changes through time and how this may correlate to an individual's dementia journey. It has been found in this study that care dyads utilise the technology in different ways, some find benefits in terms of increase independence for the person living with dementia, while others used GPS as a safety net, to mitigate risk in the later stages of a person's dementia journey. It is acknowledged that every individual's experience of dementia is different, and the dementia journey should not be viewed as linear as a person's abilities may fluctuate over time. However, it would be helpful for research to consider the changing role of GPS technology in more detail following the device through time to gain better understandings of when this technology might benefit people most.

Further work is needed to fully understand the implications of using GPS technology, and other forms of assistive technology, for working-aged care partners. This study was able to report findings in this area, however as this study only recruited participants who resided together, it would be interesting to explore the lived experiences that may be specific to care dyads who reside alone. This study also briefly considered the context within which care dyads operate and how the relationship between care dyads (spousal, parent-adult child, siblings) may influences how the devices were received, thought about and used. Further investigations are required to gain a better understanding and insight into this. Further research could also directly involve care dyads in the design, creation, and development of a GPS device, from the beginning as well as a co-created app to use the device. Whilst this study involved care dyads in selecting the device used in the main research study, devices were still pre-existing. A greater focus on involving care dyads in the early design of this technology could produce interesting findings.

Further research can build upon the work of this study, adopting similar methods and research design to explore and evaluate other off-the-shelf versions of healthcare products. As this study has shown how effective off-the-shelf GPS devices can be within dementia care, there may exist other examples of assistive technology whereby a more affordable, cost-effective solution is available.

7.2.2 Contribution to conceptual literature

This research has contributed to the literature that continues to develop our understanding of the benefits of using GPS technology for care dyads. This study also contributes to the wider literature on supporting people to live independently and also supporting care partners. This thesis details how the use of GPS technology within dementia care can support wellbeing from multiple perspectives, by aligning findings with the Kitwood (1997) model of psycho-social needs. This thesis has documented the work of the late Professor Tom Kitwood and how his pioneering views transformed dementia care, leading to a person-centered care approach. This approach focused on acknowledging a person's uniqueness and characteristics, instead of focusing on symptoms and challenges of living with dementia. By preserving personhood, wellbeing could also be preserved or even improved upon. This thesis has adopted elements of the person-centred care approach and aligned Kitwood’s work in promoting personhood, to the use of GPS technology. This alignment is unique to the field and has shown how through adopting GPS technology and focusing on the abilities that a person has retained, multiple psycho-social needs can be satisfied, and the result is increased or preserved wellbeing for not only the person living with dementia and their care partner, but in some instances, also the wider family. This research also focused on using the Kitwood (1997) model of psycho-social needs from the perspective of the care partner and explored how GPS can help satisfy the need for comfort, identity, occupation, inclusion, and attachment. This approach proved useful in expanding our understanding of the value of GPS devices to support the care partner. Through exploring lived experiences, this research was able to show examples of how people living with dementia expressed happiness at the thought of something that could make life easier for their care partner. The phrase *“when he’s happy, I’m happy”* was used by Ken (Follow-up Interview) to show how interdependent the dyad had become, whereby one person’s wellbeing is mirrored in the other person.

On page 253, this thesis considered how findings align to the work of Sabat (2001), who discussed the sense of self among people living with dementia and proposed the three selves, as set out in section 2.10 of the literature review. During the discussion chapter, links were made between Sabat’s (2001) theories on self and the use of GPS in promoting a person’s individual identity. Similarly, in chapter 6 (aim 6, page 251) this research aligns the use of GPS within dementia care with notions of ‘social citizenship’, as proposed by Bartlett and O’Connor (2007, 2010). Bartlett and O'Connor (2007) suggested Kitwood's (1997) view on personhood was limited and excluded how the socio-political sphere impacts upon daily life for a person living with dementia. They argue the case for ‘social citizenship’ that builds upon Kitwood's (1997) principles of personhood to include the view that individuals are full members of the community with equal rights. Contributions of this research has extended our knowledge of how GPS can provide opportunities for people living with dementia, to help facilitate participation in society and enable individuals to be viewed in a holistic way that looks at the whole person and not just their condition. The views of Bartlett and O’Connor (2007, 2010) in relation to social citizenship have become ingrained in recent UK policy on dementia, which aims to ensure that individuals living with dementia feel valued and able to contribute to their community. Throughout this thesis there is an emphasis that there is much more to a person than just their diagnosis of dementia, with GPS being used as a tool to help the rest of society recognise this.

7.2.3 Contributions and recommendations to policy

The WHO (2018) reported that, globally, only 1 in 10 people have access to vital assistive technology, with this largely due to a combination of the high costs of acquiring AT, a lack of awareness of what is available, trained personnel, policy, and financing. The findings of this research will be of interest to policy makers who should seek to ensure that this low-cost technology is available to everyone who may benefit from it. A national assistive technology programme is required that focuses on awareness, provision, and training. Each of these are discussed in more detail below:

1). Awareness of off-the-shelf GPS

The 2020 ‘Prime Minister’s challenge on dementia’ proposed to increase the provision of post-diagnostic support, “to encourage greater personalisation in the provision of post-diagnostic services – this means building support around the individual with dementia, their carer and family and providing them with more choice, control and flexibility in the way they receive care and support ... incorporating new ideas including technology solutions into everyday practice” (Department of Health, 2015: p.28).

This study advocates for widespread awareness about off-the-shelf GPS technology, to allow for benefits to reach individuals and care partners in a timely and appropriate manner. Findings from this study show that many individuals living with dementia and their care partners are not aware of this vital, “life-changing” (Joy, Follow-up interview) technology, despite the benefits it can provide. Evidence from this study also shows that when it comes to assistive technology, such as GPS, people living with dementia and their care partners had to find this information out for themselves or through family members and friends.

Changes are required to policy to ensure that upon diagnosis, the technological options available are made clear to people living with dementia and their care partners. Importantly, awareness should focus on the range of off-the-shelf products that are available, to show that this technology is perhaps more affordable than targeted devices would suggest. This research has shown that cost is a motivating factor for care dyads, and that there may be apprehension to purchasing technology that they have little knowledge about. There should therefore be a focus on publicising the benefits of using this technology, not through academic journals, but through mainstream channels that are more likely to reach those most in need of GPS devices.

Policy should aim to create a national assistive technology programme to increase awareness of technology and provide appropriate training as part of ongoing post-diagnosis support. It has been observed through policy that there is no overall push, from central government, towards promoting the use of GPS technology for people living with dementia and their care partners. Policy makers can advance the use of GPS technology within dementia care by increasing awareness in the main benefits of using this technology. Whilst there are areas of best practice within localities, for example Norfolk County Council (2016), who provide an assessment on how AT such as the ‘buddi’ GPS device may benefit people living with dementia, there needs to be less fragmentation, with advice and the provision of GPS technology coming from central government policy. Therefore, this study recommends that:

Information and advice related to the use of GPS within dementia care is to be provided to care dyads in a timely manner, when it is appropriate and whilst certain benefits can still be received.

2). Provision of an affordable support service

The ‘Prime Ministers challenge on dementia 2020’ described commitments to increase technology adoption within dementia care, “testing how digital technologies can support individuals and carers to monitor health, reduce social isolation and connect people” (Department of Health, 2015: p.15). The UK Government has said that it aims to bring forward a new strategy for dementia care, support, awareness, and research, with it proposed that this would be published in late 2021 (UK Parliament, 2021). At the time of writing, no further proposal has been published. This study highlights the availability of low-cost technology that can benefit people living with dementia and their care partners. This research has demonstrated that off-the-shelf GPS technology is a cost-effective option to increase freedom, independence, peace of mind, reduce social isolation and indeed connect people.

This study has also raised important questions regarding the digital divide, in particular, access to digital technologies. Current government policy recognises the importance of digital inclusion, in the NHS long term plan states “We will ensure these technologies work for everyone, from the most digitally literate to the most technology averse and reflect the needs of people trying to stay healthy as well as those with complex conditions" (NHS, 2019: p.93). The Topol Review (2019: p.23) refers to the founding principles of the NHS, of "equal and equitable access to healthcare for all UK citizens. Yet use of digital healthcare technologies could undermine these principles by exacerbating inequalities, unless consideration is given to how they affect equality and equity, including the risk that vulnerable groups might be excluded or exploited". This thesis has highlighted the existence of healthcare inequalities in relation to the use of assistive technology in the UK and worldwide. It has been found that access is not equal or equitable, with the cost of acquiring technology playing a crucial role in a person's decision to invest in this technology. For participants of this study, selecting GPS technology was seen as an 'investment' with participants considering the financial risk of more expensive devices alongside their perceived cost-effectiveness. Ensuring greater access to this technology is vital. Therefore, this study recommends that:

The UK government should commit to delivering adequate and sustained funding for the use of GPS technology within dementia care, to prevent the need for high out-of-pocket payments for care dyads who are already facing rising costs associated with dementia.

3). Appropriate training on the use of GPS technology

Whilst awareness and provision of this technology are vital, findings from this study show that without adequate and appropriate training, the benefits of GPS devices would not be gained or fully felt. Approaches taken in this thesis will prove useful in expanding our understanding of how to adequately and appropriately train potential users upon receiving this technology. Whilst one-to-one and face-to-face training is preferable, the design of this study has shown that through a user-friendly format, training and guidance can be delivered remotely. This research has often made reference to the digital divide and the existence of technical inequalities, without sufficient training for care dyads to utilise this technology, provision and awareness of GPS are meaningless. This study has also shown that through appropriate training and once the care partner is familiar with using the technology, benefits of this technology can be shared with the wider family, increasing the value of the product.

Contributions were also made in relation to how GPS technology can assist working-age care partners balance their responsibilities of work and care. This will be of interest to policy makers given the prevalence of informal caring for people living with dementia across the UK and worldwide. The WHO (2021) reported that globally, informal care partners spend an average of 5 hours per day caring for people living with dementia. Informal care can result in physical, emotional and financial pressure, and many of these informal care partners will be of working-age, attempting to combine employment with a caring role for their family member or friend. The WHO (2021) advise that increased support is required from the health, social, financial and legal sectors, with findings from this study suggesting that off-the-shelf GPS devices are one small intervention that may help ease the struggle of combining work with caring responsibilities.

This thesis has shown that training (when made appropriate for the target audience) can be delivered remotely, offering an effective and cost-effective solution that may help care dyads fully utilise this technology. Without sufficient training, for some the provision of GPS technology may be meaningless, as they may not have the digital skills to fully utilise devices to access all benefits. Therefore, this study recommends:

Policy should incorporate adequate and appropriate training for care dyads on how to use GPS technology effectively and offer ongoing technical support.

7.2.5 Contributions and recommendations to the technology focused world

The malleability of technology to support use

During section 6.4, discussions centred on factors that can result in the abandonment of this technology or influence how GPS devices are used. This thesis presents new understandings of how this technology is used and portrays the malleability of this technology in how care dyads shaped, adapted and controlled the use of their GPS device to make it work for them. This is particularly noticeable when participants discuss the battery life of the technology and how they altered the frequency of tracking outputs from the device to maximise battery capacity. In such instances, care partners were willing to receive less frequent updates on the geographical position of the device (and person living with dementia) to prolong use and thus enable greater freedom and independence for the individual living with dementia.

Literature generally suggests that in terms of the technology adoption lifecycle, shown in section 2.2.4, older users tend to be identified as ‘late majority’, or ‘laggards’. ‘Late majority’ and ‘laggards’ are often seen as sceptics or “phobics”, with low levels of computer literacy and a reluctance to embrace change. This coincides with the negative view that older people are ‘technophobes’ and as such, designers and developers tend to refrain from targeting such groups (Padgett and Conceição-Runlee, 2000). This results in the limited involvement of older adults in the design process. Similarities can be drawn with the involvement of people living with dementia in design and research, despite the valuable insights they can provide. Even in dementia literature and where people living with dementia are included, their role is still often restricted to providing their views and experiences on using existing technology, at the end of the design process.

This research study actively sought to counter this way of thinking, to show the valuable contribution that people living with dementia and their care partners can make to the early phases of technology design and innovation. The above example with regards to how participants moulded the technology, so it worked for them, is testament to that. Taking the example of how they changed the frequency of tracking outputs to maximise battery life, participants are showing that they are indeed innovators, improving the technology to make it more effective for them. These findings build upon existing evidence related to the need for adaptable technology, that can be tailored to meet a person’s needs and contexts, findings that have practical implications in relation to the design and development of GPS devices. The practical implication here is to ensure that people living with dementia, care partners and indeed older adults in general are involved in all stages of design, especially early phases, to ensure suitability, appropriateness and to help guarantee use. Care dyads should be seen as sources of innovation by developers.

This thesis contends that people living with dementia and care partners need to be on the inside of this process, from an early point, shaping the future of the technology industry. Therefore, this study recommends that:

Care dyads should be included, as stakeholders, in the agile development of hardware and software to ensure that their voice is heard and their views, opinions and experiences contribute to requirements of technology.

New knowledge was also gained in relation to how technological competency contributes to the underutilisation of GPS devices. Participants forgo potential benefits of GPS, for example, geo-fencing, out of fear of undoing the progress they had made in learning how to use this technology. This contributes to the field of dementia research and the use of assistive technology, but also adds to knowledge of the digital divide that could be researched further.

Technical Guidance

Practical technical guidance was created, incorporating ideas and feedback from people living with dementia and care partners to ensure it was appropriate and fit for use by the intended user-group. This guidance was available in both physical form (through a user guide – appendix 5), as well as through the custom-built website and online learning tool (www.dementiatech.info). This collaborative guidance is also accessible to practitioners in the field. Following the conclusion of this research, this website and online learning tool will continue to provide guidance and be updated to reflect changes in technology. The website will also serve as a means to raise awareness for the use of off-the-shelf GPS, the benefits of using GPS within dementia care and provide information as to where to purchase off-the-shelf devices. This responds to suggestions made by participants during the study who highlighted the issue of choice overload when considering online marketplaces, with this a cause for confusion and delay. This guidance will help potential users navigate the vast market of off-the-shelf GPS products and help ensure that the device they choose is suitable for them.

This thesis has also drawn comparisons between off-the-shelf GPS and those labelled ‘dementia branded’ devices. Findings support the view that, in many instances, the main difference between the two is cost. This study has set the foundations for further research to be conducted that challenges the concept of ‘dementia branding’ for GPS devices, where device specifications align with off-the-shelf devices that are available for a fraction of the cost.

7.3 Strengths and limitations of this research

7.3.1 Limitations

Every effort was made to ensure the robustness of the findings obtained over the course of both phases of this research. However, this study was limited by several factors which are outlined in detail below.

The sampling strategy used in this research presented several limitations, particularly in terms of the sample size, type and the eligibility criteria. Firstly, the number of participants included in the first phase of this research project was small. The sample consisted of two individuals living with dementia and one care partner. The participants were knowledgeable regarding the technology and the method of data collection, however a greater representation of individuals living with dementia, care partners and former care partners would have been desirable. As documented on page 84, events which led to the reduced number of participants taking part in phase one were out of my control. Despite limitations of the first phase of data collection, it is worth noting that phase one gathered informative, experiential data that was used to shape the wider study.

Phase 2 recruited 18 participants (9 care dyads) to the research and may be considered a small-scale qualitative research project. However, the rationale behind this figure of 18 was based on costs of acquiring the technology (this phase of the project was self-funded) and due to the level of technical support that may be required. As technical support was provided by myself, this phase utilised a staggered approach, with participants commencing the 3-month period of using the selected device in 3 different stages (1st: 3 care dyads, 2nd: 4 care dyads, 3rd: 2 care dyads). Notwithstanding the relatively limited sample in both phases, this thesis offers valuable insights into the lived experiences of using GPS in dementia care. Within qualitative research, the sampling debate considers that a focus should not be on how many participants attended, but rather, the emphasis should be on the richness and depth of data.

