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The lived experience of using safer walking technology - supporting meaningful occupation and identity for people with early stage dementia

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Acknowledgments

This research was undertaken part-time for over 7 years, mainly in the evenings and very early mornings whilst working as an occupational therapy lecturer and having three beautiful babies. The motivation and drive to keep going and complete the research came from a belief in the importance of good quality evidence to support occupational therapy intervention and improve the quality of life for people living with dementia. This would not have been possible without the generosity of my participants, who welcomed me into their homes and shared their experiences so openly.

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This thesis is dedicated to my PhD babies who made the whole journey that much harder and longer, yet so much more worthwhile.

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Abstract

Introduction: Safer walking technology is increasingly being used to support people with dementia to access the outdoor environment. Through the lived experience of both people living with early-stage dementia and family carers, this research sought to understand how safer walking technology is used and its potential to maintain engagement in meaningful outdoor occupations.

Methods: This qualitative research was collaboratively designed with stakeholders including occupational therapists, people with dementia, family carers and older people with an interest in technology. Data was collected from 18 in-depth interviews across two studies. These studies were analysed using phenomenological analysis techniques.

Findings: Safer walking technology is used to maintain occupational identity and well-being for some people with dementia through enabling access to meaningful outdoor occupations. Family carers and people with dementia are likely to adopt very different forms of safer walking technology, as they use it in different ways. People with dementia who took part in this study are creating their own technology solutions. Safer walking technology appears to have a 'useful window of time' for most users and participants within the study and 'giving up' the use of this type of technology was associated with experiences of loss.

Conclusion: The use of safer walking technology by people living with dementia and their carers to support access to outdoor environments is growing within the UK. There has been a shift away from the need to manage risks associated with outdoor spaces and an increased focus on the need to support independence and autonomy. This shift has been driven by both social policy and the needs and wishes of people living with dementia. The current range of safer walking technologies and smartphone apps rarely meets all the needs of people living with dementia, and so people living with dementia and family carers use what is available to them in innovative ways. Safer walking technology has the potential to prolong the maintenance of a healthy lifestyle for people with early-stage dementia, supporting their occupational identity.

Chapter 1 Introduction

1.1 Introduction

This chapter provides an overview of the thesis structure, explores key concepts from within the existing literature and provides a rationale for the research. The chapter also presents the research question, aims and objectives and a summary of key messages from this chapter.

The main body of this chapter explores existing research literature and key concepts relevant to this research, exploring the current literature and ideas through narrative review. In their paper, *'A typology of Reviews',* Grant and Booth (2009) describe a narrative literature review as a method that seeks to identify what has been accomplished previously, allowing for consolidation, for building on previous work, and for identification of omissions or gaps. Although not always systematic in literature searching methods and selection, the findings are often presented in a narrative form enabling a picture of evolving ideas and knowledge to emerge. This introductory chapter therefore presents a narrative literature review that initially looks at the main influencers on the current UK culture of dementia care, including a description of the ideas and ideologies that have influenced our understanding of dementia and how we support and care for people with dementia, such as the rise of 'person-centred care' and the influence of the social disability model.

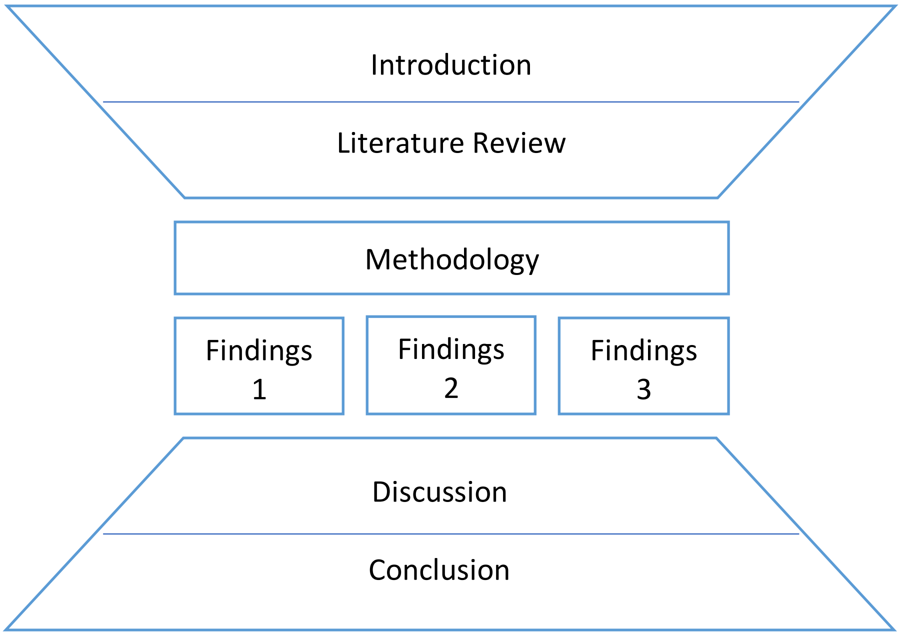
Seeking to explore the impact of dementia on the individual, the importance of identity is explored including personhood and the impact of dementia. Acknowledging the researcher's professional background as an occupational therapist, an occupational perspective is then examined, with key terms defined from the occupational therapy and occupational science literature. This leads to an examination of occupational identity and the impact of occupational deprivation on people with dementia.

This introductory chapter then explores the growing interest in 'green care', and connectedness to nature and maintaining outdoor occupations. A great deal of literature has been published on these topics for the general population and this is described and linked to an emerging body of work that considers the importance of these issues in the field of dementia care. Acknowledging that for many people with dementia there are considerable barriers to accessing outdoor environments, this chapter then goes on to identify a potential role for assistive technology in supporting people with dementia to access the outdoors.

1.2 Thesis overview

This thesis follows a traditional IMRAD model of thesis presentation: Introduction, Methodology, Results, and Discussion. This is common in science and healthcare subjects and enables a clear focus on the key areas of research to be presented (Kamler and Thomson 2014: 115).

Figure 1 Thesis structure



Introduction – *Chapters 1 + 2*

The thesis starts with two introductory chapters, the first offering a general overview of the research topic and identifying the core research question and objectives. The second chapter then offers a review of literature and a critical overview of existing published research in this field.

Methodology – *Chapter 3*

The research design consists of two studies, with identical interpretative phenomenological analysis (IPA) methodologies, but with different groups of participants. The methodology chapter examines the epistemology of the research approach and provides a full description of the methods undertaken across both studies.

Results – *Chapters 4, 5 + 6*

The findings from these two studies are presented as three separate chapters. The first of these explores the thematic findings of study 1 and the second explores the thematic findings of study 2. Additional findings identified from looking across both studies are then presented as combined findings in the third findings chapter.

Discussion – *Chapters 7 + 8*

The research is discussed across two chapters, the first of which offers an in-depth discussion of the new and original findings from this research and a consideration of the findings in the context of the wider research in this field. The final chapter then draws together the key findings and new knowledge derived from the research and offers suggestions for further research.

1.3 Dementia

Dementia is a global public health challenge and is one of the major causes of disability and dependency among older people (World Health Organisation and Alzheimer's disease International 2012). It is estimated that the global prevalence of dementia will increase to 115.4 million by 2050 (United Nations 2013). In the UK there are currently 850,000 people with dementia, and this is predicted to rise to 1 million by 2025, 2 million by 2050 (Alzheimer's Research UK 2019). The number of people recognised as living with dementia has increased significantly in recent years, in part due to a government-led initiative to increase awareness and promote early diagnosis of the condition (Brayne and Kelly 2019) but, mainly due to increased life expectancy. Dementia is an umbrella diagnosis for over one hundred different conditions, the most common of which are Alzheimer's disease and Vascular Dementia. These many varied conditions, categorised within the term Dementia, are associated with a wide range of changes within the brain – all of which contribute in some way to accelerated cell death and impaired function of the remaining cells, (McKeith and Fairbairn 2001:10).

Tom Kitwood’s (1997: 16) commonly quoted statement is that ‘when you have met one person with dementia, you have met one person with dementia’. This is an indication of the unique and personal way these progressive conditions are experienced. It is not easy to predict how the variable symptoms may manifest themselves, or how the individual and their family will respond (Whitlatch 2014:167). Therefore, the potential impact of dementia is unpredictable within the unique and complex lives of each person. Rahman and Howard (2018: 20) describe dementia as an acquired and progressive loss of cognitive functions that is enough to interfere significantly with day to day functioning. Common early symptoms of both Alzheimer's Disease and Vascular Dementia include short term memory loss, difficulties with language, concentration, planning and organising (Rahman and Howard 2018: 22). Difficulties with spatial disorientation increase as dementia progresses and over time can impact upon social activities. Teipel et al. (2016) report that patients consequently reduce outdoor mobility leading to a more sedentary lifestyle, with an impact on overall quality of life and with a secondary impact upon on cognitive functions, brain plasticity, mood, and cardiovascular function.

Dementia can be complicated and is often discussed and understood within different epistemological frameworks, including that of an ageing brain. Human ageing has many dimensions, but at its heart is a biological process, (Westendorp and Kirkwood 2007: 13); and it is this biological process that is the basis of the biomedical approach to disease and illness. The biomedical model offers the prospect of treatment for people with dementia and has led to the development of a range of drug treatments. At present these drugs seek to slow down the rate of cognitive decline and alleviate some of the symptoms of dementia but do not represent a cure (Blows 2016: 308). The power of these developments to inspire hope in those living with, and those caring for others with dementia should not be underestimated (Bailey 1997). However, the biomedical model is one part of a more complicated picture and has also been criticised for failing to consider socio-cultural factors and the experience of the person living with dementia. It was argued by Downs, Clare, and McKenzie (2006:242) that the biomedical model was the medicalisation of old age, defining all aspects of the process of ageing within the brain as a medical problem and mandating the medical profession to find some form of treatment for it (Bond 2001: 54). In the last three decades, there has been a paradigm shift in approach as a result of critique of the medical model. This has been associated with the development of psychotherapeutic approaches to the care of people with dementia. Most notably the work of Kitwood (1997), has challenged the medical model arguing that organic factors have been emphasized to the neglect of psychological ones (Balfour 2007: 224). Also drawing its principles from Rogers (1961) earlier work on client-centred care, Kitwood's model of person-centred care seeks to change the standards of care for people with dementia. The concept itself lies in the meeting of two different kinds of discourse: the ethical (what we ought to do) and the social-psychological (how we do it), (Kitwood 1997: 18). Therefore, this approach recognises the rights and values of the individual, and challenges dehumanizing care practices and behaviours which undermine a person's identity and expression. A person-centred approach to dementia care shifts the focus from a purely biological set of symptoms to a moral and ethical focus on the individual with dementia. A testament to the influence of this model, the term person-centred care has become all persuasive in the UK dementia care community, becoming synonymous with good quality care (Brooker 2004). Person-centred care shares its theoretical underpinnings with the client-centred care core to occupational therapy principles and practice, discussed later within this chapter. Within the field of dementia care, there has been a large shift towards the application of these principles to therapeutic interventions for people with dementia and the well-documented adoption of non-pharmacological interventions, (Graff 2006), with a strong evidence base for the value and effectiveness of community occupational therapy services, such as those documented by Wenbourne et al. (2016), in the VALID (Valuing Active Life in Dementia) Randomised Control Trial.