The generalisability of these findings may equate to a limitation in terms of sampling bias. For instance, participants of both phases of research were self-selecting, which may be considered a limitation, with many already holding interest in or having prior experience of the technology, potentially impacting upon their views, opinions, or experiences. This was noted during research design, with it assumed that differing levels of technological knowledge would have made for interesting comparisons. This can be noted in both phases of research, with a mixture of participants who had prior knowledge of GPS. It may also be considered a strength of the study that ultimately, whilst not intended, data related to varying levels of experience was gathered. Despite this potential limitation, this research conducted exploratory work and managed to elicit information that was key to this study.

Whilst caution must be taken when generalising these results, due to this work being not statistically representative, researchers also discuss the idea of theoretical generalisability and how findings can be generalised at a theoretical or conceptual level (Swift and Tischler, 2010). Indeed, qualititative research by its very nature will generally involve small sample sizes (Pilnick and Swift, 2011) with reasons clearly given for the sampling selection in section 3.2 in line with work by Draper and Swift (2010).

Throughout this research I have documented the rigorous approach that has been taken, to demonstrate the research’s validity and reliability. This included outlining a clear audit trail depicting the decisions that were taken throughout the research process, which included the challenges and dilemmas. In chapter 3.10, I discuss reflexivity and the process of self-reflection that I undertook. This section considers my positioning, past personal experiences, beliefs, biases and my own personal intentions in relation to the study.

The eligibility criteria required to partake in the study may also bring about limitations of the study. For example, to mitigate potential risk, all participants of phase 2 were care dyads who resided together, this part of the study therefore could not investigate issues or lived experiences that may be specific to people who reside alone. Additionally, care partners and individuals living with dementia were interviewed together, this resulted in the input to discussions not always being equal. At times during phase 2, care partners would speak on behalf of the person living with dementia, and whilst efforts were taken to direct lines of questioning solely at the person living with dementia, care partners often dominated discussions. Due to limited funds available, the eligibility criteria also stated that potential participants would require a smart phone device capable of running the ‘Trackisafe’ app, along with sufficient Wi-Fi or Mobile data connectivity to operate the app. Effects of the digital divide, discussed throughout this thesis, meant that potential participants may have been excluded from this study due to lack of access, this is a further limitation of the study.

An additional limitation of this study considers the duration of use of devices by participants of phase 2. This study has advocated for more longitudinal research that considers how the role of the device may change over the course of a person’s dementia journey, exploring interactions of people living with dementia and their care partners with GPS technology through time. However, due to university time scales, delays of the project due to COVID-19 and the time intensive nature of data analysis, 3 months (with an additional month acting as a familiarisation period) was the maximum duration that could be given. Whilst this period allowed for findings to be established, it is believed that conducting this research over a longer period may have generated greater insights into the lived experience of participants with regards to the impact of GPS.

Whilst section 7.2 documents the lessons that can be shared from this research, in terms of how to conduct research and support participants in times of crisis, the outbreak of the recent pandemic resulted in changes to the research design that may amount to limitations. For example, face-to-face training was viewed from the outset as essential, and whilst this study adapted to difficult circumstances, face-to-face training could not be achieved. This may have impacted the use of the technology in this study and whilst significant findings were still established as a result of this, alternative findings in relation to the use of GPS may have been lost.

7.3.2 Strengths

A major strength of this study was the decision to involve individuals living with dementia throughout the research process, with the views and opinions of the ‘experts through experience’ shaping the main research study. Through gathering these views and opinions and seeking to understand the lived experiences of people living with dementia, this project was able to be shaped around their needs and expectations of technology. The two phases of this research complimented each other, taking place in different settings and using participants who had differing knowledge of the research process and a variety of technical experience.

A further strength of the study lies in the custom-built online learning tool and means for remote technical assistance, developed to aid and support participants throughout the study. Online technical support was provided on demand to participants, with their queries or concerns responded to over the live chat feature of website or via phone and email. It is believed that this hands-on approach to support participants throughout the research process strengthened the study and reduced the likelihood of attrition. Throughout both phases I had gained an effective rapport with participants, and created a trusting relationship, whereby participants could freely disclose their lived experiences, concerns and worries.

Furthermore, the geographical scope of recruitment to this study can also be viewed as a major strength of the design of this research. Whilst this project initially sought to be based locally around Greater Manchester and Cheshire due to requirements of face-to-face participant recruitment and training, changes enforced due to the COVID-19 pandemic meant this was not possible. The study was extended to participants across the United Kingdom. This resulted in a diversified recruitment approach, with participants joining from across the country, enabling a greater variation of lived experiences and insights into living with dementia, findings can therefore translate nationally rather than regionally.

The dissemination of this research is underway, this is illustrated in the journal publication of the systematic review of the literature undertaken for this thesis. In addition to this, the methodology and findings from this study have been presented at regional conferences with more opportunities to present this research being explored.

A major strength of this study lies in how the research was approached. My background as a researcher plays an important role in this. Having come from a field of computer science and management studies, I took the decision to attempt to apply my knowledge and conduct this study in the field of dementia research. Motivations also come from person experiences of dementia and my own belief in the role technology has in helping people living with the condition. I feel the resulting thesis is a fusion between multiple disciplines and is therefore unique in its approach taken.

7.4 Concluding remarks

Conducting this research and the writing of this thesis has been an insightful journey of discovery and personal development. I began this research three years ago and could not have foreseen how the world would change through a global pandemic. For people living with dementia and their care partners, COVID-19 presented unparalleled challenges, and in some ways, I have felt privileged to have been able to help them regain some freedom and independence as restrictions began to lift. In exploring the experiences of using off-the-shelf GPS devices for people living with dementia and their care partners, I have been able to highlight the positive affects which this technology makes to people's lives. It is important to me that the finding of this work have some impact on reducing disparity and offering a viable alternative to those unable to buy the devices targeted at the ‘dementia market’. The other issue which has become pivotal to my study, is the need to include people with first-hand experience of dementia, to involve them in the co-design and evaluation of technology. The input and openness of the participants in this study has been incredible, and I have found the experience extremely rewarding, albeit at times, humbling. Whilst this Doctoral study undoubtedly adds to the body of knowledge, I genuinely hope that it makes a difference to people's lives.

REFERENCES

REFERENCES

Abbas, R., Michael, K., Michael, M. G., and Aloudat, A. (2011). Emerging forms of covert surveillance using GPS-enabled devices. Journal of Cases on Information Technology (JCIT), 13(2), 19-33.

Abbott, S. and Fisk, M. (1997). Independence and involvement: older people speaking. St Albans, UK: Abbeyfield Society

Age UK. (2020). 'Poverty in later life briefing 2019. Retrieved from: https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/money-matters/poverty_in_later_life_briefing_2019.pdf [Accessed on 10th March 2021]

Ahern, K. J. (1999). Ten tips for reflexive bracketing. Qualitative health research, 9(3), 407-411.

Algase, D. L., Moore, D. H., Vandeweerd, C., and Gavin-Dreschnack, D. J. (2007). Mapping the maze of terms and definitions in dementia-related wandering. Aging & Mental Health, 11(6), 686–698. doi:10.1080/13607860701366434

Ali, M. U., Hur, S., Park, S., and Park, Y. (2019). Harvesting indoor positioning accuracy by exploring multiple features from received signal strength vector. IEEE Access, 7, pp.52110-52121.

All-Party Parliamentary Group [APPG]. (2019). Hidden no more: Dementia and disability. Retrieved from: https://www.alzheimers.org.uk/sites/default/files/2019-06/APPG_on_Dementia_2019_report_Hidden_no_more_dementia_and_disability_media.pdf [Accessed on 10th June 2020]

Alvseike, H. and Brønnick, K. (2012). Feasibility of the iPad as a hub for smart house technology in the elderly; effects of cognition, self-efficacy, and technology experience. Journal of multidisciplinary healthcare, 5, p.299.

Alzheimer's Disease International [ADI]. (2020). COVID-19 deaths disproportionately affecting people with dementia. Retrieved from https://www.alzint.org/news-events/news/covid-19-deaths-disproportionately-affecting-people-with-dementia/ [Accessed 10th January 2022]

Alzheimer's Disease International [ADI]. (2021). World Alzheimer Report 2021 Journey through the diagnosis of dementia. Retrieved from https://www.alzint.org/u/World-Alzheimer-Report-2021.pdf [Accessed 10th January 2022]

Alzheimer's Society. (2012). Challenges facing primary carers of people with dementia. Retrieved from: https://www.alzheimers.org.uk/sites/default/files/2018-05/Challenges_facing_primary_carers.pdf [Accessed on 6th January 2022]

Alzheimer's Society. (2014). Dementia UK: Update - Second edition; 2014. [https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf [Accessed on 7th March 2020]

Alzheimer's Society. (2016). Factsheet – Risk factors for dementia. Retrieved from: https://www.alzheimers.org.uk/sites/default/files/pdf/factsheet_risk_factors_for_dementia.pdf [Accessed on 8th March 2019]

Alzheimer's Society. (2019a). Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040; 2019. https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf [Accessed on 19th June 2020].

Alzheimer's Society. (2019b). Sports Leisure Guide. Retrieved from: https://www.alzheimers.org.uk/sites/default/files/2019-02/19003-Sports_Leisure_guide_online.pdf [Accessed on 14th October 2020].

Alzheimer's Society. (2020a). The impact of COVID-19 on People Affected by Dementia . Retrieved from: https://www.alzheimers.org.uk/sites/default/files/2020-08/The_Impact_of_COVID-19_on_People_Affected_By_Dementia.pdf [Accessed on 10th January 2022]

Alzheimer's Society. (2020b). Fix Dementia Care: Funding. Retrieved from: https://www.alzheimers.org.uk/get-involved/campaigns/fix-dementia-care-funding [Accessed on 24th October 2020]

Alzheimer's Society. (2020c). Person Centred Care. Retrieved from: https://www.alzheimers.org.uk/about-dementia/treatments/person-centred-care [Accessed on 26th January 2021]

Alzheimer's Society. (2020d). How dementia progresses. Retrieved from: https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses [Accessed on 6th March 2021]

Alzheimer's Society. (2020e). Assistive Technology. Retrieved from: https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/assistive-technology [Accessed on 3rd April 2021]

Alzheimer's Society. (2021). Co-production for dementia. Retrieved from: https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods/co-production [Accessed on 23rd March 2021]

Alzheimer's Society. (2022a). Mapping the Dementia Diagnosis Journey to Improve Self-Guided Support. Retrieved from: https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/real-life-examples/developing-new-services/mapping-diagnosis-journey [Accessed on 14th January 2022]

Alzheimer's Society. (2022b). Find support near you. Retrieved from: https://www.alzheimers.org.uk/find-support-near-you [Accessed on 14th January 2022]

Amazon.co.uk (2021). Vodafone V-Multi Tracker, a Multi-Use Lightweight GPS Tracker, with Bluetooth. Retrieved from: https://www.amazon.co.uk/dp/B07MV16RK4/ [Accessed on 4th April 2021]

Amazon.co.uk (2022). GSM GPRS Mini GPS Tracker Locator Pendant with Google Maps SOS Alarm Real time Tracking Device Red. Retrieved from: https://www.amazon.co.uk/dp/B07H91WZH4 [Accessed on 25th January 2022]

Ananda, M. P., Bernstein, H., Cunningham, K. E., Feess, W. A., and Stroud, E. G. (1990). Global positioning system (GPS) autonomous navigation. In IEEE Symposium on Position Location and Navigation. A Decade of Excellence in the Navigation Sciences (pp. 497-508). IEEE.

André, C., and C. García, C. (2014). "Local Public Finances and Municipal Reform in Finland", OECD Economics Department Working Papers, No. 1121, OECD Publishing, Paris,

Apte, A., Ingole, V., Lele, P., Marsh, A., Bhattacharjee, T., Hirve, S., Campbell, H., Nair, H., Chan, S., and Juvekar, S. (2019). Ethical considerations in the use of GPS-based movement tracking in health research - lessons from a care-seeking study in rural west India. J Glob Health. 2019 Jun;9(1):010323. doi: 10.7189/jogh.09.010323.

Armstrong, N., Nugent, C., Moore, G., and Finlay, D. (2010). Using smartphones to address the needs of persons with Alzheimer's disease. annals of telecommunications-annales des télé communications, 65(9), 485-495.

Astell, A. (2006). Technology and personhood in dementia care. Quality in Ageing and Older Adults.

Auti, S. S., and Hulle, N. B. (2015). Advanced shoes with embedded position tracking and path guidance to keep track of Alzheimer's patients. International Journal of Scientific and Research Publications. 2015;5(1)

Ball, C., Francis, J., Huang, K.-T., Kadylak, T., Cotten, S. R., and Rikard, R. V. (2017). The Physical–Digital Divide: Exploring the Social Gap Between Digital Natives and Physical Natives. Journal of Applied Gerontology

Ball, M. M., Perkins, M. M., Whittington, F. J., Connell, B. C., Hollingsworth, C., King, S. V., and Combs, B. L. (2004). Managing decline in assisted living: The key to aging in place. Journals of Gerontology, Series B: Psychological and Social Sciences. 2004;59:202– 212. DOI:10.1093/geronb/59.4.S202

Bantry-White E, and Montgomery P. (2014). Electronic tracking for people with dementia: an exploratory study of the ethical issues experienced by carers in making decisions about usage. Dementia; 2014; 13(2):216-232. DOI: 10.1177/1471301212460445

Bantry-White, E., Montgomery, P., and McShane, R. (2010). Electronic tracking for people with dementia who get lost outside the home: a study of the experience of familial carers. British Journal of Occupational Therapy. 2010;73(4):152-159.

Bartlett, R. and Brannelly, T. (2019). On being outdoors: How people with dementia experience and deal with vulnerabilities. Social Science & Medicine. 2019. DOI:10.1016/j.socscimed.2019.05.041

Bartlett, R., and O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. Journal of Aging Studies, 21(2), 107-118.

Bartlett, R., and O'Connor, D. (2010). Broadening the dementia debate: Towards social citizenship. Policy press.

Bartlett, R., Brannelly, T., and Topo, P. (2019). Using gps technologies with people with dementia: a synthesising review and recommendations for future practice. Tidsskrift for omsorgsforskning, 5(3), 84-98

Beal, G. M, and Bohlen, J. M. (1957). "The Diffusion Process". Special Report No. 18. 1: 56–77.

Bennett, B., McDonald, F., Beattie, E., Carney, T., Freckelton, I., White, B., and Willmott, L. (2017). Assistive technologies for people with dementia: ethical considerations. Bulletin of the World Health Organization, 95(11), 749.

Berger, J. T., DeRenzo, E. G., and Schwartz, J. (2008). Surrogate decision-making: Reconciling ethical theory and clinical practice. Annals of Internal Medicine, 149(1), 48–53.

Berger, P. L., and Luckmann, T. (1966). The social construction of reality.

Berkowsky, R. W., Sharit, J., and Czaja, S. J. (2017). Factors predicting decisions about technology adoption among older adults. Innovation in aging, 1(3),

Bernard, H. R. (2017). Research methods in anthropology: Qualitative and quantitative approaches. Rowman & Littlefield.

Berry, R. (2011). Older people and the internet. UK: International Longevity Centre.

Bethell, J., Commisso, E., Rostad, H.M., Puts, M., Babineau, J., Grinbergs-Saull, A., Wighton, M.B., Hammel, J., Doyle, E., Nadeau, S., and McGilton, K.S. (2018). Patient engagement in research related to dementia: A scoping review. Dementia 17(8): 944–975.

Bharucha, A. J., Anand, V., Forlizzi, J., Dew, M. A., Reynolds III, C. F., Stevens, S., and Wactlar, H. (2009). Intelligent assistive technology applications to dementia care: current capabilities, limitations, and future challenges. The American journal of geriatric psychiatry, 17(2), 88-104.

Blaikie, N. (1993). Approaches to Social Enquiry. Polity Press, Cambridge MA.

Blaikie, N., and Priest, J. (2017). Social Research: Paradigms in Action. Polity Press.

Boot, F. H., Owuor, J., Dinsmore, J., and MacLachlan, M. (2018). Access to assistive technology for people with intellectual disabilities: a systematic review to identify barriers and facilitators. Journal of Intellectual Disability Research, 62: 900– 921. https://doi.org/10.1111/jir.12532.

Borg, J., Lindström, A., and Larsson, S. (2009). Assistive technology in developing countries: national and international responsibilities to implement the Convention on the Rights of Persons with Disabilities, The Lancet, 374(9704), pp. 1863-1865

Bowes, A., Dawson, A., and Greasley-Adams, C. (2013). Literature review: the cost effectiveness of assistive technology in supporting people with dementia. The Atlantic Philanthropies. Dementia Services Development Centre, University of Stirling. Retrieved from http://hdl.handle.net/1893/18500 [Accessed on 4th August 2019]

Bowker, R., Calvert, L., Allcroft, F., Bowker, G., Foy, P., Gandy, J., Jones, S., Bushell, S., Clark, A. and Innes, A. (2020). ‘Our voice started off as a whisper and now it is a great big roar’: The Salford Dementia Associate Panel as a model of involvement in research activities. Dementia, 19(1), pp.18-26.

Brannelly, T., and Bartlett, R. (2020). Using Walking Interviews to Enhance Research Relations with People with Dementia: Methodological Insights From an Empirical Study Conducted in England. Ethics and Social Welfare, 14(4), 432-442.

Braun, V., and Clarke, V. (2006). Using thematic analysis in psychology. Qualitative research in psychology, 3(2), 77-101.

Brittain, K., Corner, L., Robinson, L., and Bond, J. (2010). Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments. Sociology of Health & Illness, 32: 272-287. doi:10.1111/j.1467-9566.2009.01203.x

Bronswijk, J. E., Bouma, H., Fozard, J. L., Kearns, W. D., Davison, G. C., and Tuan, P. C. (2009). Defining gerontechnology for R&D purposes. Gerontechnology, 8(1), 3.

Brooker, D. (2004). What is person-centred care in dementia? Reviews in Clinical Gerontology 13, 215–222.

Brooks, E., Manson, S. M., Bair, B., Dailey, N., and Shore, J. H. (2012). The diffusion of telehealth in rural American Indian communities: a retrospective survey of key stakeholders. Telemedicine and e-Health, 18(1), 60-66.

Brooks, J., Savitch, N., and Gridley, K. (2017). Removing the 'gag': Involving people with dementia in research as advisers and participants. Social Research Practice, 3-14.

Cahill, S. (2003). Technologies may be enabling. British Medical Journal, 326

Canevelli, M., Valletta, M., Toccaceli Blasi, M., Remoli, G., Sarti, G., Nuti, F., Sciancalepore, F., Ruberti, E., Cesari, M., and Bruno, G. (2020). Facing Dementia During the COVID-19 Outbreak. Journal of the American Geriatrics Society, 68(8), 1673–1676.

Carroll, J. M. (2008). Community IT workshops as a strategy for community learning. First Monday.

CASP UK (2018). CASP tools checklist. 2018. Retrieved from: https://casp-uk.net/casp-tools-checklists/ [Accessed on 28th June 2020].

Charness, N., and Boot, W. R. (2009). Aging and Information Technology Use. Current Directions in Psychological Science, 18(5), 253–258. doi:10.1111/j.1467-8721.2009.01647.x

Chen, Y. C., and Leung, C. Y. (2012). Exploring functions of the lost seeking devices for people with dementia. Work. 2012;41(1):3093-3100.

Cho, S., Mathiassen, L., and Gallivan, M. (2008). Crossing the chasm: From adoption to diffusion of a telehealth innovation. In IFIP Working Conference on Open IT-Based Innovation: Moving Towards Cooperative IT Transfer and Knowledge Diffusion (pp. 361-378). Springer, Boston, MA.

Clark, M. S., and Bond, M. J. (2000). The effect on lifestyle activities of caring for a person with dementia. Psychology, Health & Medicine, 5(1), 13-27.

Clarke, C. L., and Keady, J. (2002). Getting down the brass tacks: A discussion of data collection with people with dementia. In H. Wilkinson (Ed.), The perspectives of people with dementia: Research methods and motivations (pp. 25–46). London: Jessica Kingsley

Clarke, C. L., Wilkinson, H., Watson, J., Wilcockson, J., Kinnaird, L., and Williamson, T. (2018). A seat around the table: participatory data analysis with people living with dementia. Qualitative Health Research, 28(9), 1421-1433.

Contreras, M. L., Mioshi, E., and Kishita, N. (2021). Factors related to the quality of life in family carers of people with dementia: A meta-analysis. Journal of Geriatric Psychiatry and Neurology, 34(5), 482-500.

Cook, L., Mukherjee, S., McLachlan, T., Shah, R., Livingston, G., and Mukadam, N. (2019). Parity of access to memory services in London for the BAME population: a cross-sectional study. Aging & mental health, 23(6), 693-697.

Cooper, C., Mansour, H., Carter, C., Rapaport, P., Morgan-Trimmer, S., Marchant, N.L., Poppe, M., Higgs, P., Brierley, J., Solomon, N. and Budgett, J., (2021). Social connectedness and dementia prevention: Pilot of the APPLE-Tree video-call intervention during the Covid-19 pandemic. *Dementia*, p.14713012211014382.

Cotten, S. R., McCullough, B., and Adams, R. (2011). Technological influences on social ties across the lifespan. Handbook of lifespan psychology, 647-671.

Cowan, D. and Turner-Smith, A. (1999). The role of assistive technology in alternative models of care for older people. In Royal Commission on Long Term Care, 2, Stationery Office: London, 325–46. Retrieved from http://citeseerx.ist.psu.edu/viewdoc/summary?doi=10.1.1.123.1879 [Accessed on 22nd July 2020]

Cridland, E. K., Phillipson, L., Brennan-Horley, C., and Swaffer, K. (2016). Reflections and Recommendations for Conducting In-Depth Interviews With People With Dementia. Qualitative Health Research, 26(13), 1774–1786. doi:10.1177/1049732316637065

Crotty, M. J. (1998). The Foundations of Social Research: Meaning and Perspective in the Research Process.

Croucher, K., Hicks, L., Bevan, M., and Serson, D. (2007). Comparative evaluation of models of housing with care for later life. 2007. Retrieved from: http://eprints.whiterose.ac.uk/73186/ [Accessed on 1st July 2020]

Czaja, S. J., Loewenstein, D., Schulz, R., Nair, S. N., and Perdomo, D. (2013). A videophone psychosocial intervention for dementia caregivers. The American Journal of Geriatric Psychiatry, 21(11), 1071-1081.

Dahl, Y., and Holbø, K. (2012). "There are no secrets here!": professional stakeholders' views on the use of GPS for tracking dementia patients. In Proceedings of the 14th international conference on Human-computer interaction with mobile devices and services. 2012:133-142. DOI:10.1145/2371574.2371595.

Dahlke, D. V. and Ory, M. G. (2020). Emerging Issues of Intelligent Assistive Technology Use Among People With Dementia and Their Caregivers: A U.S. Perspective. Retrieved from: https://www.frontiersin.org/articles/10.3389/fpubh.2020.00191/full [Accessed on 10th September 2020]

Dale, Ø. (2010). Usability and usefulness of GPS based localization technology used in dementia care. In International conference on computers for handicapped persons. Springer, Berlin, Heidelberg. 2010:300-307.

Dawe, M. (2006). Desperately seeking simplicity: how young adults with cognitive disabilities and their families adopt assistive technologies. In Proceedings of the SIGCHI conference on Human Factors in computing systems (pp. 1143-1152).

de Witte, L., Steel, E., Gupta, S., Ramos, V. D., and Roentgen, U. (2018). Assistive technology provision: towards an international framework for assuring availability and accessibility of affordable high-quality assistive technology. Disability and Rehabilitation: Assistive Technology, 13(5), 467-472.

Delello, J. A., and McWhorter, R. R. (2016). Reducing the Digital Divide. Journal of Applied Gerontology, 36(1), 3–28. doi:10.1177/0733464815589985

Dementia UK. (2019). What is dementia? Retrieved from: https://www.dementiauk.org/about-dementia/dementia-information/what-is-dementia/#:~:text=Dementia%20is%20an%20umbrella%20term,to%20remember%2C%20think%20and%20speak. [Accessed 30th March 2020]

DementiaVoices.org.uk (2021). About DEEP. Retrieved from: https://www.dementiavoices.org.uk/about-deep/ [Accessed on 3rd October 2021]

Department of Health [DoH]. (2009). Policy paper - Living Well With Dementia: a national dementia strategy. Retrieved from: https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy [Accessed on 6th March 2019]

Department of Health [DoH]. (2014). Wellbeing - Why it matters to health policy. Retrieved from:https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/277566/Narrative__January_2014_.pdf [Accessed on 18th April 2020]

Department of Health [DoH]. (2016). Prime Minister's challenge on dementia 2020: Implementation plan. London: Department of Health. Retrieved from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf [Accessed on 18th April 2020]

Department of Health [DoH]. (2018). Dementia 2020 Challenge: 2018 Review Phase 1. Retrieved from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/780777/dementia-2020-challenge-2018-review.pdf [Accessed on 18th April 2020]

Dewing, J. (2007). Participatory research: a method for process consent with persons who have dementia. Dementia, 6(1), 11-25.

Dobson, J. E., and Fisher, P. F. (2003). Geoslavery. IEEE Technology and Society Magazine, 22(1), 47-52.

Dolan, R. J., and Matthews, J. (1993). Maximizing the Utility of Customer Product Testing: Beta Test Design and Management. Journal of Product Innovation Management 10, no. 4: 318–330

Doughty, K. and Dunk, B. (2009). "Safe walking technologies for people with mild to moderate cognitive impairments", Journal of Assistive Technologies, Vol. 3 No. 2, pp. 54-59. https://doi.org/10.1108/17549450200900016

Downs, M. (2013). ‘Putting people – and compassion – first: the UK’s approach to person- centred care for individuals with dementia’, Generations, Journal of the American Society on Ageing, 37(3) 53-59.

Downs, M. (2015). Person-centred care in the community. Retrieved from: https://www.genio.ie/system/files/publications/GENIO_Person_centred_care_community.pdf [Accessed on 20th September 2020]

Draper, A., and Swift, J. A. (2011). Qualitative research in nutrition and dietetics: Data collection issues. *Journal of human nutrition and dietetics*, *24*(1), 3-12.

Du Bois, B. (1983). Passionate scholarship: notes on values, knowing and method in feminist social science. In G. Bowles and R. D. Klein (eds) Theories of Women’s Studies. London: Routledge.

Dunk, B., Longman, B., and Newton, L. (2010). GPS technologies in managing the risks associated with safer walking in people with dementia – A practical perspective. Journal of Assistive Technologies. 4. 4-8.

Dupuis, S. L., Whyte, C., Carson, J., Genoe, R., Meshino, L., and Sadler, L. (2012). Just dance with me: An authentic partnership approach to understanding leisure in the dementia context. World Leisure Journal, 54(3), 240-254.

Ellen, P. S., Bearden, W. O., and Sharma, S. (1991). Resistance to technological innovations: an examination of the role of self-efficacy and performance satisfaction. Journal of the academy of marketing science, 19(4), 297-307.

Elliott, B. A., Gessert, C. E., and Peden-McAlpine, C. (2009). Family decision making in advanced dementia: Narrative and ethics. Scandinavian Journal of Caring Sciences, 23(2), 251–258.

England, K. V. L. (1994). Getting Personal: Reflexivity, Positionality, and Feminist Research∗. The Professional Geographer, 46(1), 80–89. doi:10.1111/j.0033-0124.1994.00080.x

Ertz, M., Leblanc-Proulx, S., Sarigöllü, E., and Morin, V. (2019). Made to break? A taxonomy of business models on product lifetime extension. Journal of Cleaner Production, 234, 867-880.

Essen, A. (2008). The two facets of electronic care surveillance: An exploration of the views of older people who live with monitoring devices. Social Science & Medicine, 67, 128–136.

European Union. (2010). ICT & Ageing – Final Report. Retrieved from http://ec.europa.eu/information_society/newsroom/cf/dae/document.cfm?doc_id=952 [Accessed 10th June 2020]

Faucounau, V., Riguet, M., Orvoen, G., Lacombe, A., Rialle, V., Extra, J., and Rigaud, A. S. (2009). Electronic tracking system and wandering in Alzheimer's disease: a case study. Annals of physical and rehabilitation medicine. 2009;52(7-8):579-87. DOI: 10.1016/j.rehab.2009.07.034

Featherstone, K., and Northcott, A. (2020). Wandering the Wards: An Ethnography of Hospital Care and its Consequences for People Living with Dementia. Taylor and Francis

Feng, Z., Guan, N., Lv, M., Liu, W., Deng, Q., Liu, X., and Yi, W. (2017). Efficient drone hijacking detection using onboard motion sensors. In Design, Automation & Test in Europe Conference & Exhibition pp. 1414-1419. IEEE.

Fetherstonhaugh, D., Tarzia, L., and Nay, R. (2013). Being central to decision making means I am still here! The essence of decision making for people with dementia. Journal of Aging Studies. 27:143–50.

Finch, H. and Lewis, J. (2003). ‘Focus Groups’, in Ritchie, J. and Lewis, J. (eds) Qualitative Research Practice. London: SAGE Publications, pp. 170– 198. Retrieved from: https://mthoyibi.files.wordpress.com/2011/10/qualitative-research-practice_a-guide-for-social-science-students-and-researchers_jane-ritchie-and-jane-lewis-eds_20031.pdf [Accessed 30th March 2020]

Fischer, B., Peine, A., and Östlund, B. (2020). The importance of user involvement: a systematic review of involving older users in technology design. The Gerontologist, 60(7), e513-e523.

Francis, J., Ball, C., Kadylak, T., and Cotten, S. R. (2019). Aging in the Digital Age: Conceptualizing Technology Adoption and Digital Inequalities. Ageing and Digital Technology, 35–49. doi:10.1007/978-981-13-3693-5_3

Frennert, S. A., Forsberg, A., and Östlund, B. (2013). Elderly people's perceptions of a telehealthcare system: Relative advantage, compatibility, complexity and observability. Journal of Technology in Human Services, 31(3), 218-237.

Frost, R., Walters, K., Wilcock, J., Robinson, L., Dening, K.H., Knapp, M., Allan, L. and Rait, G. (2020). Mapping post-diagnostic dementia care in England: an e-survey. Journal of Integrated Care.

Fuller, D., Shareck, M., and Stanley, K. (2017). Ethical implications of location and accelerometer measurement in health research studies with mobile sensing devices. Social Science & Medicine, 191, 84-88.