The sociological perspective adds, to this person-centred approach, a greater concern for the social and environmental context in which illness arises (Jones 1994: 64). From this perspective has arisen the social disability model, in which disability is perceived as being caused, not by the person's impairment but, by the physical and social barriers which restrict a person's opportunity to engage fully in society (Oliver 1990). Although this model has been widely accepted within the care of people with physical disabilities, it has only been applied to those with cognitive impairment, such as people with learning disabilities or dementia relatively recently to those with dementia. Yet, many researchers have called for the fundamental principles of the social model of disability to be extended to include those with cognitive impairment (Bartlett and Connor 2007; Brittain et al. 2010). Framing dementia within the context of a disability has many benefits to people with dementia and how they are viewed by society (Gilliard et al. 2005). The focus of the social disability model is on remaining abilities, instead of losses and the recognition of discrimination within society, challenges us as health professionals to view the person living with dementia differently (Harding and Palfrey 1997: 104).

The application of the principles of the social disability model to the wider environment in which people with dementia live has seen a range of ‘age-friendly' and ‘dementia-friendly' initiatives developed. The World Health Organisation (WHO) has identified the need for age-friendly cities as they encourage active ageing by optimising opportunities for health, participation, and security to enhance the quality of life as people age. According to the WHO guide to global age-friendly cities (WHO 2007:13), one key feature of an age-friendly city is the importance of green spaces to promote both ‘green exercise', such as walking, and space for connections to nature. This has, in turn, led to several research studies championing the need for greater access to outdoor environments to promote wellbeing and quality of life in older people (I’DGO 2013). These studies focus on changing the fundamental design of our shared community environments to be more inclusive and accessible to older people and people with dementia. Other research suggests that improved quality of life could be achieved for people with dementia by changing factors such as street signage, pavement surfaces, street lighting as well as having accessible green spaces (Sugiyama, Thompson, and Alves 2009). In 2012, the then Prime Minister David Cameron launched The Prime Minister’s Challenge on dementia, which was a call to drastically improve quality of life for people with dementia, their families and friends. The Challenge’s substantial programme covered three areas, one of which is dementia-friendly communities (Department of Health 2012). The development of these strategies demonstrates the practical application of the social disability model, identifying the challenges and barriers in communities and environments rather than focussing upon the limitations or difficulties experienced by individuals.

1.4 Personhood and identity in dementia

First-hand accounts and ‘insider literature' from the perspective of people with dementia were a rarity in the published literature until the mid-1990s. Since then a steady stream of books has been published, written with or by people with dementia (Simpson and Simpson 1999; DeBaggio 2002; McGowin 2004). These have included books such as Christine Bryden’s ‘*Will I Still Be Me? Finding a Continuing Sense of Self in the Lived Experience of Dementia,’* (Bryden 2018). Written as an exploration of the author's ‘journey' through her dementia, Bryden explores and challenges notions of losing her sense of ‘self’ and the fundamental traits and experiences that make up her identity. As seen in the following extract from the first chapter:

“The journey of becoming, of leaving behind previous perceptions of who we are, is common to us all, as part of our life’s narrative. We discover new aspects of ourselves as time goes by. Yet those of us diagnosed with dementia fear a very different journey – one of loss, of losing our relationships, not only with others but with what gives us meaning in life." (Bryden 2018: 15).

Discussions of self-identity, loss of self and the importance of identifying what gives meaning in life all occur frequently within the first-person literature (Bute 2018) and in recent years have also been common themes within the many blogs, written and published online by people with dementia (Mitchell 2018; Rook 2018). For many years the voices of those with dementia were largely ignored in the research literature. In the United States, the subjective experience of Alzheimer's disease was discussed most notably by Sabat and Harre (1992). However, these discussions were largely confined to within the dementia research community, Harris (2002:201). In the UK it was the work of Kitwood and Benson (1995: 29) that advocated a shift in emphasis towards understanding dementia as a subjective experience. These subjective ‘lived’ experiences highlighted that a diagnosis of irreversible, progressive memory loss or dementia can have an impact on how a person views themselves i.e. their ‘personhood’. This concept of personhood is central to Kitwood’s model of ‘person-centred care’ and Kitwood’s writing focuses on how dementia care practices can act to either strengthen or undermine an individual’s sense of themselves, defined as their ‘personhood’

(Kitwood 1997: 47). Key to Kitwood's work is the concept of 'malignant social psychology' and with it the potential harm that poor or ill-considered practices can have upon an individual's personhood. Yet, Kitwood's work on identity is limited, not least by his identification of personhood as 'status bestowed upon one human being by others' (Kitwood 1997: 18). Despite this, the term personhood has become incorporated into a common understanding of self –identity in dementia, and there is a small but notable collection of published 'self-help' books for people with dementia. Such publications offer advice on a range of relevant areas from diagnosis to advanced planning and often incorporate advice on 'how to maintain personhood' (Burgener and Twigg 2007:24).

It was at this time that Cheston and Bender (1999: 214) also began to develop the model of 'person-focused care', in which the provision of care is designed to meet the emotional needs of the person living with dementia. This approach attempts to view the world through the eyes of the person living with dementia and seeks to increase their emotional security and overall well-being. They argue that the ability of an individual living with dementia to feel sufficiently secure in their social environment and to share their feelings and emotions depends upon the extent of their cognitive impairment and the social context in which they exist (Bender and Cheston 1997). They advocate for the development of services that enable individuals with dementia to maintain a sense of their own identity, but some of their argument is problematic in a modern context, for example, they go on to describe how professionals must *allow* them to retain a sense of personal continuity (Cheston and Bender 1999: 231). Cheston and Bender's work argues for a tolerance of otherwise inexplicable behaviours, and for attempts to try to understand and respond accordingly rather than attach a label to the behaviour and not look further. The key to all of the approaches so far is that they focus on the behaviour of others around the person with dementia. Contrasting to this is the research of Sabat (2002) whose work provides an in-depth exploration of the notion of self in dementia and how experiencing dementia impacts upon the person's self-identity. Sabat acknowledges the important influence of carers, family, and professionals in how a person experiences their dementia, often referencing Kitwood's (1997: 45) work on malignant social psychology. Sabat also highlights the fundamental role the person's psychological reaction to their dementia has on their sense of self and self-identity (Sabat, 2014: 119). In recent years the research interest in self-identity for people with dementia has increased and a systematic review (Caddell and Clare 2010) identified that there was some debate in the literature about the extent to which a sense of self and identity are retained by people as their dementia develops. Within a recent article on the continued sense of self within the lived experience of dementia, Bryden (2018) advises that although people with dementia experience a change in their cognitive sense of self, there are still important aspects of self that remain: a sense of being; an embodied self, in relationship with others; and being able to find meaning in the present moment. Research by Andrew, Philipson, and Sheridan (2018) supports this and identified that maintaining meaningful roles and associated identities were significant in the person with dementia's perception of themselves and their self–curated identity.

1.5 An occupational perspective

The clinical experience of the researcher as a specialist occupational therapist in dementia has strongly influenced the development of this research. Occupational therapy is a client-centred health profession concerned with promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life, (World Federation of Occupational Therapists 2010). The profession aspires to keep occupation at the core of practice by understanding and respecting how people value different occupations, and how these come to shape identity (Pentland 2018: 54). Creek et al. (2005) describe occupational therapy as a complex intervention and suggest that there can be no standardised interventions within the discipline because of the unique life histories, social contexts and occupational needs of their clients (Creek 2005: 283).

A review of occupational therapy (OT) intervention with people who have dementia reported by Schmid et al. (2015) confirms the wide variety of interventions commonly identified within the research literature. These included studies which described a wide range of non-pharmacological interventions that focused on the delay of functional decline in people with dementia at home. These included maintaining a person’s ability to participate in societal activities and improving quality of life via home modification, occupation-based activities, and caregiver education. (Kim et al. 2012; McLaren, LaMantia and Callahan 2013; Gitlin, Kales and Lyketsos 2012). Key to this research is an understanding of the theoretical underpinnings of the OT profession, these include an understanding of people as occupational beings and the core concepts of client-centred practice, occupational well-being, occupational deprivation, and occupational justice; each of these concepts is explored in the discussion below. Occupational therapy core principles are fundamentally underpinned by Carl Roger's (1961) work on client-centred practice but have reflected a holistic approach to the individual and an understanding of the important relationship between 'doing' and wellness for over 100 years (Thibeault 2001: 232). Christiansen and Townsend define occupations as "all the things people do every day that are purposeful, meaningful and culturally relevant" (2004: 74). A deep-rooted belief within the profession of occupational therapy is that a balance exists between the ability to look after oneself (self-care), contribute to society and be economically active (productivity), while also enjoying life and having fun (leisure) and that this maintains health and well-being (Zemke and Clark 1996: 2; Reed and Sanderson 1999:32; Turner 2002:29). Occupational therapists have a strong belief in the importance of occupation and the recognition of individuals as occupational beings by nature and have the capacity and need to participate in occupation, (Yerxa et al. 1989). Occupational therapists believe: that people have an intrinsic drive to be active; that engaging in satisfactory, meaningful occupations is key to promoting health and wellbeing (Wilcock 1998: 104; Wensley and Slade 2012); have long asserted the role of occupations in influencing people's health and well-being across the life cycle (Wilcock 2001). "Occupational well-being is an experience in which people derive satisfaction and meaning from how they have orchestrated their occupational lives" (Doble and Caron Santha 2007:69). Occupational therapy also emphasises the transformative nature of occupation as a therapeutic medium, promoted through the concepts of 'Doing, Being, Becoming.' (Wilcock 1998:249). Constructing a healthy occupational life is complex and dynamic, shifting according to the changing needs of the person and their context (Pentland 2018: 4)

Consideration of how self-identity is influenced by the ability to engage in meaningful occupations has led to a greater discussion on how engaging in these occupations is key to the development and maintenance of people's occupational identity (Howie, Coulter and Feldman 2004) and how life meaning and self-esteem are linked to this concept (Braveman and Helfrich 2001). The concept of occupational identity has been proposed as central to understanding the role occupation plays in human life (Rudman and Dennhardt 2008).

Christiansen initially proposed the connection between occupation and an individual's personal and social identity in the occupation focused literature; he states that 'when we build our identities, through occupations, we provide ourselves with the contexts necessary for creating meaningful lives, and life meaning helps us to be well' (Christiansen 1999: 547). This suggests that engaging in occupations helps shape our personal or self-identity. This seminal work has served as an important foundation for advancing conceptualisations of occupational identity in occupation-based disciplines (Phelan and Kinsella 2009). Occupational identity is a core concept of the person as an occupational being (Unruh 2004) and gives a composite sense of who one is and wishes to become as an occupational being generated from one's history of participation (Keilhofner 2002: 120). In support of this, research by Howie, Coulter, and Feldman (2004) links the ability to shape our occupational identities to our choice of the occupations we engage in. For example, someone who regularly engages in a particular occupation, such as cycling, does so because they enjoy the activity, but may also reflect their self-selected identity as a 'cyclist', which forms part of their overall occupational identity. Christiansen (1999) describes occupational identity as the unique way we choose to 'orchestrate our lives'; our unique and individual sense of self is expressed by selecting how we occupy our time, particularly our leisure time. Phelan and Kinsella (2009) argue that occupations are key, not just to be a person but, to be a particular person, and thus creating and maintaining an identity. Pentland (2018: 4) also maintains that understanding people as occupational beings place occupation as foundational to who we are and whom we will become. Whilst many factors are known to limit individual choice, fundamentally it is argued that adults can control the balance of their occupations (Turner 2002:27). Occupations come together within the contexts of our relationships with others to provide us with a sense of purpose and structure in our day-to-day activities, as well as over time.

The Royal College of Occupational Therapists' (RCOT) definition of occupational therapy (RCOT 2014: 2) describes these fundamental values and beliefs in the following statement:

"Occupational therapists view people as occupational beings. As occupational beings, people are intrinsically active and creative, needing to engage in a balanced range of activities in their daily lives to sustain health and wellbeing. People shape, and are shaped by, their experiences

and interactions with their environments. They create identity, purpose, and meaning through what they do and have the capacity to transform themselves through conscious and autonomous action.”

The link between identity and occupation is supported by a growing body of qualitative research, such as that of Rudman (2002) who identified across many studies an important relationship between the ability or inability of participants to engage in meaningful activities and how the participants perceived themselves (personal identity). Vrkjan and Polgar (2007) also noted the importance of understanding how changes in the ability to participate in meaningful occupations may challenge an individual’s perceived occupational identity.

Unruh et al. (2002) proposed that changes in health or life circumstances can lead to crisis and necessitate re-formulation of occupational identity. Yet, Vrkljan and Polgar (2007) identify that it is also important to explore how changes in the ability to participate in meaningful occupations may challenge the perceived occupational identity of the individual, especially where that occupational identity is strong and is a long-held part of the individual's life. Occupational therapists also, therefore, recognise the potential for occupational deprivation; Whiteford (2000:201) defines occupational deprivation as “a state of prolonged preclusion from engagement in occupations of necessity and/ or meaning due to factors which stand outside the control of the individual.” Whiteford (2010: 309) also distinguishes occupational deprivation from occupational disruption, a temporary condition that may be due to a period of illness (Durocher, Gibson and Rappolt 2014). Examples of occupational deprivation from practice can be seen in the research of Vrkljan and Polgar (2007) who explore driving cessation for older adults. Driving cessation is a commonly discussed area within research and practice that includes both the processes of reducing driving activities and stopping driving altogether. Their findings highlight the impact of both of these on the person’s ability to participate in meaningful occupations and the consequential impact on their occupational identities, overall health and well-being. Unruh, Versnel, and Kerr (2002) also proposed that changes in health or life circumstances (such as a diagnosis of dementia) can lead to a crisis in occupational identity. The impact of dementia on occupational well-being, identity, and health is explored within published literature, but there is a tendency to focus upon the experience of occupational deprivation of those with dementia living in institutional care (Mozley 2001;

O’Sullivan 2010; Hocking and Wright-St. Clair 2011). There is a paucity of research that directly explores how living with early-stage dementia at home can impact a person's occupational choices and occupational identity, yet a review of research literature which explored dementia and occupation identified that occupational therapists have a major role in addressing occupational performance issues among people with dementia (Egan, Hobson, and Fearing 2006).

1.6 Outdoor occupations, nature, and greencare

Sempik, Hine, and Wilcock (2010: 1) describe ‘green care' as an umbrella term for a broad spectrum of health-promoting interventions that use nature within their approaches. Enabling access to outdoor spaces and supporting outdoor occupations within them is commonly addressed within occupational therapy practice (Wensley and Slade 2012). Duggen et al. (2008) also identify that the outside spaces and interactions within it are also important sources of identity. The importance of connectedness to nature was first described by Wilson (1984: 1), who explains the concept of ‘Biophilia’ as an instinctive tendency to make contact with nature. Barton and Pretty (2010) found that improved self-esteem and mood can be experienced from as little as five minutes spent in natural environments, whether these be green (plant-based) or blue (water-based). There is a large body of research from both the health and environmental psychology fields to support the contention that people derive both physical and psychological benefits from spending time in the natural world (Pretty 2004, Pretty et al. 2009, Mayer et al. 2009, Burls 2007, MIND 2007). This research suggests that connections and contact with natural environments enable greater opportunity to undertake ‘green exercise’, and improve psychological health by reducing stress, improving mood and providing a restorative environment (Sempik, Hine, and Wilcock 2010: 19). In recent years recognition of these benefits has seen the rise of ‘Forest Schools’ for younger people (Waite, Bowling, and Bentsen 2016). Wyles et al. (2017) also found natural environments and connectedness to nature enhance psychological restoration. From this research therapeutic intervention has been designed to promote maintenance of good mental health in a range of settings through associations between nature connectedness and mindfulness (Howell et al. 2011) and nature-assisted therapies (Annerstedt and Wahrborg 2011; Poulsen, Stigsdotter, and Refshage 2015.)

Connectedness to nature has also been explored within the international public health research field, with research demonstrating that contact with nature also has the potential to improve health through facilitating social opportunities and encouraging physical exercise (Health Council of the Netherlands 2004). In response to this growing body of research, there has been an increase in public health promotion of 'green exercise' (Pretty et al. 2005) and in particular the use of walking to promote good health and wellbeing. Research studies in this area indicate that accessing outdoor green environments improves health among older people (Rappe Kivela and Rita 2006) and has positive effects on long-term functioning and health benefits, if undertaken daily (Jacobs et al. 2008). Orr et al. (2016) found that older people derive considerable pleasure from being and doing in nature, which in turn has a positive impact on their well-being and quality of life. They identified that time spent in nature enriches the everyday life of older people, helping them maintain a sense of self. In addition to the health and well-being benefits discussed above, connections to nature have been shown to improve communication, bring joy and provide sensory stimulation to people with dementia (Chalfont 2006). There is a strong commercial and research interest in the development and use of outdoor 'dementia-friendly' gardens in care facilities that have been well documented for many years (Charras et al. 2018). Yet, Blackman et al. (2003) have argued that there has been little consideration of how people with dementia might be assisted to maintain personally meaningful outdoor occupations such as walking, cycling or fishing as traditional views of dementia have focussed upon minimising risks and therefore supported confinement indoors. The exception to this is in the field of horticultural therapy, where there is limited but persuasive literature demonstrating an awareness of its benefits when undertaken with people with dementia (Hall et al. 2018; Blake and Mitchell 2015).

Within dementia research literature there is a growing interest in the benefits of outdoor environments and greater access to the natural world (Chalfont 2005; Rappe, Kivela and Rita 2006; Duggen at al. 2008; Mapes 2010). Gilliard and Marshall 2012:11). Duggen et al. (2008) report that outdoor environments are important to people with dementia identifying that there is a need to hear more from people with dementia themselves about how dementia affects their 'ordinary' lives. Their research focussed on the views of 22 people with dementia and their family carers about their use of the outdoor environment. The results suggested that people with dementia face a ‘shrinking world’, where the combined impact of reduced confidence, fear of getting lost and increased anxiety have the potential to reduce the areas they feel comfortable in accessing independently. This research area has been expanded over the past two decades by both Chalfont (2005) and Mapes (2010, 2012, 2013, 2016), whose research into the benefits and barriers of accessing natural environments has re-shaped our understanding of what people with dementia want in terms of outdoor access and how to support them to achieve this. Mapes identifies that:

“There is something deeply personal and deeply emotional about our connection with nature. It is essential that we strive to find ways to enable this personal and emotional connection to remain in the presence of advancing dementia”. (Mapes 2010: p7)

Chalfont first published a bibliography of all available literature on the benefits of natural environments for people with dementia in 2005, with his research focus on promoting access to nature through environmental design. Mapes’ subsequent research has then built on this and included further research such as *‘Living with dementia and connecting with nature – looking back and stepping forwards*’ (2010) which explored the experiences of people with dementia engaging in green exercise programs such as organised walks. Also, of note is his work with the Woodland Trust exploring an action research project *‘Wandering in woodland’* (2012) and more recently Natural England commissioned reports *‘Greening Dementia’* (2013) and *‘Is it nice outside?’* (2016). Significant to the potential impact of these studies is their central placement of the person living with dementia in the data, seeking to understand their personal experiences and meaning making within the natural environment.

Brittain et al. (2010) found that accessing natural outdoor spaces within communities can be challenging for people with dementia. Mapes’ (2013) systematic review of published literature on the benefits and barriers facing individuals living with dementia in accessing natural environments and local greenspace identified that evidence of benefits, for people with dementia, from access to natural environments is limited and greater research into this area is needed (Mapes 2013: iii). However, the general findings of the review indicated an overwhelmingly positive impact upon people with dementia when they had access to natural environments, with clear evidence of improved emotional state, physical health, verbal expression, memory and attention, awareness, sense of wellbeing, social interaction and sense of wellbeing. Most people with dementia in the UK are living in the community (Alzheimer's Society 2015) and the findings of Mapes' review also identified that people with dementia in the community face many barriers to accessing natural environments. Within his review, Mapes (2013) also identified barriers that particularly affect people with dementia include: concerns about how they are perceived; a lack of awareness of the needs of people with dementia among greenspace organisations and their staff: the costs of resourcing visits; and the impact of risk aversion among people with dementia, their family carers, and service providers. Mapes' (2013) recommendations included the need for greater research and evaluation of studies to quantify benefits of engaging with nature for people with dementia, particularly regarding the mental and physical benefits and the cost benefits of different intervention involving nature. Mapes also recommended that critical to all future research is that it be user-led, with greater inclusion of people with dementia in helping shape the research and initiatives

Taylor and Donnely (2006) found that the realities of enabling access for people with dementia to outdoor environments are complex in an increasingly risk-averse society. The consequences of becoming lost can be as severe as death, with numerous such cases of deaths having been reported in the news media after individuals with dementia became lost (Rowe, Feinglass and Wiss 2004). The potential to become lost, combined with an inability to return home independently, compromises the person's safety and well-being, causing great distress and anxiety to the person with dementia, their families and carers (Dunk, Longman, and Newton 2010). Spatial disorientation and associated problems with wayfinding or getting lost are common experiences in early-stage dementia (Pai and Jacobs 2004; Yew et al. 2013). This can lead to people with dementia getting lost and behaviours traditionally labelled as 'wandering'. In their seminal work in this area entitled 'Dementia: walking not wandering', Marshall and Allan (2006: 11) sought to reframe what is meant by the widely used but non-specific term 'wandering'. They argue that wandering should be more accurately described as walking and viewed as a healthy activity, fully understood by professionals as a beneficial activity and not categorised as a 'problem' behaviour. Yet, Wherton et al. (2018) acknowledge an ongoing discourse within both policy and clinical literature between the understanding of 'wandering behaviour' from a biomedical perspective and a person-centred tradition. The focus within a biomedical perspective is on the observed characteristics of this behaviour with terminology such as 'eloping' and 'pacing' often used to describe what is seen as 'aimless' wandering (Halek and Bartholomayczik 2012; Algase et al. 2010.) Conversely within the person-centred literature this behaviour is described as walking or wayfaring *with a purpose,* expressing social practice through habitual embodied actions and routines (Martin, Kontos and Ward 2013; Graham 2017).