Gelman, S. A., Martinez, M., Davidson, N. S., and Noles, N. S. (2018). Developing digital privacy: Children's moral judgments concerning mobile GPS devices. Child development, 89(1), 17-26.

Genoe, M. R., and Dupuis, S. L. (2012). The role of leisure within the dementia context. Dementia, doi: 10.1177/1471301212447028

Gibbs, A. (1997). Focus groups. Social research update, 19(8), 1-8.

Gibson, G., Dickinson, C., Brittain, K., and Robinson, L. (2015). The everyday use of assistive technology by people with dementia and their family carers: a qualitative study. BMC geriatrics. Dec;15(1):1-0.

Giebel, C., Lord, K., Cooper, C., Shenton, J., Cannon, J., Pulford, D., Shaw, L., Gaughan, A., Tetlow, H., Butchard, S. and Limbert, S., (2021). A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers. International journal of geriatric psychiatry, 36(3), pp.393-402.

Glasser, D. J., Goodman, K. W. and Einspruch, N.G. (2007). Chips, tags and scanners: Ethical challenges for radio frequency identification. Ethics Information and Technology 9: 101. https://doi.org/10.1007/s10676-006-9124-0

Gonyea, J. G., O'Connor, M., Carruth, A., and Boyle, P. A. (2005). Subjective appraisal of Alzheimer's disease caregiving: The role of self-efficacy and depressive symptoms in the experience of burden. American Journal of Alzheimer's Disease & Other Dementias®, 20(5), 273-280.

Goodman-Casanova, J. M., Dura-Perez, E., Guzman-Parra, J., Cuesta-Vargas, A., and Mayoral-Cleries, F. (2020). Telehealth Home Support During COVID-19 Confinement for Community-Dwelling Older Adults With Mild Cognitive Impairment or Mild Dementia: Survey Study. Journal of medical Internet research, 22(5), e19434.

GPS.gov (2017). 'How accurate is GPS?' Retrieved from https://www.gps.gov/systems/gps/performance/accuracy/ [Accessed 2nd August 2019]

GPS.gov (2020). GPS: The Global Positioning System; 2020. [Accessed 2020 Feb 26]. https://www.gps.gov/

Gurley, K., and Norcio, A. F. (2009). A Systematic Review of Technologies Designed to Improve and Assist Cognitive Decline for Both the Current and Future Aging Populations. Internationalization, Design and Global Development. N. Aykin, ed. Springer Berlin Heidelberg. 156–163. Retrieved from https://link.springer.com/chapter/10.1007/978-3-642-02767-3_17

Hammersley, M. (2013). What is Qualitative Research? Bloomsbury Academic. DOI: 10.5040/9781849666084

Hersh, M. A., and Johnson, M. A. (2010). A robotic guide for blind people. Part 1. A multi-national survey of the attitudes, requirements and preferences of potential end-users. Applied Bionics and Biomechanics, 7(4), 277-288.

Hettinga, M., De Boer, J., Goldberg, E., and Moelaert, F. (2009). Navigation for people with mild dementia. InMIE. 2009:428-432.

Higgs, P., and Gilleard, C. (2016). Interrogating personhood and dementia, Aging & Mental Health, 20:8, 773-780, DOI: 10.1080/13607863.2015.1118012

Hillcoat-Nalletamby S. (2014). The Meaning of "Independence" for Older People in Different Residential Settings. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences. 2014,69(3):419–430. DOI:10.1093/geronb/gbu008

Holbø, K., Bøthun, S., and Dahl, Y. (2013). Safe walking technology for people with dementia: What do they want? Proceedings of the 15th International ACM SIGACCESS Conference on Computers and Accessibility. Retrieved from https://www.researchgate.net/publication/262310380_Safe_walking_technology_for_people_with_dementia_What_do_they_want [Accessed on 27th May 2019]

Holthe, T., Halvorsrud, L., Thorstensen, E., Karterud, D., Rudman, D. L., and Lund, A. (2020). Community health care workers' experiences on enacting policy on technology with citizens with mild cognitive impairment and dementia. Journal of Multidisciplinary Healthcare, 13, 447.

Holzinger, A., Searle, G., and Wernbacher, M. (2011). The effect of previous exposure to technology on acceptance and its importance in usability and accessibility engineering. Universal Access in the Information Society, 10(3), 245-260.

Huawei. (2019). ‘Huawei Band 2 / Huawei Band 2 Pro’. Retrieved from https://consumer.huawei.com/en/wearables/band2/ [Accessed 20th July 2019]

Hughes, J. C., Newby, J., Louw, S. J., Campbell, G., and Hutton, J. L. (2008). Ethical issues and tagging in dementia: a survey. Journal of Ethics in Mental Health.

Hunsaker, A., and Hargittai, E. (2018). A review of Internet use among older adults. New Media & Society, 20(10), 3937–3954. https://doi.org/10.1177/1461444818787348

Ienca, M., Fabrice, J., Elger, B., Caon, M., Pappagallo, A. S., Kressig, R. W., and Wangmo, T. (2017). Intelligent Assistive Technology for Alzheimer’s Disease and Other Dementias: A Systematic Review. Journal of Alzheimer’s Disease, 56(4), 1301–1340. doi:10.3233/jad-161037

Independent Age. (2016). The overlooked over-75s: Poverty among the ‘Silent Generation’ who lived through the Second World War. Retrieved from: https://www.independentage.org/sites/default/files/2016-05/pensioner-poverty-report_final_website.pdf [Accessed 10th February 2020]

Innes, A. (2009). Dementia studies: A social science perspective. Sage.

Innes, A., Chesterton, L., Morris, L., Smith, S. K., and Bushell, S. (2021). Perspectives of people living with dementia and their care partners about the impact on social health when participating in a co-designed Dementia café. Health & Social Care in the Community.

Innes, A., Smith, S. K., Wyatt, M., and Bushell, S. (2021). “It is just so important that people's voices are heard”: The dementia associate panel. Journal of Aging Studies, 59, 100958.

Innes, A., Szymczynska, P., and Stark, C. (2014). Dementia diagnosis and post-diagnostic support in Scottish rural communities: Experiences of people with dementia and their families. Dementia, 13(2), 233–247. https://doi.org/10.1177/1471301212460608

International Organization for Standardization. (2018). ‘Ergonomics of human-system interaction — Part 11: Usability: Definitions and concepts’. Retrieved from https://www.iso.org/obp/ui/#iso:std:iso:9241:-11:ed-2:v1:en [Accessed on 22nd December 2021]

Johannessen, T. B., Storm, M., and Holm, A. L. (2019). Safety for older adults using telecare: Perceptions of homecare professionals. Nursing open. 6(3):1254-61.

Kacen, L., and Chaitin, J. (2006). “The Times They are a Changing” 1 : Undertaking Qualitative Research in Ambiguous, Conflictual, and Changing Contexts . The Qualitative Report, 11(2), 209-228. Retrieved from https://nsuworks.nova.edu/tqr/vol11/iss2/1 [Accessed on 10th March 2020]

Karantzoulis, S., and Galvin, J. E. (2011). Distinguishing Alzheimer’s disease from other major forms of dementia. Expert review of neurotherapeutics, 11(11), 1579-1591.

Keady, J. D. (1999). The dynamics of dementia: A modified grounded theory study. Bangor University: United Kingdom.

Kearns, W. D., Rosenberg, D., West, L., and Applegarth, S. (2007). Attitudes and expectations of technologies to manage wandering behavior in persons with dementia. Gerontechnology, 6(2), 89.

Kelly, F. (2010). Recognising and supporting self in dementia: A new way to facilitate a person-centred approach to dementia care. Ageing and Society, 30(1), 103-124. doi:10.1017/S0144686X09008708

King's Fund. (2001). Consultation Meeting on Assistive Technology, London, King's Fund.

Kintsch, A., and DePaula, R. D. (2005). A framework for the adoption of assistive technology. Centre for Lifelong Learning and Design, University of Colorado

Kitwood, T. M. (1997). Dementia reconsidered: The person comes first (Vol. 20, pp. 7-8). Buckingham: Open university press.

Kitzinger, J. (1995). Qualitative research: introducing focus groups. BMJ, 311(7000), 299-302.

Kolakowski, J., Djaja-Josko, V., Kolakowski, M. and Broczek, K. (2020). UWB/BLE Tracking System for Elderly People Monitoring. *Sensors*, 20, 1574.

Kramer, B. (2014). Dementia caregivers in Germany and their acceptance of new technologies for care: the information gap. Public Policy & Aging Report, 24(1), 32-34.

Krothe, J. S. (1997). Giving voice to elderly people: Community-based long-term care. Public Health Nursing. 1997;14(4):217-26.

Krueger, R. A. (1994). Focus groups: A practical guide for applied research (2nd ed.). Thousand Oaks, CA: Sage Publications.

Kuźma, E., Lourida, I., Moore, S. F., Levine, D. A., Ukoumunne, O. C., and Llewellyn, D. J. (2018). Stroke and dementia risk: a systematic review and meta-analysis. Alzheimer's & Dementia, 14(11), 1416-1426.

Lancioni, G. E. (2018). Assistive technology programs to support persons with neurodevelopmental disorders.

Landau, R., and Werner, S. (2012). Ethical aspects of using GPS for tracking people with dementia: Recommendations for practice. International Psychogeriatrics, 24(3), 358-366. doi:10.1017/S1041610211001888.

Landau, R., Auslander, G.K., Werner, S., Shoval, N., and Heinik, J. (2010). Families' and professional caregivers' views of using advanced technology to track people with dementia. Qualitative health research. 2010;20(3):409-19.

Landau, R., Werner, S., Auslander, G. K., Shoval, N., and Heinik, J. (2009). Attitudes of Family and Professional Care-Givers towards the Use of GPS for Tracking

Patients with Dementia: An Exploratory Study, The British Journal of Social Work, 39(4), pp. 670–692.

Langley, J., Wheeler, G., Partridge, R., Bec, R., Wolstenholme, D., and Sproson, L. (2020). Designing with and for older people. In Design of assistive technology for ageing populations (pp. 3-19). Springer, Cham.

Lee, J. (2017). Why Technology for Caregivers Fail: A Qualitative Study of GPS-Based Technology Supporting Alzheimer's Caregivers. 2017. Retrieved from: http://hdl.handle.net/11603/7796 [Accessed on 21st February 2020]

Lewis, F., Karlsberg-Schaffer, S., Sussex, J., O'Neill, P., and Cockcroft, L. (2014). Trajectory of Dementia in the UK – Making a Difference, report produced the Office of Health Economics for Alzheimer's Research UK; 2014. Retrieved from: https://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/OHE-report-Full.pdf [Accessed on 10th April 2020]

Li, Z., Pei, Q., Markwood, I., Liu, Y., Pan, M., and Li, H. (2018). Location Privacy Violation via GPS-Agnostic Smart Phone Car Tracking, IEEE Transactions on Vehicular Technology, 67(6), pp. 5042-5053

Lin, Q., Liu, H., and Wang, W. (2018). GPS Trajectories Based Personalized Safe Geofence for Elders with Dementia, IEEE SmartWorld, pp. 505-514. Retrieved from https://ieeexplore.ieee.org/abstract/document/8560089/ [Accessed on 6th March 2020]

Lin, Q., Zhang, D., Connelly, K., Ni, H., Yu, Z., and Zhou, X. (2015). Disorientation detection by mining GPS trajectories for cognitively-impaired elders. Pervasive and mobile computing. 2015;19:71-85.

Lin, Y. J., Chen, H. C., and Su, M. J. (2015). "A cloud based Bluetooth Low Energy tracking system for dementia patients," Eighth International Conference on Mobile Computing and Ubiquitous Networking (ICMU), Hakodate, pp. 88-89.

Lindqvist, E., Nygard, L., and Borell, L. (2013). Significant junctures on the way towards becoming a user of assistive technology in Alzheimer's disease. Scand J Occup Ther. 2013;20(5):386–96.

Litherland, R. (2019). Innovations in dementia. Retrieved from: www.innovationsindementia.org.uk/2019/03/i-want-to-speak-please/ [Accessed 10th January 2020]

Liu, L., Cruz, A. M., Ruptash, T., Barnard, S., and Juzwishin, D. (2017). Acceptance of Global Positioning System (GPS) Technology Among Dementia Clients and Family Caregivers, Journal of Technology in Human Services, 35:2, 99-119

Loopstra, R., McKee, M., Katikireddi, S. V., Taylor-Robinson, D., Barr, B., and Stuckler, D. (2016). Austerity and old-age mortality in England: a longitudinal cross-local area analysis, 2007–2013. Journal of the Royal Society of Medicine, 109(3), 109-116.

Lorenz, K., Freddolino, P. P., Comas-Herrera, A., Knapp, M., and Damant, J. (2017). Technology-based tools and services for people with dementia and carers: Mapping technology onto the dementia care pathway. Dementia, 18(2), 725–741. Retrieved from https://doi.org/10.1177/1471301217691617 [Accessed on 3rd July 2020]

Louis, K. S., and Barton, A. C. (2002). Tales from the science education crypt: A critical reflection of positionality, subjectivity, and reflexivity in research. In Forum Qualitative Sozialforschung/Forum: Qualitative Social Research, 3.3.

Lyon, D. (2001). Surveillance society: Monitoring everyday life. UK: McGraw-Hill Education.

Mack, R., Salmoni, A., Viverais-Dressler, G., Porter, E., and Garg, R. (1997). Perceived risks to independent living: The views of older, community-dwelling adults. The Gerontologist. 37(6):729-36.

Maher, F. A., and Tetreault, M. K. (1994). The feminist classroom: An inside look at how professors and students are transforming higher education for a diverse society. New York: Basic Books.

Mahoney, E. L., and Mahoney, D. F. (2010). Acceptance of wearable technology by people with Alzheimer’s disease: issues and accommodations. American Journal of Alzheimer's Disease & Other Dementias, 25(6), 527-531.

Mannheim, I., Schwartz, E., Xi, W., Buttigieg, S. C., McDonnell-Naughton, M., Wouters, E. J., and Van Zaalen, Y. (2019). Inclusion of older adults in the research and design of digital technology. International journal of environmental research and public health, 16(19), 3718.

Mao, H. F., Chang, L. H., Yao, G., Chen, W. Y., and Huang, W. N. (2015). Indicators of perceived useful dementia care assistive technology: caregivers' perspectives. Geriatrics & gerontology international. 15(8):1049-57.

Marr, J. (1989). Care of the elderly. Electronic tagging. Nursing Standard. Nov 22-28;4(9):54. doi: 10.7748/ns.4.9.54.s56.

Marshall, M. and Allen, K. (2006). Dementia : Walking not Wandering : Fresh Approaches to Understanding and Practice, Hawker, London.

Maslow, A. H. (1943). A theory of human motivation. Psychological Review, 50(4), 370–396. https://doi.org/10.1037/h0054346

McCabe, L., and Innes, A. (2013). Supporting safe walking for people with dementia: User participation in the development of new technology. Gerontechnology. 2013; 12(1):4-15.

McCabe, L., Dawson, A., Douglas, E., and Barry, N. (2021). Using Technology the Right Way to Support Social Connectedness for Older People in the Era of COVID-19. International Journal of Environmental Research and Public Health, 18(16), 8725.

McConnell, T., Sturm, T., Stevenson, M., McCorry, N., Donnelly, M., Taylor, B. J., and Best, P. (2019). Co-producing a shared understanding and definition of empowerment with people with dementia. Research Involvement and Engagement, 5(1), 1-11.

McCue, T. J. (2017). Elderly and Disabled Assistive Technology Market to Surpass $26 Billion By 2024. Forbes (Mar 21 2017). Retrieved from: https://www.forbes.com/sites/tjmccue/2017/03/21/elderly-and-disabled-assistive-technology-market-to-surpass-26-billion-by-2024/?sh=11ed957069ea [Accessed on 23rd July 2019]

McHugh, J. E., Wherton, J. P., Prendergast, D. K., and Lawlor, B. A. (2012). Identifying opportunities for supporting caregivers of persons with dementia through information and communication technology. Gerontechnology, 10(4), 220-230.

McIntosh, M. J., and Morse, J. M. (2015). Situating and constructing diversity in semi-structured interviews. Global qualitative nursing research, 2, 2333393615597674.

McKinstry, B., and Sheikh, A. (2013). The use of global positioning systems in promoting safer walking for people with dementia. Journal of telemedicine and telecare, 19(5), 288-292.

McMurray, J., Strudwick, G., Forchuk, C., Morse, A., Lachance, J., Baskaran, A., Allison, L., and Booth, R. (2017). The importance of trust in the adoption and use of intelligent assistive technology by older adults to support aging in place: scoping review protocol. JMIR research protocols, 6(11), p.e218.

Mcnamee, A. (2005). Ethical issues arising from the real time tracking and monitoring of people using GPS-based location services.

McShane, R., and Skelt, L. (2009). GPS tracking for people with dementia. Working With Older People.

Meade, P. T., and Rabelo, L. (2004). The technology adoption life cycle attractor: Understanding the dynamics of high-tech markets. 71(7), 667–684. doi:10.1016/j.techfore.2004.01.008

Means, R. (1997). Home, independence and community care: time for a wider vision?. Policy & Politics. 25(4):409-19.

Megges, H., Freiesleben, S. D., Jankowski, N., Haas, B., and Peters, O. (2017). Technology for home dementia care: A prototype locating system put to the test. Alzheimer's & Dementia: Translational Research & Clinical Interventions. 2017;3(3):332-8. DOI: 10.1016/j.trci.2017.04.004

Meiland, F., Innes, A., Mountain, G., Robinson, L., van der Roest, H., García-Casal, J. A., Kelly, F., Gove, D., Thyrian, J. R., Evans, S., Dröes, R. M., Kurz, A., Casey, D., Szcześniak, D., Dening, T., Craven, M. P., Span, M., Felzmann, H., Tsolaki, M., and Franco-Martin, M. (2017). Technologies to support community-dwelling persons with dementia: a position paper on issues regarding development, usability, effectiveness and cost-effectiveness, deployment, and ethics. JMIR rehabilitation and assistive technologies, 4(1), e1.

Miah, J., Parsons, S., Lovell, K., Starling, B., Leroi, I. and Dawes, P. (2020). Impact of involving people with dementia and their care partners in research: a qualitative study. BMJ open, 10(10), p.e039321.

Michael, M. G., Fusco, S. J., and Michael, K. (2008). A research note on ethics in the emerging age of überveillance, Computer Communications, 31(6) pp. 1192-1199

Miguel Cruz, A., Daum, C., Comeau, A., Salamanca, J. D. G., McLennan, L., Neubauer, N., and Liu, L. (2021). Acceptance, adoption, and usability of information and communication technologies for people living with dementia and their care partners: A systematic review. Disability and Rehabilitation: Assistive Technology, 1-15.

Milne, H., van der Pol, M., McCloughan, L., Hanley, J., Mead, G., Starr, J., Sheikh, A., and McKinstry, B. (2014). The use of global positional satellite location in dementia: a feasibility study for a randomised controlled trial. BMC psychiatry, 14, 160. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4053578/ [Accessed on 23rd Jan 2020].

Miranda-Castillo, C., Woods, B., and Orrell, M. (2013). The needs of people with dementia living at home from user, caregiver and professional perspectives: a cross-sectional survey. BMC health services research, 13(1), 1-10.

Mirick, R. G., Davis, A., and Wladkowski, S. P. (2017). Understanding sampling and recruitment in social work dissertation research. Advances in Social Work, 18(2), 415-436.

Moore, R. C., and Hancock, J. T. (2020). Older Adults, Social Technologies, and the Coronavirus Pandemic: Challenges, Strengths, and Strategies for Support. Social Media + Society. https://doi.org/10.1177/2056305120948162

Moore, S. K. (2017). Super accurate GPS Chips Coming to Smartphones in 2018. [Online] Retrieved from: https://spectrum.ieee.org/tech-talk/semiconductors/design/superaccurate-gps-chips-coming-to-smartphones-in-2018 [Accessed 10th April 2019]

Morbey, H., Harding, A.J., Swarbrick, C., Ahmed, F., Elvish, R., Keady, J., Williamson, P. R. and Reilly, S. T. (2019). Involving people living with dementia in research: an accessible modified Delphi survey for core outcome set development. Trials, 20(1), pp.1-10.

Morbey, H., Harding, A.J., Swarbrick, C., Ahmed, F., Elvish, R., Keady, J., Williamson, P.R. and Reilly, S.T. (2019). Involving people living with dementia in research: an accessible modified Delphi survey for core outcome set development. Trials, 20(1), pp.1-10.

Morgan, D. L. (1988). Focus Groups as Qualitative Research. Thousand Oaks, CA: Sage

Morgan, D. L., and Krueger, R. A. (1993). When to use focus groups and why. Successful focus groups: Advancing the state of the art, 1, 3-19.

Morgan, D. L., and Krueger, R. A. (1998). The focus group guidebook. Sage.

Morgan, L. A., Frankowski, A. C., Roth, E. G., Keimig, L., Zimmerman, S., Eckert, J. K. (2012). Quality assisted living. Informing practice through research. New York, NY: Springer Publishing Company. 2012.

Morisio, M., and Torchiano, M. (2002). Definition and classification of COTS: a proposal. In International Conference on COTS-Based Software Systems (pp. 165-175). Springer, Berlin, Heidelberg.

Murphy, K., Jordan, F., Hunter, A., Cooney, A., and Casey, D. (2015). Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies. Dementia, 14(6), 800-824.

Nakashima, R. (2018). *Google tracks your movements, like it or not*. AP News. Retrieved from https://www.apnews.com/828aefab64d4411bac257a07c1af0ecb [Accessed on 16th September 2020]

National Health Service [NHS]. (2017). Vascular dementia. Retrieved from: https://www.nhs.uk/conditions/vascular-dementia/ [Accessed on 5th May 2019]

National Health Service [NHS]. (2019). Online version of the NHS Long Term Plan. Retrieved from: https://www.longtermplan.nhs.uk/online-version/chapter-5-digitally-enabled-care-will-go-mainstream-across-the-nhs/1-empowering-people/ [Accessed on 25th June 2021]

National Health Service [NHS]. (2020a). Recorded Dementia Diagnoses June 2020. Retrieved from: https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/june-2020 [Accessed on 3rd July 2020]

National Health Service [NHS]. (2020b). Dementia Prevention. Retrieved from: https://www.nhs.uk/conditions/dementia/dementia-prevention/ [Accessed on 16th March 2021]

National Health Service [NHS]. (2020c). Advice for people at high risk from coronavirus (shielding). Retrieved from: https://www.nhs.uk/conditions/coronavirus-covid-19/people-at-higher-risk/advice-for-people-at-high-risk/ [Accessed on 18th May 2021]

Nauta, J., Brangert, J., Roest, M., Janssen, R., and Hettinga, M. (2013). TalkMeHome: an in situ evaluation of a service to guide a lost person with dementia home safely. Journal of the International Society for Telemedicine and EHealth, 1(2), 54-61.

Neubauer, N., Spenrath, C., Philip, S., Daum, C., Liu, L., and Miguel-Cruz, A. (2021). Identifying adoption and usability factors of locator devices for persons living with dementia. Dementia, 14713012211065381.

Niemeijer, A. R., Depla, M. F., Frederiks, B. J., and Hertogh, C. M. (2015). The experiences of people with dementia and intellectual disabilities with surveillance technologies in residential care. Nursing Ethics, 22(3), 307–320.

Oberndorf, P. A. (1997). Facilitating component-based software engineering: COTS and open systems. In Proceedings Fifth International Symposium on Assessment of Software Tools and Technologies (pp. 143-148). IEEE.

Ochieng, J., Knerr, B., Owuor, G., and Ouma, E. (2018). Strengthening collective action to improve marketing performance: evidence from farmer groups in Central Africa. The journal of agricultural education and extension, 24(2), 169-189.

Øderud, T., Landmark, B., Eriksen, S., Fossberg, A.B., Aketun, S., Omland, M., Hem, K.G., Østensen, E. and Ausen, D. (2015). Persons with Dementia and Their Caregivers Using GPS. In AAATE Conf. pp. 212-221.

Olsson, A., Engström, M., Åsenlöf, P., Skovdahl, K., and Lampic, C. (2015). Effects of tracking technology on daily life of persons with dementia: three experimental single-case studies. American Journal of Alzheimer's Disease & Other Dementias. 2015;30(1):29-40.

Östlund, B. (2004). Social Science Research on Technology and the Elderly--Does it Exist? Science Studies, 17(2).

Oswald, F., Wahl, H. W., Voss, E., Schilling, O., Freytag, T. I., Auslander, G., Shoval, N., Heinik, J., and Landau, R. (2010). The use of tracking technologies for the analysis of outdoor mobility in the face of dementia: First steps into a project and some illustrative findings from Germany. Journal of Housing for the Elderly. 2010;24(1):55-73.

Padgett, D. L., and Conceição-Runlee, S. (2000). Designing a faculty development program on technology: If you build it, will they come?. Journal of Social Work Education, 36(2), 325-334.

Palumbo, F., Barsocchi, P., Chessa, S., and Augusto, J. C. (2015). A stigmergic approach to indoor localization using Bluetooth Low Energy beacons. 2015 12th IEEE International Conference on Advanced Video and Signal Based Surveillance (AVSS). doi:10.1109/avss.2015.7301734

Park, J., Kim, K., and Cho, Y. K. (2016). Framework of automated construction-safety monitoring using cloud-enabled BIM and BLE mobile tracking sensors. Journal of Construction Engineering and Management, 143(2), 05016019.

Parry, J., Vegeris, S., Hudson, M., Barnes, H., and Taylor, R. (2014). Independent living in later life. Research Report No 216. 2004. Retrieved from: https://www.researchgate.net/profile/Jane_Parry2/publication/242521642_Independent_Living_in_Later_Life/links/0c96052e0f7311646b000000/Independent-Living-in-Later-Life.pdf [Accessed on 2nd July 2020]

Perusco, L., and Michael, K. (2007). Control, trust, privacy, and security: evaluating location-based services, *IEEE Technology and Society Magazine*, 2007, 26(1), 4-16.

Retrieved from http://ro.uow.edu.au/cgi/viewcontent.cgi?article=1521&context=infopapers [Accessed on 12th September 2020]

Petrie, H., Carmien, S., and Lewis, A. (2018). Assistive Technology Abandonment: Research Realities and Potentials. In: Miesenberger, K., Kouroupetroglou, G. (eds) Computers Helping People with Special Needs. ICCHP 2018. Lecture Notes in Computer Science(), vol 10897. Springer, Cham. https://doi.org/10.1007/978-3-319-94274-2_77

Pettus-Davis, C., Grady, M. D., Cuddeback, G. S., and Scheyett, A. (2011). A practitioner’s guide to sampling in the age of evidence-based practice: Translation of research into practice. Clinical Social Work Journal, 39(4), 379-389.

Phillips, B., and Zhao, H. (1993). Predictors of assistive technology abandonment. Assistive technology, 5(1), 36-45.

Pilnick, A., and Swift, J. A. (2011). Qualitative research in nutrition and dietetics: assessing quality. *Journal of Human nutrition and Dietetics*, *24*(3), 209-214.

Plastow, N. A. (2006). Is Big Brother Watching You? Responding to Tagging and Tracking in Dementia Care. British Journal of Occupational Therapy, 69(11), 525–527.

Porock, D., Clissett, P., Harwood, R. H., and Gladman, J. R. (2015). Disruption, control and coping: responses of and to the person with dementia in hospital. Ageing & Society, 35(1), 37-63.

Pot, A. M., Willemse, B.M., and Horjus S. (2012). A pilot study on the use of tracking technology: feasibility, acceptability, and benefits for people in early stages of dementia and their informal caregivers. Aging & mental health. 2012;16(1):127-34.

Powell, J., Gunn, L. E. E., Lowe, P. A. M., Sheehan, B., Griffiths, F., and Clarke, A. (2010). New networked technologies and carers of people with dementia: An interview study. Ageing & Society, 30(6), 1073-1088.

Prince, M., Comas-Herrera, A., Knapp, M., Guerchet, M. and Karagiannidou, M. (2016). World Alzheimer report 2016: improving healthcare for people living with dementia: coverage, quality and costs now and in the future.

PRISMA (2015). PRISMA Checklist. 2015. Retrieved from: http://www.prisma-statement.org/PRISMAStatement/Checklist [Accessed on November 11th 2020].

Punch, M. (1986). The politics and ethics of fieldwork. Thousand Oaks, CA: Sage

Rasquin, S. M., Willems, C., De Vlieger, S., Geers, R. P. J., and Soede, M. (2007). The use of technical devices to support outdoor mobility of dementia patients. Technology and disability, 19(2-3), 113-120.

Rivett, E. (2017). Research involving people with dementia: A literature review. Working with Older People.

Robinson, L., Brittain, K., Lindsay, S., Jackson, D., and Olivier, P. (2009). Keeping In Touch Everyday (KITE) project: Developing assistive technologies with people with dementia and their carers to promote independence. International Psychogeriatrics, 21(3), 494-502.

Robinson, L., Cotten, S. R., Ono, H., Quan-Haase, A., Mesch, G., Chen, W., Schulz, J., Hale, T. M. and Stern, M. J. (2015). Digital inequalities and why they matter. Information, communication & society, 18(5), pp.569-582.

Robson, C. (2002). Real world research: A resource for social scientists and practitioner-researchers. Wiley-Blackwell.

Robson, C., and McCartan, K. (2016). *Real world research 4th Ed*. John Wiley & Sons.

Rogers, C. (1951). Perceptual reorganization in client-centered therapy.

Rogers, C. (1959). A theory of therapy, personality and interpersonal relationships as developed in the client-centered framework. In (ed.) S. Koch, Psychology: A study of a science. Vol. 3: Formulations of the person and the social context. New York: McGraw Hill.

Rogers, C. (1961). On Becoming a person: A psychotherapists view of psychotherapy. Houghton Mifflin.

Rogers, C. (1995). On becoming a person: A therapist's view of psychotherapy. Houghton Mifflin Harcourt.

Rogers, E. M. (1962). Diffusion of Innovations, New York: Free Press of Glencoe.

Rogers, E. M. (2003). Diffusion of Innovations, Fifth Edition, Free Press

Rohwerder, B. (2018). Assistive Technologies in Developing Countries. K4D Helpdesk Report. Brighton, UK: Institute of Development Studies. Retrieved from https://assets.publishing.service.gov.uk/media/5af976ab40f0b622d4e9810f/Assistive_technologies_in_developing-countries.pdf [Accessed on 18th August 2019]

Rosenberg, L., Kottorp, A., and Nygård, L. (2012). Readiness for technology use with people with dementia: the perspectives of significant others. Journal of applied gerontology, 31(4), 510-530.

Ryan, G. (2018). Introduction to positivism, interpretivism and critical theory. Nurse researcher, 25(4), 41-49.

Sabat, S. (2001). The experience of Alzheimer’s disease: Life through a tangled veil, Oxford: Blackwell.