1.7 Safer walking technology and dementia

Orr et al. (2016) found that older people, particularly those with dementia, may need additional support to enjoy the natural environment. Duggen et al. (2008) argue that assistive technology which tracks or locate people with dementia might offer some solutions to these difficulties. Technology offers much potential and can make a very significant difference in the lives of people with dementia (Cahill et al. 2007). Definitions of technology are variable and contradictory, each seeking to clearly define the sub-category of technology described. For example, use of the term Assistive Technology (AT) is widely accepted for most electronic or digital forms of technology used to support or aid people with an illness or disability (Abbott 2007). Within the published literature other technology such as automatic opening doors or electronically controlled curtain/ blinds, are often described as an everyday technology, but could be adopted to support a person with an illness or disability (Malinowsky et al. 2010). Brittain, et al. (2010) explored the lived experiences of people with dementia who regularly accessed outdoor environments and found that 'everyday' technology mediates between people with dementia and their physical and social environments, promoting the outside as an 'enabling space' for many. For this thesis, in an attempt to capture the widest possible use of technology, all descriptive terms including every day and assistive technology are accepted.

Despite various forms of assistive technology being recommended by The Department of Health (2018) and National Institute for Health and Care Excellence (NICE) (2013), knowledge about how technology can be used by people with dementia and access to assistive technology is variable (The Alzheimer's Society 2011). Godwin (2012) reports that this is partially due to ethical concerns about its use but may also be related to the rapidly changing nature of the technology itself (Cahill et al. 2007). There is also an acknowledged danger of assistive technology being viewed as a panacea (Woolham 2006:5) and in the wake of their rollout, the very real and subtle needs of the individual may be lost (Gilliard 2001). Wey (2006) argues for a person-centred approach to how assistive technology is used and Astell (2006) challenges us to question what drives these developments and whether the need and wishes of people with dementia, or the priorities and concerns of caregivers? Or are advances determined by the potential of the technology and its developers? These three motivations for technological developments have considerably different implications for people with dementia.

There is also some variability in the level of priority that the provision of assistive technology has been given by local authorities and health trusts. Levels of investment in the provision of assistive technology have varied across local authorities and health trusts in the UK. This is unsurprising, as research evidence such as the Whole Systems Demonstrator (WSD) report (Steventon et al. 2013), indicated that the provision of assistive technologies such as telecare systems did not have a significant impact on measurable outcomes. A national survey 'The Using Telecare for Older People in Adult Social Care' (UTOPIA) study (Woolham et al. 2018: 41) neither supports nor rejects the WSD findings but does point to variation in practice which might affect telecare effectiveness and outcomes. Evidence from the UTOPIA project suggests that it is how technology is being implemented and supported rather than the technology itself that can reduce effectiveness of delivery of the desired outcomes.

In some parts of the UK, the provision of assistive technology for people with dementia from social services and health trusts has included the availability of GPS tracking technology. There has been a rise of interest in locating or tracking technology designed for use by people with dementia and their family carers, due to several contributory factors and including:

- wider availability of technology that includes Global Positioning Systems (GPS) (Which? 2016);
- a greater focus on technology designed for supporting the independence of people with dementia at home (Gibson 2016);
- the increased acceptability of wearable technology (Elman 2018).

Blackman et al. (2003) argue that older people’s research focuses too much on their experiences inside their homes. Brittain et al. (2010) found that people with dementia can sometimes feel ‘out of place in outside space’ and call for a greater understanding of how the use of technology in outside spaces can support and enable people with dementia. A range of assistive technology solutions known as ‘Safer Walking Technology' has been developed which seek to track, locate, support or safeguard individuals with dementia when accessing outdoor environments.

The Alzheimer’s Society (2015:2) supports the use of safer walking technology, stating that it has the potential to enable some people with dementia to have greater freedom and independence. Currently, safer walking technology comes in several different formats and is being developed by a range of companies, but can be broken down into three main types:

- Global Positioning Satellite (GPS) Locating Technology, which informs the user of their whereabouts, such as hand-held satellite navigation, ideal for rambling in open countryside.
- GPS Tracking Technology which informs the user where someone else is, typically worn as a watch or on a keychain. These are useful for identifying a current location, for returning to a specific location such as home, a parked car or finding a lost person.
- Mobile Technology, with GPS technology built into smartphone or tablet devices. These are mainly being developed as apps and have the potential to do both tracking and locating and can, in some cases, be tailored to meet very specific needs.

Safer walking technology is used by people with dementia and their family carers for a range of uses and to meet a variety of individual needs. The technology in this field was initially developed to manage behaviour perceived as challenging and reduce the risk of harm if an individual were to become lost (Robinson et al. 2007). There has been a limited provision of this technology through social services in some areas of the UK, but there is also a growing market for the mainly online private purchase of specially designed trackers as well as integration of everyday GPS locating technology within smartphones and apps. More recently safer walking technology has been used to promote greater confidence amongst people with dementia to go out independently and engage in outdoor activities such as walking to support their well-being (Olsson et al. 2015). Within the dementia community, there is a growing interest in the use of this technology, especially by people living with early-stage dementia who wish to maintain outdoor occupations such as dog walking or cycling but wish to avoid becoming disorientated or lost. However, this same technology also has the potential to decrease autonomy and restrict movement, raising questions about confidentiality and loss of privacy (Hughes and Louw 2002). A systematic literature review of published research involving the use of safer walking technology for people with dementia over the past 11+ years is presented in chapter 2 of this thesis.

1.8 Research outline

1.8.1 Personal Context

Whilst the previous section has provided an objective rationale for the studies of this thesis, this section will outline the researcher's personal and professional interest in the study subject area. Within clinical practice, the researcher observed many people with early-stage dementia who experienced occupational deprivation. They stated that they felt unable to access previously enjoyed occupations, particularly those in outdoor environments, due to a perceived risk of harm or embarrassment through getting lost. Losing access to the green outdoor environments and engagement in meaningful occupations appeared to have a significant impact upon their health and well-being and in some cases the individual's sense of occupational identity. In contrast, another aspect of the therapeutic clinical work undertaken by the researcher in her role as an occupational therapist focused on enabling people with dementia to engage in green outdoor environments through occupations such as country walking groups, therapeutic horticulture allotment projects and promoting engagement in volunteer roles locally with the Woodland Trust. These outdoor occupations were used therapeutically by the occupational therapist to meet the individual goals and identified needs of each person, often resulting in improved health and well-being outcomes, greater occupational balance and a renewed or maintained sense of occupational identity.

It was observed by the researcher that several individuals and family carers were seeking to use mainstream and assistive technology, known as 'safer walking technology', to overcome the practical difficulties posed by their dementia. Whilst still, at the time, a developing genre of assistive devices, some clients found them helpful and they enabled greater access to green outdoor spaces and previously enjoyed occupations such as dog walking or 'rambling' in the countryside. However, such devices were not routinely provided or recommended by statutory services and little had been written about their use. The evidence base for using such technology in this field was, at that time, very limited, yet anecdotal experience informed the researcher that there was great potential for the use of this technology to support people with dementia to engage in meaningful occupations outdoors. To understand how best to support people with dementia, it was felt important to first understand how they experienced using safer walking technology themselves, what motivated them individually and what aspects of this experience held meaning to them. For some people with dementia the decision to start using safer walking technology was initiated by their family carer and the technology itself was often operated by family carers. The following research question aim, and objectives were developed:

1.8.2 Research question

What are the experiences of people living with early-stage dementia and family carers of using safer walking technology to maintain outdoor occupations?

1.8.3 Research aim

The aim of the research is to identify how safer walking technology is currently being used and the potential it has for supporting occupational identity and well-being through enabling access to meaningful outdoor occupations for people living with early-stage dementia.

1.8.4 Research objectives

1. To understand the experience of using safer walking technology from both the perspective of people with early-stage dementia and family carers.

2. To identify which forms of safer walking technology are being used and what barriers and enablers users experienced.

3. To determine the potential role of safer walking technology in supporting occupational identity and well-being for people living with early-stage dementia.

1.9 Key Messages

- Dementia is an umbrella term for a set of complex conditions that affect each individual differently; it is prevalent in the UK and internationally and is set to increase significantly in coming years. Social and person-centred perspectives of dementia care ensure the needs and wishes of the person are at the centre of the way we view and support people with dementia in our communities.

- Occupational identity is shaped by the meaningful occupations we choose. Identity and personhood are important issues in maintaining health and well-being for people with dementia, who are at risk of occupational deprivation if unable to engage in meaningful occupations.

- Safer walking technology has the potential to support meaningful outdoor occupations. In addition to maintaining occupational identity, enabling access to outdoor environments has additional health and well-being benefits, through enabling increased physical exercise, reduction in psychological symptoms and the restorative impact of connections to nature.

- This research seeks to identify how safer walking technology is currently being used and the potential it has for supporting occupational identity and well-being through enabling access to meaningful outdoor occupations for people living with early-stage dementia.

The next chapter presents a literature review which, through a systematic approach, explores the research literature on the use of safer walking technology published over the last 11+ years.

Chapter 2 Literature review

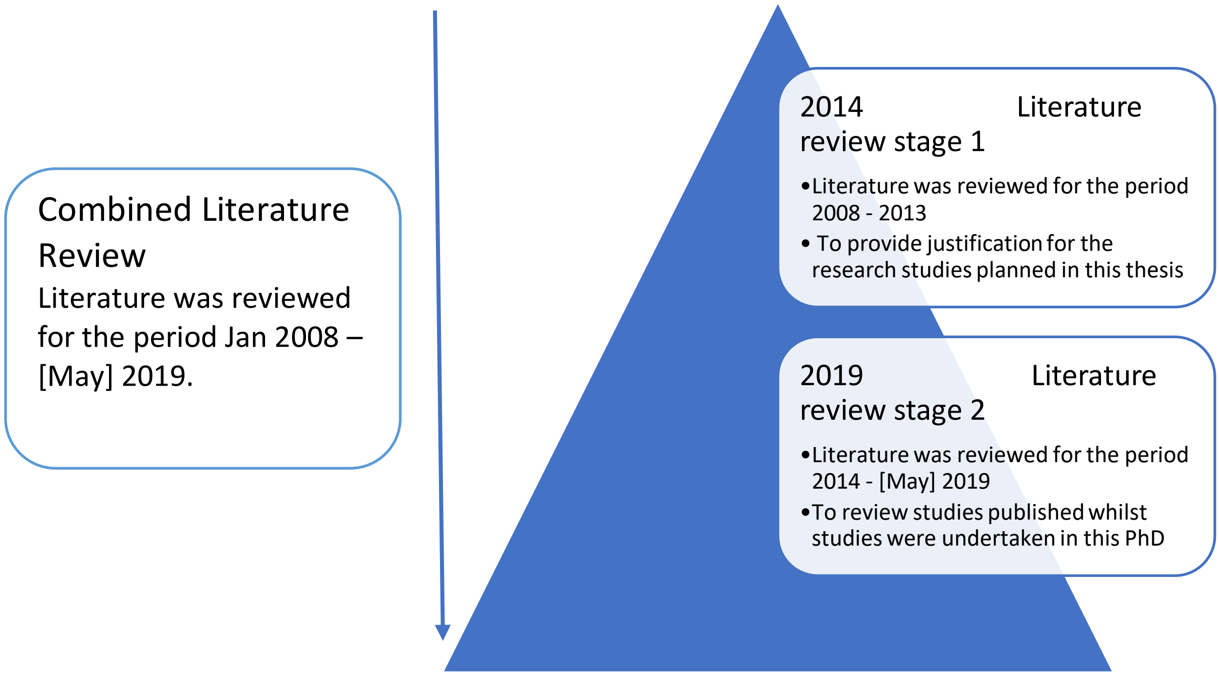
2.1 Introduction

This chapter presents and discusses a literature review undertaken to identify and evaluate research evidence around the use of safer walking technology for people with dementia. As identified in the introductory chapter, safer walking technology comes in several different formats and is being developed by a range of manufacturers/ suppliers. Recently there has also been an increased interest in wearable, trackable technology by the general public (Williamson et al. 2017) and so technology which enables the tracking and locating of individuals has become more available and mainstream. Tracking and locating functions are often found within the functions of common everyday technology such as smartphones, activity monitors and running watches. For the purposes of this review and to capture the widest possible use of the technology by people with dementia, all descriptive terms for the technology, and all forms of safer walking or locating technology were accepted within the literature review.

The review methodology described in this chapter includes a detailed account of all research synthesis and appraisal processes employed. Key findings from each stage of the literature review are presented before a final discussion of their overall meaning and implications drawn for this research project and its design. The purpose of this review was to identify the current knowledge and gaps in research within this field. Highlighting areas of research interest and where there is a need for further research, the synthesis of existing research also provides a background and context to the studies undertaken in this thesis.

A robust search strategy, described later within this chapter, enabled the literature in this field to be identified and reviewed in a systematic way. The review process was undertaken at two points in time during the overall research process, firstly in 2014 and then again in 2019. In each instance the research literature was searched for the previous 6 years, enabling a combined overview of the literature from this field for the past 12 years. As shown in figure 2.

Figure 2 Literature review timeline



Combined Literature Review
Literature was reviewed for the period Jan 2008 – [May] 2019.

2014 Literature review stage 1
- Literature was reviewed for the period 2008 - 2013
- To provide justification for the research studies planned in this thesis

2019 Literature review stage 2
- Literature was reviewed for the period 2014 - [May] 2019
- To review studies published whilst studies were undertaken in this PhD

Traditional literature reviews typically present research findings relating to a topic of interest and summarise what is known on this topic (Gough, Oliver and Thomas 2012: 5), as seen in the previous chapter where key concepts were explored using a narrative review. A more systematic approach to searching, appraising and synthesising the literature was adopted within both stages of the review presented within this chapter. The knowledge in a particular field or topic is often seen as the starting point for the development of new primary research studies, with researchers identifying the ‘evidence gaps' in existing knowledge. Put simply, without a review of previous research, the need for new primary research is unknown, (Gough, Oliver and Thomas 2012: 3). However, a literature review should do more than simply present a synthesis of existing research findings, it should offer a quality appraisal of the evidence being presented, (Glasziou et al 2001: 95). A good research synthesis frequently highlights weaknesses in the evidence, (Booth, Papaioannou and Sutton 2012: 3). This chapter, therefore, seeks to present a critical synthesis of the existing research on the development and use of safer walking technology for people with dementia.

2.2 Methodology

2.2.1 Ethics

A small preliminary review was conducted in 2013 to enable the development of the appropriate key terms and search criteria. Ethical approval was sought and gained for this and both main literature reviews conducted in 2014 and 2019. All projects were approved as low-risk projects, reflecting some low-level risks associated with using the internet and accessing both government websites and online databases. Ethics certificates for the preliminary searches, 2014 stage 1 searches and the 2019 stage 2 searches can be found in Appendices 1, 2 and 3 respectively.

2.2.2 Literature Identification

Before conducting the main literature searches, a preliminary search of the databases was undertaken to get an overview of the existing literature within the field. Initially, 11 databases were identified through the university subject catalogues and advice from a Coventry University Health Studies subject librarian. These are shown in Table 1 on the following page. Following the review of this preliminary search, several of the databases initially identified were rejected for use within the main review due to no papers of relevance being identified; these were Compendex, PeDro, GreenFILE, and OT Seeker. The preliminary search was also used to identify effective subject headings for use within the main review. Subject headings were used as they support and promote accurate searching. The most appropriate subject headings for use within this review were identified during the preliminary search on a database-by-database basis. For example, within CINAHL the subject heading 'Assistive Technology' was available for use, but the database Academic Search Complete did not have this category. On closer inspection, however, it was clear that in Academic Search Complete, all research identified as Assistive Technology is held within the subject heading 'Self Help Devices for people with disabilities.

From the review of the preliminary search and discussion with the university subject librarian, it was also decided that in addition to the use of subject headings, additional keywords would enhance the search strategy for the main review. Using both keywords and subject headings together greatly increased the scope of the literature search; this is particularly helpful where no 'defined terms' or vocabulary exist within the literature, (Hart 2001: 28). Keywords were identified from reviewing common terms and keywords within the papers identified by the preliminary search. When undertaking the main review, all keywords were searched for within both the title and the abstract of the research. In acknowledgment of the changing terminology in this field and the increase in the use of the term ‘locating technology' within the literature, this term was added to the keywords for the 2019 updated searches. Keywords and subject headings used within the main review search can be found in Table 1 below.

Table 1 Literature review database search strategy

Database	Subject Database within Locate	Subject Headings Identified	Key Words
CINAHL	Allied Health Assistive Technology	Dementia Alzheimer’s Disease Technology Assistive Technology	Dementia OR Alzheimer’s Disease AND Assistive Technology OR Tagging OR Tracking OR Outdoor Mobility OR Safer Walking OR Locating technology* **2019 searches only*
MEDLINE	Allied Health Assistive Technology	Dementia Alzheimer’s Disease Self Help Devices	
AMED	Allied Health Assistive Technology	Dementia Alzheimer’s Disease Technology	
PsycINFO	Allied Health Assistive Technology	Not available in database	
Academic Search Complete	Allied Health Assistive Technology	Dementia Alzheimer’s Disease Self Help Devices	
ASSIA	Allied Health Assistive Technology	Not available in database	
SCOPUS	Allied Health Assistive Technology	Not available in database	
COMPENDEX	Engineering Assistive Technology	Not available in database	Eliminated from the review after a preliminary search
PEDrO	Allied Health Assistive Technology Physiotherapy	Not available in database	
GreenFILE	Geography and Environmental Design	Not available in database	
OT Seeker	Allied Health Assistive Technology	Not available in database	

2.2.3 Screening

The main search strategy resulted in the identification of 608 published papers in stage 1 (2014 search) and 2306 published papers in stage 2 (2019 search). The databases from which these papers were found is shown in Appendix 4. The papers were then reviewed by reading their title and abstract, after which they were either categorised as relevant to the literature review or were rejected. Research papers were rejected for a range of reasons including the focus being on ‘Technology for use within care homes’ or ‘the use of technology to support independence within a client’s own home’ or ‘use of safer walking technology for diagnostic/ medical purpose’. For example, many papers were identified within the search within stage 2 that reported upon research into eye tracking gaze technology being used within the field of dementia research. The use of the word ‘tracking' in combination with ‘dementia' or ‘Alzheimer's' identified these studies within the literature review, but on closer examination, they were rejected as they were not about the use of safer walking technology. A breakdown of the reasons for rejection is also shown in Appendix 4. The total number of papers identified as being relevant to the review was 112 in stage 1 and 404 in stage 2.

All papers screened and identified as relevant to the review had their references checked in a process of citation tracking, then the research references in these new papers were also searched in a process known as ‘snowballing’ (Booth, Paoaioannou and Sutton 2012: 78). Finally, hand searching the contents of key journals identified within the preliminary search was completed, although this did not identify any new studies. The journals searched were ‘Technology and Disability’, ‘Assistive Technology’, ‘Gerontechnology’ and ‘The Journal of Dementia Care’ ‘Journal of Assistive Technology’.

2.2.4 Eligibility for inclusion in the review

The literature review sought to specifically identify all primary research studies within the published literature. All of the papers identified were then read in full, and the inclusion/ exclusion criteria were applied (Table 2).

Table 2 Inclusion / exclusion criteria

Inclusion	*Exclusion*
Mention of safer walking technology	No mention of safer walking technology
Primary Research Study	Secondary research, review or opinion
Published in a peer review journal	Not published in a peer review journal

Application of the inclusion/ exclusion criteria reduced the total number of studies for inclusion in the review to 19 papers for stage 1, and 11 papers for stage 2. The papers which did not meet the inclusion/exclusion criteria were retained and used within the wider research project to provide contextual and background material.

2.2.5 Quality Appraisal

Failure by reviewers to apply systematic methodologies to the process of reviewing evidence can lead to bias in conclusions, (Wallace et al. 2004). One systematic approach to appraising research literature is the NHS Critical Appraisal Skills Programme (CASP 2002). Based upon an appraisal tool originally published by Oxman, Cook, and Guyatt (1994), CASP consists of ten questions designed to highlight key components of good quality studies. The first two questions within CASP are designed for screening; after these the following eight questions allow a robust appraisal. Across the literature, there is no consensus about the use of such appraisal tools, and it has been argued that quality cannot be determined by following prescribed formulas, (Buchanan, 1992). Whilst acknowledging this debate, the first two screening questions from the CASP tool were used, in this chapter of the thesis, to specifically identify those studies that were fundamentally flawed or particularly weak in methodology, by being based upon opinion or conjecture. The two screening questions from the CASP used within this review are shown in Table 3 below.