Sabat, S. (2002). Surviving manifestations of selfhood in Alzheimer’s disease. Dementia, 1, 1, 25–36.

Sabat, S. (2003). ‘Malignant positioning and the predicament of Alzheimer’s disease’, in Harre, R. and Moghaddam, F.M., eds., The self and others: positioning individuals and groups in personal, political and cultural contexts, Westport, Connecticut: Greenwood Publishing Group.

Sabat, S. and Harre´, R. (1992). The construction and deconstruction of self in Alzheimer’s disease. Ageing & Society, 12, 4, 443–61

Satariano, W. A., Scharlach, A. E., and Lindeman, D. (2014). Aging, place, and technology: Toward improving access and wellness in older populations. Journal of aging and health, 26(8), 1373-1389.

Scherer, M. J. (2017). Technology adoption, acceptance, satisfaction and benefit: integrating various assistive technology outcomes. Disability and Rehabilitation: Assistive Technology, 12(1), 1-2.

Schulz, R., Wahl, H. W., Matthews, J. T., De Vito Dabbs, A., Beach, S. R., and Czaja, S. J. (2015). Advancing the aging and technology agenda in gerontology. Gerontologist, 55(5), 724-734. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4592332/ [Accessed 10th June 2020]

Scottish Dementia Working Group (2014). Core principles for involving people with dementia in research: innovative practice. Dementia (London, England), 13(5), 680–685. https://doi.org/10.1177/1471301214533255

Shippee T. P. (2012). On the edge: Balancing health, participation, and autonomy to maintain active independent living in two retirement facilities. Journal of Aging Studies. 26:1–15. DOI:10.1016/j. jaging.2011.05.002

Sixsmith A. (1986). Independence and home in later life. Dependency and interdependency in old age: Theoretical perspectives and policy alternatives. 1986:338-347.

Sixsmith, A. and Sixsmith, J. (2008). Ageing in place in the United Kingdom. Ageing International. 32(3):219-35.

Sloan, R. H., and Warner, R. (2015). I'll See: How Surveillance Undermines Privacy by Eroding Trust. Santa Clara High Tech. LJ, 32, 221. Retrieved from https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2747435 [Accessed on 13th September 2020]

Smebye, K. L., Kirkevold, M., and Engedal, K. (2015). Ethical dilemmas concerning autonomy when persons with dementia wish to live at home: a qualitative, hermeneutic study. BMC health services research, 16(1), 21. Retrieved from https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-015-1217-1 [Accessed on 16th March 2020]

Smithson, J. (2000). Using and analysing focus groups: Limitations and possibilities. International Journal of Social Research Methodology, 3(2), 103–119. https://doi.org/10.1080/136455700405172

Spradley, J. (1979). Asking descriptive questions. The ethnographic interview, 1, 44-61.

Straub, E. T. (2009). Understanding technology adoption: Theory and future directions for informal learning. Review of educational research, 79(2), 625-649.

Stubbs, E. (2015). Road to healthcare devolution. Civitas: Institute for the Study of Civil Society. Retrieved from: https://www.civitas.org.uk/content/files/TheRoadtoDevolution.pdf [Accessed on 19th May 2019]

Stuckler, D., Reeves, A., Loopstra, R., Karanikolos, M., and McKee, M. (2017). Austerity and health: the impact in the UK and Europe. European journal of public health, 27(suppl_4), 18-21.

Swift, J. A. and Tischler, V. (2010). Qualitative research in nutrition and dietetics: getting started. *J. Hum. Nutr. Diet.* **23**, 559– 566.

Taylor-Robinson, D., Gosling, R., Harrison, D., Khan, M., and Barr, B. (2013). Austerity measures hit the sickest hardest. BMJ: British Medical Journal, 347.

TechSilver. (2019). 'Dementia Tracker GPS Watch w/ 2-Way SOS Calls'. Retrieved from https://www.techsilver.co.uk/product/dementia-tracker-gps-watch/ [Accessed on 10th November 2019]

TechSilver. (2021). 'Small GPS Tracker w/ Extra Long-Life Battery For Elderly / Kids / Cars / Pets' Retrieved from https://www.techsilver.co.uk/product/small-gps-tracker-dementia-child/?v=79cba1185463 [Accessed on 4th April 2021]

TechSilver. (2022). Dementia Tracker GPS Keyring / Necklace for Elderly w/ SOS. Retrieved from: https://www.techsilver.co.uk/product/dementia-tracker-keyring/?v=79cba1185463 [Accessed on 25th January 2022]

The British Academy. (2020). What factors make a community more vulnerable to COVID-19? Retrieved from: https://www.thebritishacademy.ac.uk/documents/2700/What-factors-make-a-community-more-vulnerable-to-COVID-19.pdf [Accessed 15th November 2021]

The British Academy. (2021). THE COVID DECADE Understanding the long-term societal impacts of COVID-19. Retrieved from: https://www.thebritishacademy.ac.uk/documents/3238/COVID-decade-understanding-long-term-societal-impacts-COVID-19.pdf [Accessed 10th December 2021]

The TOPOL Review. (2019). Preparing the healthcare workforce to deliver the digital future. Retrieved from: https://topol.hee.nhs.uk/wp-content/uploads/HEE-Topol-Review-2019.pdf [Accessed on 19th May 2021]

Thimbleby, H. (2013). Technology and the future of healthcare. Journal of public health research, 2(3).

Topfer, L. A. (2016). GPS locator devices for people with dementia. In CADTH Issues in Emerging Health Technologies. Canadian Agency for Drugs and Technologies in Health. https://www.ncbi.nlm.nih.gov/books/NBK391026/

Torke, A. M., Alexander, G. C., and Lantos, J. (2008). Substituted judgment: the limitations of autonomy in surrogate decision making. Journal of general internal medicine, 23(9), 1514–1517.

Trenfield, S. J., Awad, A., Madla, C. M., Hatton, G. B., Firth, J., Goyanes, A., Gaisford, S. and Basit, A.W., (2019). Shaping the future: recent advances of 3D printing in drug delivery and healthcare. Expert opinion on drug delivery, 16(10), pp.1081-1094.

UK Parliament (2021). All Party Parliamentary Group on Dementia report. Retrieved from: https://lordslibrary.parliament.uk/all-party-parliamentary-group-on-dementia-report/ [Accessed on 10th January 2022]

United Nations [UN]. (2017). World Population Ageing. Retrieved from: https://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2017_Report.pdf [Accessed 2nd April 2020]

United Nations [UN]. (2021). Speakers Highlight Role of Digital Technology in Confronting COVID-19 Pandemic’s Ill Effects, as Social Development Commission Continues Session. Retrieved from: https://www.un.org/press/en/2021/soc4893.doc.htm [Accessed 3rd January 2022]

US Department of Defence. (2008). Global Positioning System Standard positioning service performance standard. Retrieved from: https://www.gps.gov/technical/ps/2008-SPS-performance-standard.pdf [Accessed on 29th July 2019]

Van Dijk, J., and Hacker, K. (2003). The digital divide as a complex and dynamic phenomenon. The information society, 19(4), 315-326.

Vaportzis, E., Giatsi Clausen, M., and Gow, A. J. (2017). Older adults perceptions of technology and barriers to interacting with tablet computers: A focus group study. Frontiers in Psychology, 8, Article 1687. https://doi.org/10.3389/fpsyg.2017.01687

Wan, L., Mueller, C., Wulf, V., and Randall, D. (2014). Addressing the subtleties in dementia care: Pre-study & evaluation of a GPS monitoring system. Conference on Human Factors in Computing Systems - Proceedings. Retrieved from https://www.wineme.uni-siegen.de/paper/2014/p3987-wan.pdf [Accessed on 10th September 2020]

Wang, H., Li, T., Barbarino, P., Gauthier, S., Brodaty, H., Molinuevo, J.L., Xie, H., Sun, Y., Yu, E., Tang, Y. and Weidner, W. (2020). Dementia care during COVID-19. The Lancet, 395(10231), pp.1190-1191.

Wang, J., Katz, I., Li, J., Wu, Q., and Dai, C. (2021). Mobile digital divide and older people’s access to ‘Internet plus social work’: Implications from the COVID-19 help-seeking cases. Asia Pacific Journal of Social Work and Development, 31(1-2), 52-58.

Wangmo, T., Lipps, M., Kressig, R. W., and Ienca, M. (2019). Ethical concerns with the use of intelligent assistive technology: findings from a qualitative study with professional stakeholders. BMC medical ethics, 20(1), 1-11.

Werner, S., Auslander, G. K., Shoval, N., Gitlitz, T., Landau, R., Heinik, J. (2012). Caregiving burden and out-of-home mobility of cognitively impaired care-recipients based on GPS tracking. International psychogeriatrics. 2012;24(11):1836.

Wheeler, S. and Holloway, I. (2002). Qualitative research in nursing and healthcare. Wiley-Blackwell book

White, E. B., and Montgomery, P. (2014). Electronic tracking for people with dementia: An exploratory study of the ethical issues experienced by carers in making decisions about usage. Dementia, 13(2), 216–232. https://doi.org/10.1177/1471301212460445

Wilkinson, H. (2002). Including people with dementia in research. The perspectives of people with dementia: Research methods and motivations, 9-25.

Williams, G., King, P., and Doughty, K. (2011). Practical issues in the selection and use of GPS tracking and location technologies to support vulnerable people at risk of becoming lost or threatened. Journal of Assistive Technologies, 5(3), 146-151.

Williams, K., Arthur, A., Niedens, M., Moushey, L., and Hutfles, L. (2013). In-home monitoring support for dementia caregivers: a feasibility study. Clinical nursing research, 22(2), 139-150.

Williamson, B., Aplin, T., de Jonge, D., and Goyne, M. (2017). Tracking down a solution: exploring the acceptability and value of wearable GPS devices for older persons, individuals with a disability and their support persons. Disability and Rehabilitation: Assistive Technology, 12(8), 822-831.

Wittenberg, R., Knapp, M., Hu, B., Comas-Herrera, A., King, D., Rehill, A., Shi, C., Banerjee, S., Patel, A., Jagger, C. and Kingston, A., (2019). The costs of dementia in England. International journal of geriatric psychiatry, 34(7), pp.1095-1103.

Wong, G., and Knapp, M. (2020). Should we move dementia research funding from a cure to its care?. Expert review of neurotherapeutics, 20(4), 303-305.

World Health Organisation [WHO]. (2012). Dementia Report; 2012. Retrieved from: https://www.who.int/mental_health/publications/dementia_report_2012/en/ [Accessed on 9th March 2020]

World Health Organisation [WHO]. (2017). Global priority research agenda for improving access to high-quality affordable assistive technology. Geneva: World Health Organization. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/254660/WHO-EMP-IAU-2017.02-eng.pdf;jsessionid=3B2217F76ACF88AF222FAFF33ACEAFD9?sequence=1 [Accessed on 10th December 2019]

World Health Organisation [WHO]. (2018). ‘Assistive technology’. Retrieved from https://www.who.int/news-room/fact-sheets/detail/assistive-technology [Accessed on 22nd July 2020]

World Health Organisation [WHO]. (2020). ‘Rolling updates on coronavirus disease (COVID-19)’. Retrieved from: https://www.who.int/emergencies/diseases/novel-coronavirus-2019/events-as-they-happen [Access on 23rd March 2021]

World Health Organisation [WHO]. (2021a). Dementia Factsheet. https://www.who.int/news-room/fact-sheets/detail/dementia [Accessed on 18th November 2021]

World Health Organisation [WHO]. (2021b). COVID-19 disproportionately impacts vulnerable populations. Retrieved from: https://www.who.int/news-room/spotlight/the-impact-of-covid-19-on-global-health-goals [Accessed on 16th January 2022]

World Health Organization [WHO]. (2012). Dementia, a public health priority [Online], Retrieved from: http://www.who.int/mental_health/publications/dementia_report_2012/en/ [Accessed on 8th October 2019].

Wu, C. L., Wu, B. H., Lin, Y.T., Wang, P., and Zhou, Y. (2016). Moments A Wearable Device for Early Stage AD Patients to Maintain Their Autonomy. In Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems; 2016 May 7 (pp. 74-79).

Yang, Y. T., and Kels, C. G. (2017). Ethical considerations in electronic monitoring of the cognitively impaired. J Am Board Fam Med, 2017;30(2):258-263. Retrieved from: https://www.jabfm.org/content/30/2/258 [Accessed on 20th February 2020]

Yilmaz, K. (2013). Comparison of Quantitative and Qualitative Research Traditions: epistemological, theoretical, and methodological differences. E J of Education. Retrieved from: https://onlinelibrary.wiley.com/doi/abs/10.1111/ejed.12014 [Accessed on 10th November 2020]

Zheng, H., Nugent, C., McCullagh, P., Huang, Y., Zhang, S., Burns, W., Davies, R., Black, N., Wright, P., Mawson, S., Eccleston, C., Hawley, M., and Mountain, G. (2010). Smart self-management: assistive technology to support people with chronic disease. Journal of Telemedicine and Telecare, 16(4), 224–227.

Zuboff, S. (2019). The age of surveillance capitalism: The fight for a human future at the new frontier of power. Profile Books.

Zwijsen, S. A., Depla, M. F., Niemeijer, A. R., Francke, A. L., and Hertogh, C. M. (2012). Surveillance technology: an alternative to physical restraints? A qualitative study among professionals working in nursing homes for people with dementia. International Journal of Nursing Studies. 2012;49(2):212-9.

APPENDICES

APPENDICES

Appendix 1: Selection of GPS Devices

A. Huawei Band 2 Pro. Cost £30.00

Suitable for care partners and individuals living with dementia who reside together. Watch has GPS tracking capabilities for 3.5 hours without phone present. Smartphone Required. No SIM required

LINK

B. Kimfly mini Real Time GPS tracking device. Cost £29.99

Suitable for all users. Smartphone REQUIRED, and SIM Required for use

LINK

C. Micodus Personal GPS Tracker. Cost £36.99

Suitable for all users. Smartphone required and SIM included for use

LINK

D. Hangang GPS Watch. Cost £50.10

GPS + LBS + WiFi Triple Positioning. GPS is mainly for outdoor position and LBS is mainly for indoor position. Smartphone required and sim required for use

LINK

E. KALENJI ONMOVE 220 GPS RUNNING WATCH. Cost £59.99

GPS. No Sim Required

Link

G. Super-Mini s3 GPS Tracker 400M$_{a}$H

GPS + GSM + Wi-fi + LBS. Sim required

LINK

H. Super-Mini s3 GPS Tracker 1000M$_{a}$H

GPS + GSM + Wi-fi + LBS. Sim required

LINK

I. Personal Smart Sports Watch GPS Tracker. Cost £35

GPS + SOS Two-Way Talking Fashion Geo-Fence Vibration, Real Time Position, Alarm Device.

LINK

J. Mini GPS Tracking Watch. Cost £30

GPS Tracking Watch

LINK

K. ZX612 Mini Hidden GPS Tracker Positioner Locator SOS Alarm. Cost £18

GPS + SOS Two-Way Talking Fashion Geo-Fence Vibration, Real Time Position, Alarm Device.