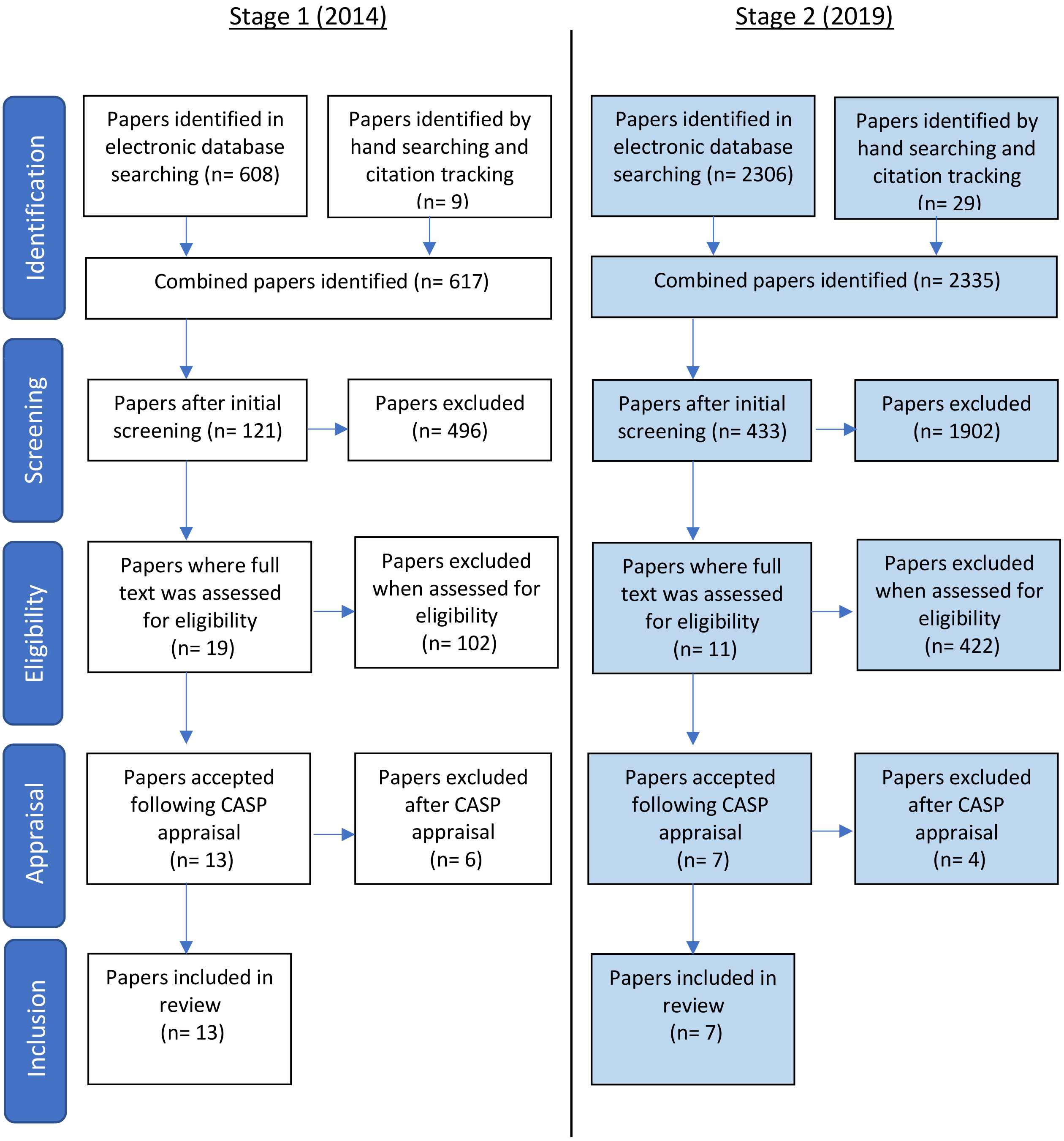
Table 3 CASP screening questions

1	Did the research ask a clearly focused question? Consider if the question is ‘focused’ in terms of: – the population studied – intervention given or exposure – the outcomes considered	2	Did the research include the right type of study? Consider if the included studies: – address the review’s question – have an appropriate study design

The application of CASP to assess quality reduced the final number of studies to be included in the review to 13 papers for stage 1 and 7 papers in stage 2.

The full process of literature selection is summarised in the subsequent PRISMA figure (Figure 3).

Figure 3 Literature selection process



A full list of the papers included within each stage of the review can be found in appendices 5 and 6.

2.2.6 Data Extraction and Analysis

Once all the research had been identified, the process of analysing and synthesising the findings of the papers could begin. Data extraction is key to a systematic approach as it seeks to extract data from disparate sets of studies and facilitates comparison in what is reported and what is not, (Booth, Papaioannou and Sutton 2012: 128). A data extraction form was developed for this review (Appendix 5), enabling the researcher to 'look across' the research studies to assess similarities and differences between the studies and develop a greater understanding of how the findings of these studies related to each other.

Thematic analysis of the papers was then conducted, following Braun and Clarke's (2006) method. Thematic analysis is a method that is often used to analyse data in primary qualitative research, but it is increasingly being used to bring together and integrate the findings of multiple qualitative studies in systematic reviews, (Thomas and Harden 2008). The researcher took a reflexive and iterative approach (Srivastava and Hopwood 2009) and the analysis revealed several key themes within the literature; these are discussed in the findings below.

2.3 Findings

2.3.1 The type of research being conducted

Twenty papers were included in the combined review, thirteen from stage 1, which were published in the period 2008 – 2013, and a further seven during stage 2, which covered the period 2014 – May 2019. A list of the papers included, and a basic overview of each paper's focus and methodology is provided in Tables 4 and 5 for review stages 1 and 2 respectively. Although a greater number of papers was identified in the earlier first stage of the review, several of these report on the same original research data by Landau et al., (2009, 2010, 2011, 2012) reporting on different findings and presenting different aspects of the research in each paper. This pattern was also seen in the work of Bantry White and Montgomery, (2010, 2012) who wrote two of the papers included in the earlier stage 1 review, which drew on the same original data. Therefore, the difference in the number of papers identified in each stage of the review does not represent a reduction in primary research being conducted in this field, as it might initially appear. What is clear is that the overall number of research papers identified within this field had grown considerably since the earlier stage 1 review. The increase in published literature in this field is due to an increased number of opinion pieces, commentaries and guidance documents, whilst the number of primary research studies has remained consistently small.

Table 4 Earlier papers included within stage 1

	Author's	Year	Purpose	Participants	Methodology
Stage 1 (2008 – 2013)	Hughes, J. C., Newby, J., Louw, S. J., Campbell, G., and Hutton, J. L.	2008	To identify ethical issues associated with tagging in dementia	People with dementia, Carers, professionals	Vignette and questionnaire
	Landau, R., Werner, S., Auslander, G. K., Shoval, N., and Heinik, J.	2009	To understand the attitude of family and professional carers towards the use of GPS	Family carers and professionals	Questionnaires
	Landau, R., Werner, S., Auslander, G. K., Shoval, N., and Heinik, J.	2010	To understand the attitude of 'cognitively intact' older people to the use of GPS	Cognitively intact people	Focus groups and questionnaires
	Bantry White, E., Montgomery, P., and McShane, R.	2010	To understand the experience of family carers who use electronic tagging	Family carers	Focus groups and questionnaires
	Landau, R., Auslander, G. K., Werner, S., Shoval, N., and Heinik, J.	2011	To determine who should make decisions about the use of GPS tracking in dementia	Combined findings from previous studies	Qualitative and quantitative
	Sorri, L., Leinonen, E., and Ervasti, M.	2011	Trial of a new GPS technology device	9 people with dementia	Researcher observations
	Grierson, L., E.M., Zelek, J., Lam, I., Black, S., E., and Carnahan, H.	2011	Evaluation of a tactile based technology trial	People with dementia	Researcher observations
	Werner, S. and Landau, R.	2011	Explores social workers attitudes towards the use of GPS tracking in dementia	Social workers and student social workers	Questionnaire
	Landau, R. and Werner, S.	2012	Identify the feasibility, acceptability, and benefits of GPS trackers for people with dementia	Cognitively intact elderly, family carers, professionals	Questionnaires
	Dahl, Y. and Holbø, K.	2012	Exploration of values biases of sensor-based assistive technology	3 people with dementia	Case Studies
	Bantry White, E. and Montgomery, P.	2012	Understanding ethical issues faced by carers making decisions about tracking	Carers	Focus groups and interviews
	Pot, A. M., Willemse, B. M., and Horjus, S.	2012	Feasibility, acceptability, and benefits of safer walking technology	33 carers and 33 people with dementia	questionnaires
	McCabe, L. and Innes, A.	2013	User participation in technology development	Family carers, people with dementia and older people	Focus groups

Table 5 Recent papers included within stage 2

	Author's	Year	Purpose	Participants	Methodology
Stage 2 (2014 – 2019)	Milne, H., Pol, M. v. d., McCoulghan, L., Hanley, J., Mead, G., Starr, J., Sheikh, A., and McKinstry, B.	2014	Feasibility study to for a randomized control trial	People with dementia, carers, professionals	Interviews
	Øderud, T., Landmark, B., Erikson, S., Fossberg, A., Akentun, S., Omland, M., and Ausen, D.	2015	The aim of the study is to generate knowledge on the use GPS to support autonomy and independence	People with dementia and family carers	Interviews and questionnaires
	Olsson, A., Engstrom, M., Asenlof, P., Skovdahl, K., and Lampic, C.	2015	Identifying the impact of tracking on a person with dementia's daily activities	3 people with dementia and their family carers	Experimental case studies
	Wherton, J., Greenhalagh, T., Procter, R., Shaw, S., and Shaw, J.	2018	To understand how GPS tracking impacts wandering for people with dementia	7 people with dementia	Action research trial of technology use
	Maze, J. and Hunt, L.	2018	Training a person with dementia to use a smartphone	Researcher observations	Single case report
	Liu, L., Miguel Cruz, A., and Juzwishin, D.	2018	Can family caregivers be used as a proxy for people with dementia when reporting on technology use?	People with dementia and their family carer	Survey and Interviews
	Kwan, R. Y. C., Cheung, D. S. K., and Kor, P. P	2018	Evaluating wayfinding using smartphones for people with dementia	People with dementia and older people	Observations, interviews, and surveys

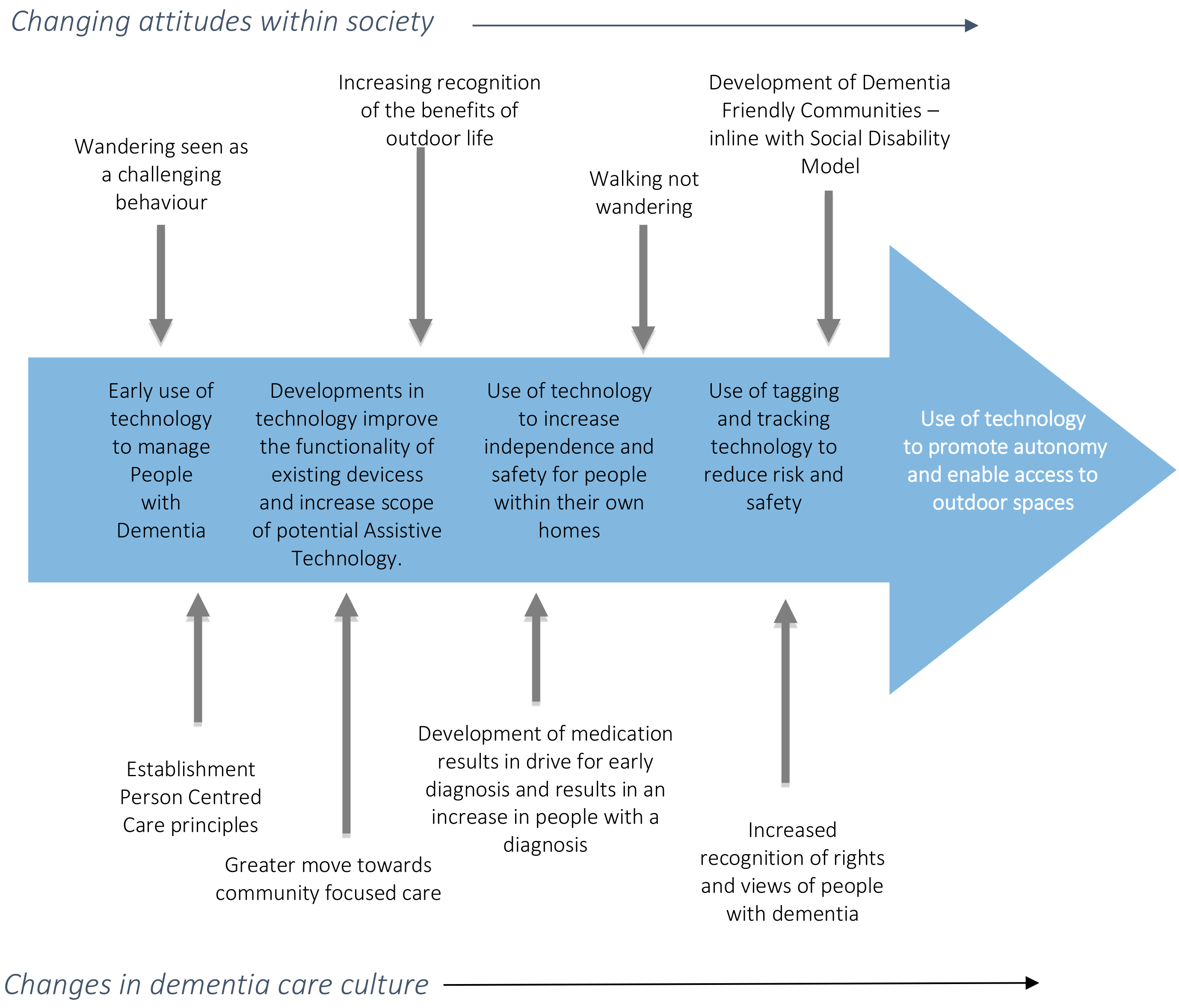
Although all the papers included within this review look at the use of safer walking technology by people with dementia, they varied considerably in both methodological approach and purpose. Of the thirteen earlier studies included within stage 1 of the review, two were based around the development or specific design of a technology product; the remaining eleven studies all sought to explore views and attitudes towards the use of safer walking technology, although only three of the studies specifically included people who had experience of using this technology. There was a clear interest in the kinds of factors that potentially informed decision-making in the use of the technology and the reviewed studies also collected information from a wide range of stakeholders including people with dementia, cognitively intact older people, family carers, professional carers, and other health and social care professionals.

Within the more recent papers, identified in stage 2 of this literature review, most of the research studies focussed on the experience of people living with dementia and the effectiveness of the technology as a potential tool for improving or maintaining quality of life. Across the seven more recent studies, a wide range of research methodologies were employed, including in-depth interviews, questionnaires, validated scales, participant diaries, and researcher observations. The participant numbers ranged from single case studies, as seen in Dahl and Holbø (2012), to much larger cohort studies, such as Øderud et al. (2015), where 208 people living with dementia participated.

2.3.2 The development of safer walking technology

The research described within the literature review paints an evolving story of the use of technology by people with dementia (Figure 4). The research examined in this literature review reveals the development of safer walking technology in the context of more prevalent community living and earlier diagnosis. Throughout its development, safer walking technology is influenced by the limitations and advances of the technology itself (Dale 2010, Miskelly 2004, Rasquin et al. 2007) and by the shifting culture of dementia care within society. As this culture changes, the trends within the literature indicate changing attitudes and terminology in viewing walking and outdoor mobility for people with dementia. Throughout this period there are key debates and concepts that feature within the literature, which evolve from discussions of risk and control (McShane et al. 1998) to ethical debates (Hughes and Louw 2002, Plastow 2006, Robinson et al. 2007) and more recently to promoting choice, autonomy, and empowerment (Mahoney and Mahoney 2010, Wigg 2010).

Figure 4 The development of safer walking technology (Wood, Ward and Woolham 2015)



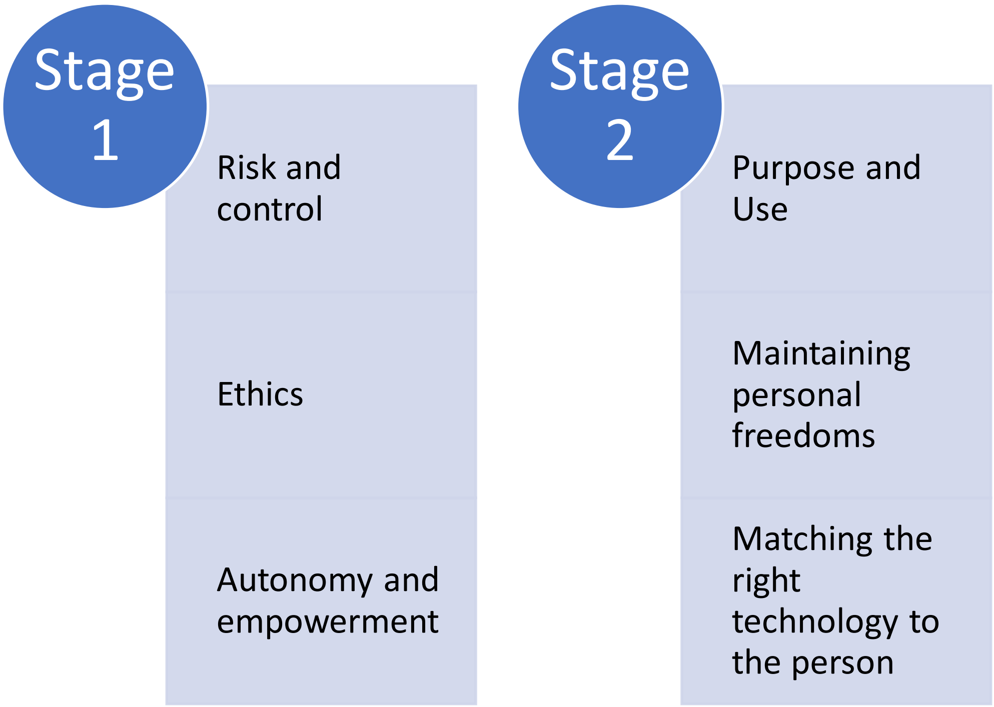
What was not apparent in the findings of stage 1 was the speed at which this form of assistive technology would develop. Due to the rapidly advancing and evolving nature of technology in this field, the types of locating technology, GPS trackers and personal locators being discussed by researchers in the second literature review varied considerably from those in the first. The increased development of smartphone apps may continue to enable greater accessibility and usability of safer walking technology (Armstrong et al. 2010). Within the last

5 years, there has also been cross-disciplinary research interest in the field that has developed with a significant increase in engineering and technology research being undertaken (Pulido 2017), as well as health and social research (Neubauer et al. 2018). Overall, the papers included within this literature review describe the emergence of safer walking technology as a developing form of assistive technology, increasing in popularity and use as the available technology evolves.

2.3.3 An evolving debate identified though the themes

Combining both stages of the literature review offers a comprehensive and wide-ranging overview of the published primary research since the initial development of commercial safer walking technology over a decade ago. Split into two time periods, the analysis of this literature highlighted six common themes within the research findings of the twenty papers included (Figure 5).

Figure 5 Six themes across the literature



The emerging themes from the reviewed literature differed between the earlier research in stage 1 and the more recent research in stage 2. This reflects the wider changes in attitude and approach to using such technology by people living with dementia and their family carers. Themes in stage 1 focussed mainly on ethical debates about **if** such technology should be used, whereas in stage 2 the themes reflect a greater focus on **how** safer walking technology could be used. This may be reflective of a greater acceptance of their use, technological developments and the wider availability of safer walking technology to the general public. All six identified themes are explored in detail within the following discussion section of this chapter.

2.4 Discussion

The first three themes identified within the early literature from stage 1 of the literature review focussed on concerns about managing perceived and actual risk, ethical debates about privacy and wider discussions about the opportunity for autonomy and empowerment of people with dementia. Analysis of the seven more recent studies in stage 2 revealed three further key themes within the literature, which focussed on the different purposes and use of the technology, maintaining personal freedoms and the need for individualised assessment and support. These stage 2 themes differ from those identified in stage 1 of the literature review and reflect the changing dialogue, evolving use, and technological developments within this field. The six themes are discussed in detail below.

2.4.1 Risk and control

The first theme from stage 1 of the literature review was risk and control. The issue of risk and control featured heavily in the published literature and discussion around the use of safer walking technology was often framed within the context of reducing 'wandering behaviour' rather than the support of outdoor mobility and/ or safer walking (Robinson et al. 2007). Safer walking technology was originally aimed at managing risk and safeguarding individuals by enabling lost individuals to be found, (McShane et al. 1998). Early versions of tracking technology were often underused, perhaps because they were bulky, expensive and in the early stages of development (Rowe and Benito 2007). Yet, the 'management of risky behaviour' and prevention of harm continued to be a key motivating factor in the ongoing development of safer walking technology.

Risk management and safety issues for older people have tended to be discussed in ways that reflect an inherent 'vulnerability' because of physical or mental impairments. Within the described papers in stage 1 of the literature review, these issues were explored from several perspectives, including both professional and family carers. Universally, participants in the studies identified that issues of reducing risk and increasing safety were key to the use of safer walking technology. Within two papers in this literature review (Bantry White, Montgomery and McShane 2010; Bantry White and Montgomery 2012), the authors drew on the same data to explore the experiences of family carers in using safer walking technology; they found that family carers in the sample drew upon concerns of potential harm to justify usage on the grounds of enhanced safety, and risk-taking was consistently judged negatively. However, their findings did indicate that although GPS tracking was most commonly used as a back-up to other strategies of support, for a minority it was used to enable the person to go out alone. Similar findings were shown in Landau et al. (2010) which sought the views of ‘cognitively intact older people'. Landau et al. (2010) did not explore the specific reasons for sampling this group of cognitively intact older people, but it is inferred that because of the participant's closeness in age to most people with dementia they represent views likely to be similar to those of people with dementia. A limitation of Landau et al.’s (2010) study was a failure to also collect data from people with dementia. Within this study, these authors found that participants supported the use of tracking technology to offer reassurance and peace of mind to caregivers, reflecting empathy and concern for caregiver well-being. Landau et al. (2010) concluded that caregiver participants valued the safety and protection of people with dementia even if by doing so they disregarded their autonomy and privacy.

Werner and Landau (2011) found that social care professionals were more likely to acknowledge the decisions made autonomously by the person with dementia. They suggested that this is due to a focus on concepts of autonomy, beneficence, and justice within their professional training, although the application of these principles in practice was challenging. Dahl and Holbø (2012) explored the use of tracking technology within a group of different professional stakeholders and found that the main issue was finding the right balance between what was thought to benefit the individual with dementia and the preservation of their right to privacy. Dahl and Holbø (2012) found that professional stakeholders had different attitudes towards electronic tracking of people with dementia, dependent upon their specific responsibilities; this finding was reflected in Hughes et al. (2008), who also sought the views of different professional groups, noting that although professionals shared the same concern with safety, Community Psychiatric Nurses (CPNs) veered to a more noticeable focus on respecting autonomy.

2.4.2 Ethics

The second theme from the early literature in stage 1 of this literature review was ethics; consideration of ethical issues surrounding the use of safer walking technology has been present since the early developments of tracking technology, (McShane and Hope 1994). The association, particularly for tracking technology, with its use to track and locate both animals and criminals has raised a number of objections within the UK press (The Telegraph 2013) and professional literature, (O'Neil 2003). There is also well-documented concern about the individual right to privacy (Astell 2006) and the potential reduction in human contact from the introduction of tracking devices (O'Neil 2003). Despite these concerns, there have been continual demands for use of tracking technology to support people with dementia, (Dahl and Holbo 2012, Hughes et al. 2008, McShane et al. 1998).