LINK

L. Mini GPS Tracker. Cost £7

GPS + GSM

LINK

M. Mini GPS Tracking device. Cost £5.50

GPS + with listening feature and magnetic attachment

LINK

N. GF-07 Mini GPS Tracking Device Real-time Locator. Cost £5.45

GPS + with listening feature and magnetic attachment

LINK

O. Q90 Smart Watch with GPS Tracker. Cost £19

Touch Screen WIFI Positioning SOS Call Location Finder Device Tracker

LINK

P. Mini Personal GPS Tracker L70 Portable Pendant. Cost £26

High Level Waterproof GPS Locator with SOS Call function

LINK

Q. Mini GPS Tracker and Listening Device A9. Cost £25.50

GPS Locator 5 Days Standby

LINK

R. GT012 Ultra-thin Card style Mini GPS Tracker. Cost £11.20

Potential device to fit into the insole of a shoe

LINK

S. GPS Real Time Tracking Locator. Cost £13.50

Potential device to fit into the insole of a shoe

LINK

T. GT012 Ultra-thin Card style Mini GPS Tracker. Cost £11.20

Potential device to fit into the insole of a shoe

LINK

U. V-Multi Tracker – Trackisafe by Vodafone . Cost £19.99

Multipurpose device with multiple accessories and attachments

LINK

Appendix 2: Evaluation table of available GPS devices

This product comparison table to provide a product specification summary for each device listed above.

	Product																				
	A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**	**M**	**N**	**O**	**P**	**Q**	**R**	**S**	**T**	**U**
SIM Required	N	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Approximate Cost (£)	37	30	37	50	60	55	18	22	35	30	18	7	5.5	5.45	19	26	25.50	11	13.5	11.2	19.99
Size of device (cm)	4.0 x 1.5 x 0.8	3.1 x 1.5 x 1.0	3.9 x 3.9 x 1.7	4.0 x 3.0 x 1.2	3.0 x 3.0 x 1.0	8.4 x 4.6 x 1.3	4.2 x 2.4 x 1.2	5.5 x 2.2 x 1.5	5.0 x 3.0 x 2	3.8 x 3.8 x 1.3	5.0 x 3.0 x 1.5	4.2 x 3.2 x 1.4	4.2 x 2.5 x 1.6	3.5 x 2.0 x 1.4	5.0 x 4.0 x 2.1[5]	4.6 x 4.6 x 1.5	3.9x 3.9x 1.7	8.6 x 5.5 x 0.6	4x 2x 1.4	4.5 x 4.5 x 1.6	3.9x 3.9x 1.0
Weight (g)	20	25	22	35	35	55	22	38	54	22	38	30	20	20	35	25	22	40	30	33	20
Battery life Standby (Hours)	48	72	120	24	18	100	96	240	96	120	35	120	288	80	48	60	120	30[6]	240	96	48
Battery life working (Hours)	3	48	120	10	6	72	48	120	?	60	18	72	96-144	48	48	40	?	30[6]	120	48	48
2-way voice	N	Y	Y	N	N	N	N	N	Y	Y	N	N	N	N	Y	Y	Y	N	N	Y	N
1-way voice	N	Y	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	Y	N

Geofencing	Y	Y	Y	?	?	Y	Y	Y	Y	Y	Y	?	?	Y	?	Y	Y	Y	Y	Y	Y
SOS Alarm included	N`	N	Y	N	N	Y	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	N	Y	Y
On going cost	N	N[1]	N	N	N	N[1]	N[1]	N[1]	N[1]	N[1]	N[1]	N[1]	N[1]	N[1]	N[1]	N[1]	N[1]	N[1]	N[1]	N[1]	Y
Type[2]	1	3	2	1	1	3	3	3	1	1	3	3	3	3	1	2	2	2	3	2	2
Waterproof	Y	?	Y	Y	Y	Y	?	?	?	?	?	?	Y	Y	Y	Y	Y	Y	Y	Y	Y
Accuracy Outdoors (m)	10	10	5-15	10	10	5-10	10	10	5-10	5-15	10-20	10	10	10	5-15	5-10	5-10	<10	5-10	<10	5-10
Accuracy Indoors (m)	20	5-20	10-20	20	20-50	20	5-20	5-20	5-?	5-?	20	<20	5-20	5-20	5-20	5-20	20-50	<20	5-20	5-20	<10
Rechargeable	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y[3]	Y	Y	Y	Y[4]	Y	Y	Y	Y	Y

---

[1] Whilst there is no monthly fee to use the tracking feature, when the device has added capabilities for 1 or 2 way voice calling, the cost for making such calls would be taken from credit loaded onto the SIM card

[2] The devices are categorised as the following: 1 – GPS tracking wristwatch, 2 – GPS wearable tracking unit (e.g. pendant, broach, insole), 3 – Carried GPS tracking unit

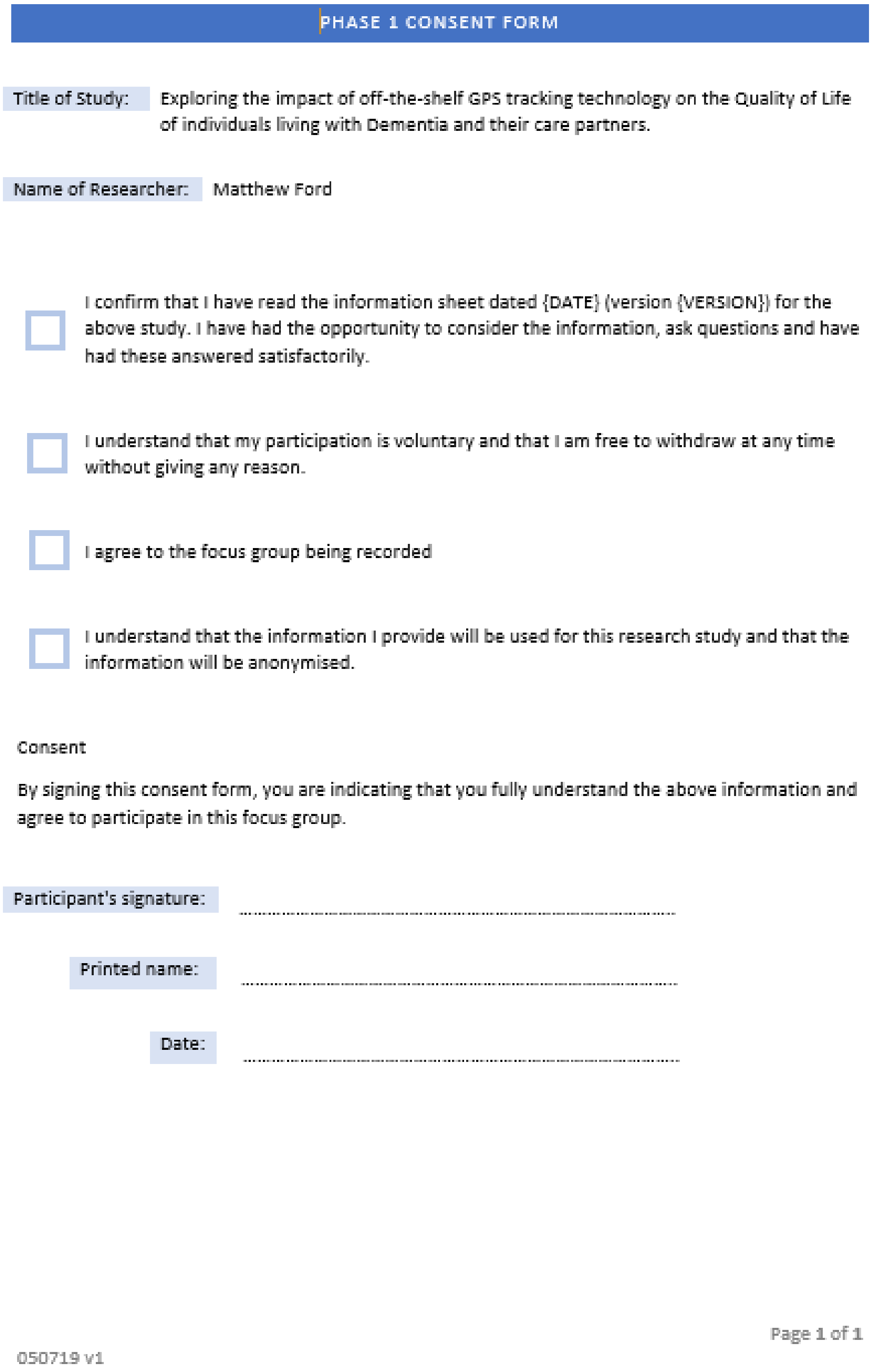
[3] Device L requires the user to remove the SIM card when recharging, this may prove to be a difficult task for some users

[4] This device has a magnetic charging function, making recharging the device easier for the user

[5] With type 1 devices (Wristwatches) the size of the device is measured only as the watch face, rather than including the watchstrap

[6] The battery life of this device was only listed as “longer than 30 hours”, more research would be required, including the testing of this device to find a more accurate figure.

Appendix 3: Phase 1 Consent form



PHASE 1 CONSENT FORM

Title of Study: Exploring the impact of off-the-shelf GPS tracking technology on the Quality of Life of individuals living with Dementia and their care partners.

Name of Researcher: Matthew Ford

☐ I confirm that I have read the information sheet dated {DATE} (version {VERSION}) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

☐ I agree to the focus group being recorded

☐ I understand that the information I provide will be used for this research study and that the information will be anonymised.

Consent

By signing this consent form, you are indicating that you fully understand the above information and agree to participate in this focus group.

Participant's signature: ……………………………………………………………………………

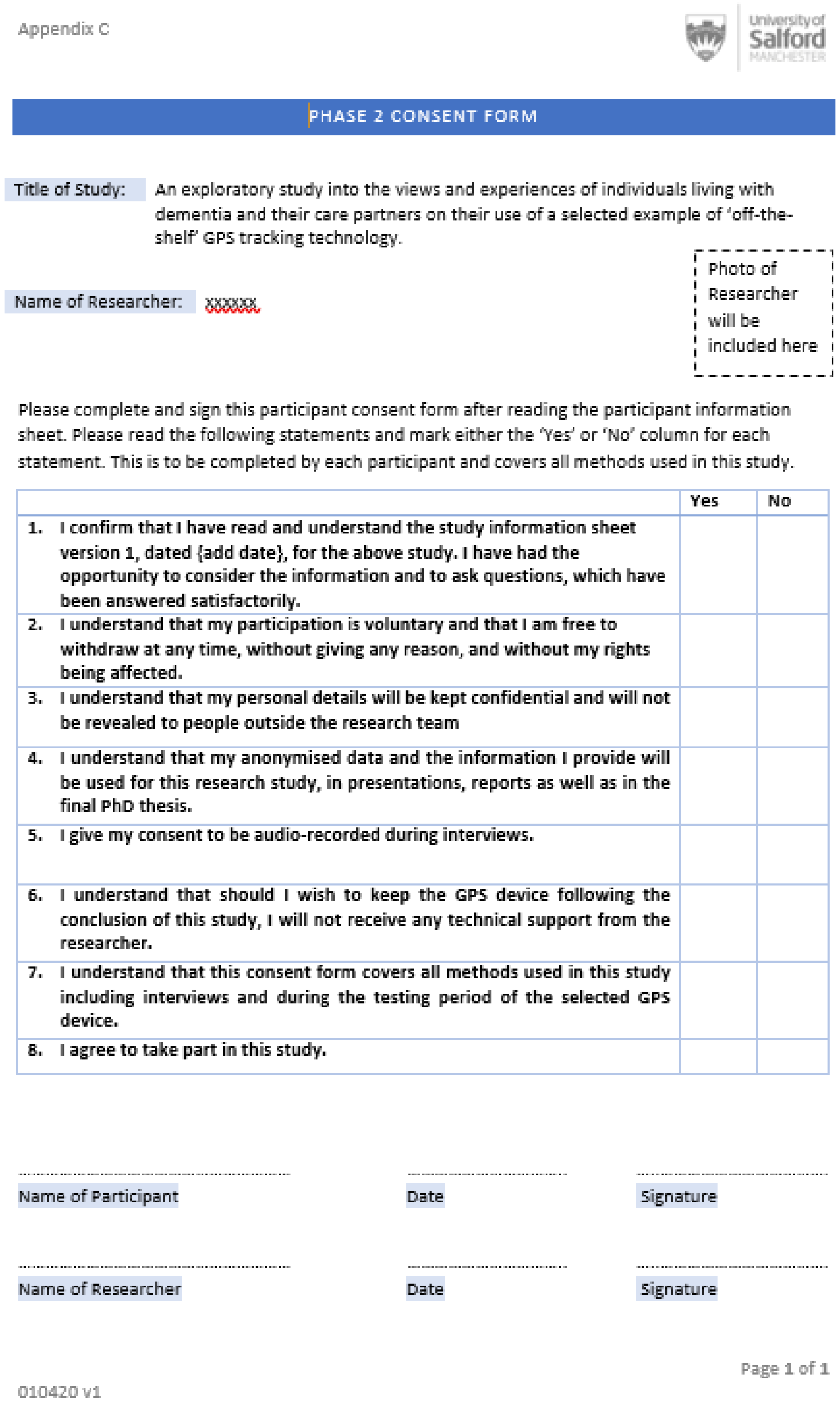
Printed name: ……………………………………………………………………………

Date: ……………………………………………………………………………

Page 1 of 1

050719 v1

Appendix 4: Phase 2 Consent form



Appendix C

University of Salford
MANCHESTER

PHASE 2 CONSENT FORM

Title of Study: An exploratory study into the views and experiences of individuals living with dementia and their care partners on their use of a selected example of 'off-the-shelf' GPS tracking technology.

Name of Researcher: xxxxxx

Photo of Researcher will be included here

Please complete and sign this participant consent form after reading the participant information sheet. Please read the following statements and mark either the 'Yes' or 'No' column for each statement. This is to be completed by each participant and covers all methods used in this study.

	Yes	No
1. I confirm that I have read and understand the study information sheet version 1, dated {add date}, for the above study. I have had the opportunity to consider the information and to ask questions, which have been 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 my rights being affected.		
3. I understand that my personal details will be kept confidential and will not be revealed to people outside the research team		
4. I understand that my anonymised data and the information I provide will be used for this research study, in presentations, reports as well as in the final PhD thesis.		
5. I give my consent to be audio-recorded during interviews.		
6. I understand that should I wish to keep the GPS device following the conclusion of this study, I will not receive any technical support from the researcher.		
7. I understand that this consent form covers all methods used in this study including interviews and during the testing period of the selected GPS device.		
8. I agree to take part in this study.		

…………………………………………………	……………………………	………………………………
Name of Participant	Date	Signature
…………………………………………………	……………………………	………………………………
Name of Researcher	Date	Signature

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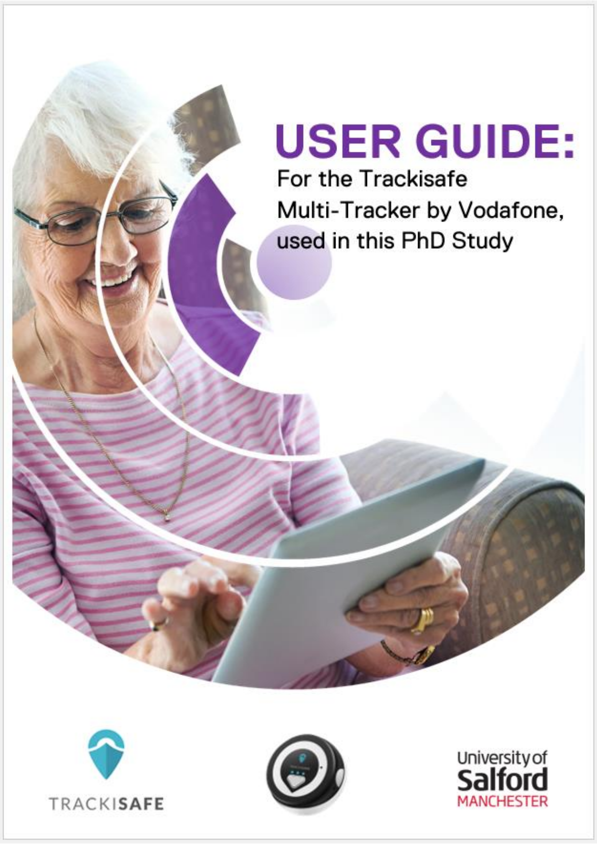
010420 v1

Appendix 5: Phase 2 User Guide



USER GUIDE:

For the Trackisafe
Multi-Tracker by Vodafone,
used in this PhD Study

TRACKISAFE

University of
Salford
MANCHESTER

2

CONTENTS

PRODUCT PARTS

What's in the box? Each tracking device comes with the accessories listed below, Including:


Clip

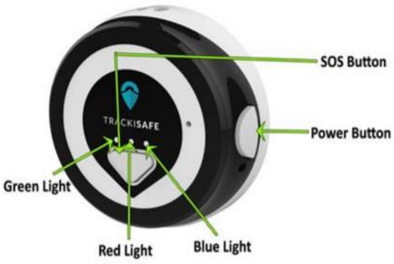

Clip Box


Magnetic Charging Cable


Storage Pouch


Clip catch


Lanyard



CHARGING THE DEVICE

If the device has indicated it is low on battery, or you have received a low battery alert from the TrackiSafe app, follow these steps to charge the device.

1. On the back of the device you will find the Charging Port

2. Take the Magnetic Charging Cable device out of the box and hold close to the charging port, the magnets will automatically align the charger to the port, you will hear a slight click as the charger connects to the device

3. The charger should now be connected as seen in the image above (Colour of charging cable may be black or white).

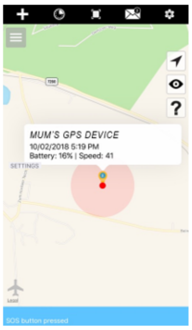
4. The USB end of the charger can now be connected to a USB port or a USB to Mains adapter.

5. When the Red light is solidly lit up the device is fully charged

Note: You can save battery life by increasing the tracking interval in the TrackiSafe app. As soon as the battery level is low, the red light will start to blink.

FEATURES

Speed Limit On
Low Battery On
Moving Start On
Light detection Off
Bluetooth proximity
SETTINGS
Device Name
Track Every 5
Flight Mode Off



MUM'S GPS DEVICE
10/02/2018 5:19 PM
Battery: 16% | Speed: 41

SOS button pressed

GEO-FENCING

A geofence is a self-defined virtual boundary. You will receive a notification If the tracker goes into or out of this area.

1. Select the tracker on the Trackisafe homepage or in your app.

2. Click on “fence”.

3. Click on the “Create a new fence” button. A pink rectangular fence will be created around your device’s current location (or in the centre of the map).

– You can also enter an address to position a fence.

– You can choose a pre-defined size.

– You can change the size by making the sides of the rectangle bigger or smaller, or by moving the rectangle.

4. Once your fence has been created, you can give your geofence a name and click on “Save”.

5. You will receive a notification in the TrackiSafe app every time your tracker enters or leaves this area. If you want to receive email notifications as well, tap on "Share", then on “New contact”. You will then be able to add an email address for this alert.

SOS BUTTON

If you press the SOS button for at least 3 seconds, the location and a text message will be sent to the e-mail you have provided.

SPEED ALERT

You will receive a notification as soon as the tracker moves faster than the speed pre-defined by you.

1. Select the tracker on the Trackisafe homepage or in your app.

2. Go to “Settings”.

3. Enable the alert by checking the Speed alert box.

4. Enter a speed.

5. Add a contact where required.

6. Click on “Save”.

7. If you want to receive a notification via email as well, go to the Settings area in the app, swipe right on the "Speed alert", then tap on "Share" then on "New contact". You will then be able to add an email address for this alert.

MOVEMENT ALERT

You will receive a notification as soon as the tracker starts to move.

1. Select the tracker on the TrackiSafe app.

2. Go to “Settings”.

3. Set the "Start moving alert" to ON.

4. Enable the alert by checking the "Start Moving alert" box

5. Click on “Save”.

6. If you want to receive a notification via email as well, go to the Settings area in the app, swipe right on the "Moving Start alert", then tap on "Share" then on "New contact". You will then be able to add an email address for this alert.

LOW BATTERY ALERT

You will receive a notification in the TrackiSafe app when battery level is low.

1. Select the tracker in the TrackiSafe app.

2. Go to “Settings”.

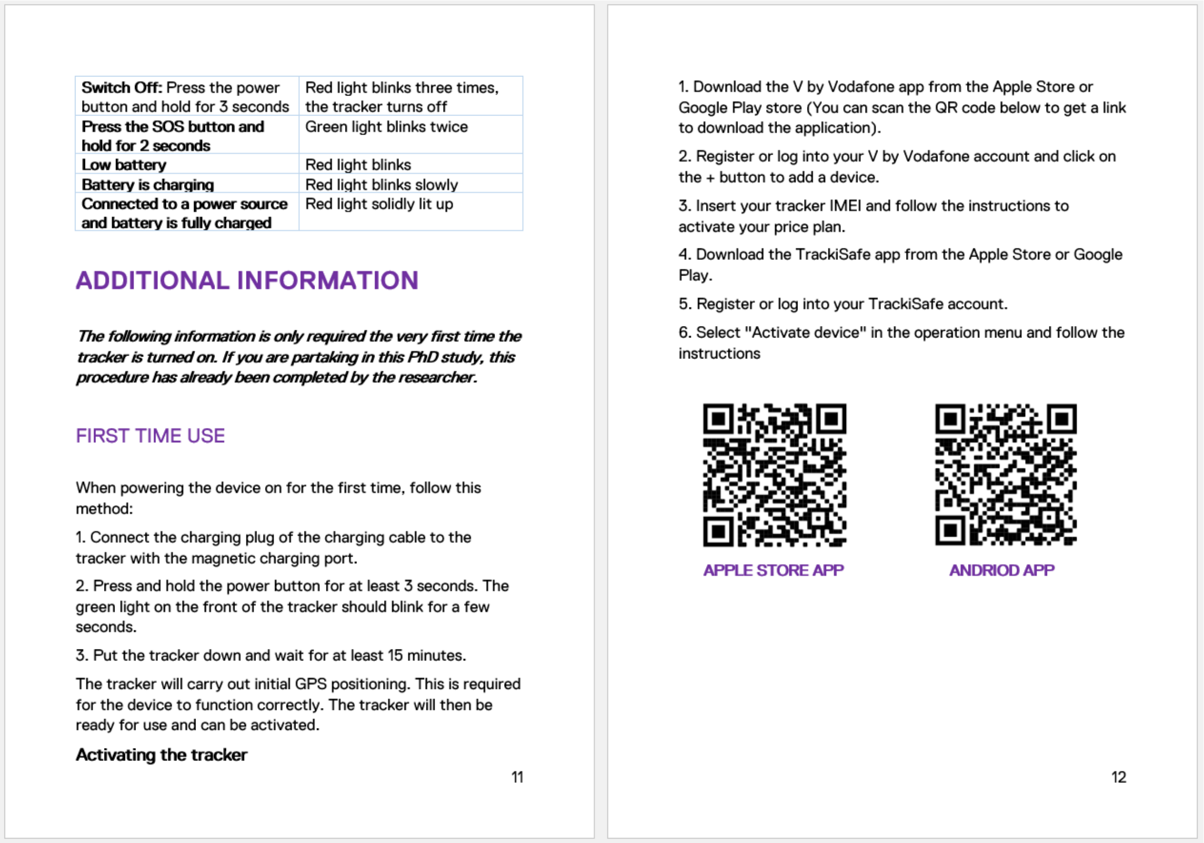
3. Set the “Low battery alert” to ON

4. Click on “Save”

5. If you want to receive a notification via email as well, go to the Settings area in the app, swipe right on the "Low battery alert", then tap on "Share" then on "New contact". You will then be able to add an email address for this alert

WHAT DOES EACH LIGHT MEAN?

Action	Light
Switch On: Press the power button and hold for 3 seconds	Green light blinks twice, the tracker starts up
Check if the device is to the mobile network: Press the on/off button and quick release	If device is connected: Green light turns on for 3 seconds If device is not connected: Red light blinks on and off for about 5 seconds
When device connects with cellular network and GPS: Press the on/off button and quick release	Blue light turns on for 3 seconds
Check if the device is ON or OFF: Press the power button quickly	If the device is on, green lights turns on for 3 seconds. If it is off, no lights turn on



Switch Off: Press the power button and hold for 3 seconds	Red light blinks three times, the tracker turns off
Press the SOS button and hold for 2 seconds	Green light blinks twice
Low battery	Red light blinks
Battery is charging	Red light blinks slowly
Connected to a power source and battery is fully charged	Red light solidly lit up

ADDITIONAL INFORMATION

The following information is only required the very first time the tracker is turned on. If you are partaking in this PhD study, this procedure has already been completed by the researcher.

FIRST TIME USE

When powering the device on for the first time, follow this method:

1. Connect the charging plug of the charging cable to the tracker with the magnetic charging port.

2. Press and hold the power button for at least 3 seconds. The green light on the front of the tracker should blink for a few seconds.

3. Put the tracker down and wait for at least 15 minutes.

The tracker will carry out initial GPS positioning. This is required for the device to function correctly. The tracker will then be ready for use and can be activated.

Activating the tracker

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1. Download the V by Vodafone app from the Apple Store or Google Play store (You can scan the QR code below to get a link to download the application).

2. Register or log into your V by Vodafone account and click on the + button to add a device.

3. Insert your tracker IMEI and follow the instructions to activate your price plan.

4. Download the TrackiSafe app from the Apple Store or Google Play.

5. Register or log into your TrackiSafe account.

6. Select "Activate device" in the operation menu and follow the instructions

APPLE STORE APP

ANDRIOD APP

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Appendix 6: Letter of Ethical Approval for Phase 1 of this study, dated 23rd December 2019

University of
Salford
MANCHESTER

Research, Enterprise and Engagement
Ethical Approval Panel

Doctoral & Research Support
Research and Knowledge Exchange,
Room 827, Maxwell Building,
University of Salford,
Manchester
M5 4WT

T +44(0)161 295 2280

www.salford.ac.uk

23 December 2019

Dear Matthew,

RE: ETHICS APPLICATION–HSR1920-008 – Exploring the impact of off-the-shelf GPS tracking technology on the Quality of Life of individuals living with Dementia and their care partners.

Based on the information you provided, I am pleased to inform you that application HSR1920-008 has been approved.

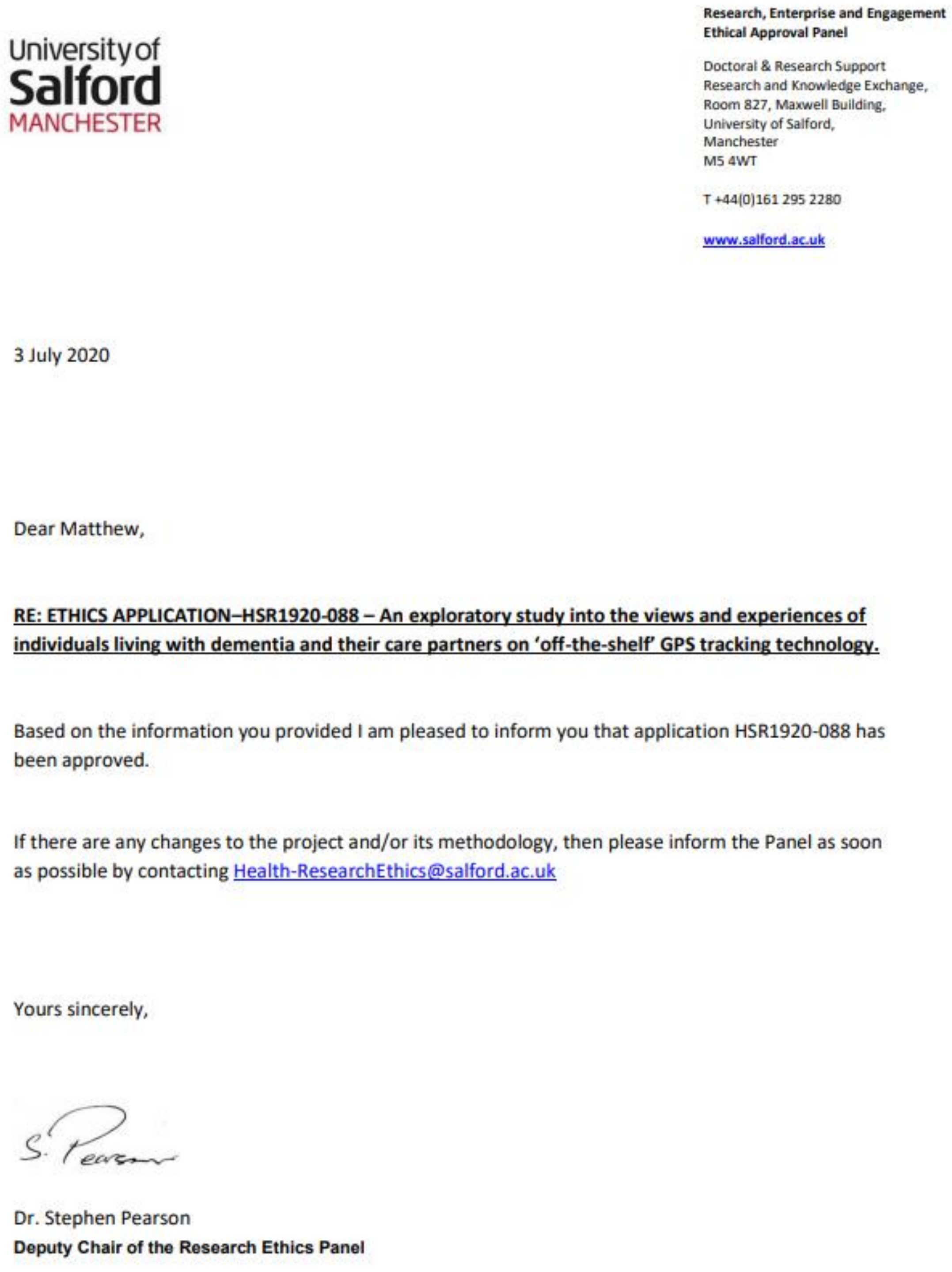
If there are any changes to the project and/or its methodology, then please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Yours sincerely,

K. Szczepura

Dr. Katy Szczepura
Deputy Chair of the Research Ethics Panel

Appendix 7: Letter of Ethical Approval for Phase 2 of this study, dated 3rd July 2020



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Research and Knowledge Exchange,
Room 827, Maxwell Building,
University of Salford,
Manchester
M5 4WT

T +44(0)161 295 2280

www.salford.ac.uk

3 July 2020

Dear Matthew,

RE: ETHICS APPLICATION–HSR1920-088 – An exploratory study into the views and experiences of individuals living with dementia and their care partners on 'off-the-shelf' GPS tracking technology.

Based on the information you provided I am pleased to inform you that application HSR1920-088 has been approved.

If there are any changes to the project and/or its methodology, then please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Yours sincerely,

S. Pearson

Dr. Stephen Pearson
Deputy Chair of the Research Ethics Panel

Appendix 8: Signed Ethics Amendment notification form, dated 4th December 2020

Amendment Approved:	**YES**	***Date of Approval:***	**04/12/2020**

Chair's Signature:

S. Pearson

Once completed you should submit this form and any additional documentation to the RKE Ethics Team at ethics@salford.ac.uk