Two of the papers identified within stage 1 of this literature review (Hughes et al. 2008; Landau and Werner 2012), specifically explored ethical issues surrounding the use of safer walking technology for people with dementia. Hughes et al. (2008) draw on evidence from previous research (Hughes and Campbell 2003) to discuss the need for protocols and risk assessments to enhance the ethical process and support the use of safer walking technology. Hughes et al. (2008) concluded that despite the concerns about liberties, stigma, and dignity, electronic tagging was an ethically justifiable way to support people with dementia; this view was also supported in the findings of Landau and Werner (2012) which reviewed existing research within this field and presented 8 recommendations to guide ethical practice in using safer walking technology for people with dementia. (A copy of these is in Appendix 6). These recommendations cover a variety of issues including joint decision–making, informed consent and balancing the protection and safety of the individual with the need for autonomy and privacy, and are not dissimilar to those found in earlier published guides for general implementation of assistive technology, such as the ASTRID guide (Marshall 2000). Landau and Werner's (2012) recommendations are brief but specific to the use of safer walking technology and written in an accessible way.; they are based on a substantial body of research and offer clear guidance, to professionals and family carers alike, about the ethical use of safer walking technology.

Astell (2006) asked us to consider what might be driving an increased interest in this field, whether it is the needs and wishes of people with dementia, the priorities and concerns of professionals and caregivers, or the potential of the technology itself. The importance of bearing in mind these differing drivers are of relevance when considering the work of Sorri, Leinonen and Ervasti (2011) and Grierson et al. (2011) who both explored the development of wayfinding technology for use by people with dementia. Both studies focused on the use of the technology to guide a person with dementia around a specific pre-determined route. The findings of both Sorri, Leinonen and Ervasti (2011) and Grierson et al. (2011) indicate potential for the development of safer waking technology to provide a means for greater autonomy and independence for people with dementia in navigating successfully around both indoor and outdoor environments. This initially appeared to be a more person-centred approach to using this technology, focussed on the promoting independence, however, both studies showed little consideration of the attitudes, goals and values of the person with dementia. In Sorri, Leinonen and Ervasti they did not question participants about their experiences at all, whilst in Grierson et al. a short questionnaire was administered following the technology trial to collect nominal data about the effectiveness of the technology, with the researchers collecting most of their data through researcher observation. Both these studies also overlook the question of acceptability and stigma in the product design, a significant factor described by Landau et al. (2010) as essential to effective safer walking technology and discussed at some level in all of the other studies. Similarly, the equipment needed for the technology described by Grierson et al. included both a 10-inch screen fitted to a walking frame, vibrating wristbands and a Bluetooth earpiece. The study did not consider the acceptability or wearability of this technology.

Referring back to the recommendations for the ethical use of safer walking technology, described by Landau and Werner (2012), and found in Appendix 6, 'Recommendation 8' states that 'devices used to support people with dementia need to be lightweight, small and comfortable to wear and use.' The technology described in the studies above were none of these things. The recommendation was developed by Landau and Werner in response to participant concerns within their study, about the stigma associated using these devices. This sentiment also correlates with McCabe and Innes (2013) findings, where they used focus groups to explore the ideas and opinions of potential users about a specific GPS device, to demonstrate that people with dementia were less concerned about the wider ethical debate around privacy and tracking, but did have concerns about the potential stigma arising from product design. The importance of designing products which are acceptable, discreet and do not increase stigma is well documented within the wider literature in assistive technology (McCreadie and Tinker 2005, Westphal, Dingjan and Attoe 2010, Zwijsen, Niemeijer and Hertogh 2011) and should be a priority for the development of all forms of assistive technology, including safer walking technology.

2.4.3 Autonomy and empowerment

The third and final theme from stage 1 of this literature review was autonomy and empowerment, this is seen prominently within the research by Pot, Willemse and Horjus (2012), who collected both the views of people with dementia and their family carers. Through a quantitative survey, Pot, Willemse and Horjus (2012) explored the views and experiences of 343 people with dementia and their main family carer, all of whom had undergone a trial of safer walking technology. The study found that almost half of the participants with dementia experienced more freedom and were less worried when they were using safer walking technology when outside on their own; a quarter mentioned that they were outside independently more often. However, the study did have some attrition of participants as it progressed, which they suggest may be because the technology used in the study was only appropriate for those with early-stage dementia. Pot, Willemse and Horjus (2012) also suggested that decision-making around the use of safer walking technology should include the person with dementia, and professionals involved in their care.

Landau et al. (2009) explored the attitudes of family and professional carers towards the use of GPS tracking technology and found that, across both groups, attitudes varied and were complex; family carers showed higher support, than professional carers, for the use of safer walking technology, both for their own peace of mind and the safety of the person with dementia. However, they also noted that when compared with family carers, professional carers attached a higher value on respect for a person's autonomy and greater support for the person with dementia's participation in the decision- making process. This is also supported in part by their later study (Werner and Landau 2011) which explored the attitudes of both student and experienced social workers and found that for this professional group, the value of respecting a person’s autonomy is perceived as independent of, not contradicting the use of safer walking technology.

However, other research within this literature review (White and Montgomery 2012) indicated that family carers described being motivated by a desire to enable the person to go out and enjoy lifelong interests. Bantry White and Montgomery interviewed 10 family carers of people with dementia who were using electronic tracking to explore the ethical issues experienced by them in making decisions around its use. The research found that despite the risks posed by going outside of the home, independence and freedom were valued as significant to the quality of life. Family carers also described being motivated by a desire to enable the person to continue to go out alone and enjoy lifelong interests. Throughout the interviews, the authors found that family carers did not suggest that electronic tracking was stigmatising and did not make negative comparisons – for example, with ‘tagged’ offenders. It has long been recognised within the published literature that the way that technology is used, rather than the technology itself, can be stigmatising (McShane, Hope and Wilkinson 1994). Family carers within this study describe their use of safer walking study in the context of ‘enabling’ and supporting the quality of life for the person they cared for, making decisions about its use jointly, where possible, and with the ‘best interests' of the person in mind.

2.4.4 Purpose and use of the technology

The first theme from the more recent research in stage 2 of the literature review examines the purpose and use of safer walking technology, indicating, across the seven papers, an evolving use of safer walking technology for a range of purposes including to track, locate, enable, support and guide people with dementia. This emphasis on tracking and locating a person remains consistent within the literature and can be seen prominently in Milne et al. (2014) where the range of technology in this field are described by the authors as ‘lost seeking solutions.'; this mixed methods study sought the views of a range of professionals and family carers, as well as gathering a range of data about the person with dementia's contact with services before and during the trial. The paper focused on the usability of a range of nonelectronic, electronic and biometric ‘lost seeking’ solutions, and used effectiveness outcomes such as frequency of getting lost episodes and time spent searching for missing persons. Absent from this set of ‘lost seeking devices' in this study was the presence of any form of a smartphone, handheld navigational or wayfinding device for use by the person with dementia themselves.

Although a wide range of safer walking technology devices is evidenced by Milne et al. (2014), most of the papers identified within this literature review explore the use of small handheld devices, used to enable family carers to track people living with dementia. Electronic tracking through GPS can locate a person at any given moment by positioning the device through satellite technology and sending information via the mobile phone network to a personal computer, a call-centre or a mobile phone (Kearns and Fozard 2007). This technology was developed considerably in recent years and so the accessibility, usability and reliability of devices has improved. Within one of the recent papers identified in stage 2 of this literature review, Liu,Cruz and Juzwishin (2018) examine the use of GPS technology to enable family carers to track a person with dementia. However, the main purpose of this paper was to report upon the potential reliability of carers as a proxy for the views of people with dementia when conducting GPS technology research. Their findings indicate that the questionnaire responses for carers and people with dementia correlate well, and in circumstances where people with dementia cannot report accurately upon their experiences it is acceptable to use the views of their family carers. This is useful information for researchers in this field and to those looking at the use of such technology with people living with moderate and advanced forms of dementia. However, the research discussed in stage 1 of this literature review identified the importance of including a greater emphasis on the ‘voice of people living with dementia', with much of the research in the previous five years calling for greater inclusion of their experiences of using safer walking technology. Analysis of the research from stage 2 of this literature review suggests fundamental reasons for the continued absence of this voice, stemming from key questions about how and why the technology is being used. In stage 1 of this literature review Bantry White and Montgomery (2012) described that the decision to use electronic tracking reflects, in part, the need for carers to have reassurance, space from the person, and time out from the caring role. This raises questions about who the technology is for and why is it being adopted. Certainly, a consistently positive outcome reported across research studies in both the early and recent literature in both stages of this literature review is that the technology is most often provided with the aim of providing family carers with ‘peace of mind'. It could, therefore, be surmised that the purpose of the technology is still to support carers, rather than people with dementia.

The picture within the recent published literature indicates that the purpose and use of safer walking technology is now more complex than this, with users seeking to balance the needs of carers and of people with dementia; this also reflects the way that the research literature in this field traditionally framed outdoor activities and most prominently the activity of wandering or walking. As discussed in the introductory chapter (Chapter 1), Marshall and Allen (2006:10) described this as the paradox that walking is normal and healthy but that when people with dementia do it, it is viewed negatively and labelled as wandering. Within one of the recent papers from stage 2 of this literature review, Wherton et al. (2018) highlight the evolving policy and clinical discourse on wandering, arguing that in recent years a shift in opinion has occurred within the public and professional view of this activity. Wherton et al. (2018) emphasise the need to see walking as a potentially meaningful and worthwhile activity. This change in perception is seen in several of the other papers in stage 2 of this literature review (Milne et al. 2014, Olsson et al. , 2015, Liu, Cruz and Juzwishin 2018, Kwan Cheung and Kor 2018), which all acknowledge that for many people with dementia walking is a meaningful outdoor activity. It is within this context that the research papers demonstrate a change in purpose for the use of safer waking technology, with a greater focus on enabling meaningful outdoor occupations such as walking.

As discussed previously, Milne et al. (2014) described the effectiveness of the technology by measuring instances of getting lost, but this is limited and does not capture the whole range of impacts the technology might have. Yet, in comparison, Olssen et al. (2015) describe the number of times a person with dementia went out each day and the percentage of days with independent outdoor activity during the intervention periods. This flipped approach, focussing on the person with dementia themselves, also correlates with the publication of research which seeks to understand how safer walking technology can be used effectively by people with dementia to support independent wayfinding outdoors, as seen in Kwan, Cheung and Kor (2018); in this study a trial of smartphone uses to support wayfinding in dementia is described. GPS is now commonly used for wayfinding within the adult population and it can be launched on most smartphone platforms. The range of variable settings such as using auditory navigational control, or ‘hands-free' functions, increases the accessibility for people with dementia as it reduces the need for divided attention, (Liu 2001). This is a far cry from the impractical and potentially stigmatising wayfinding technology described earlier within stage 1 of this literature review in the papers by Sorri, Leinonen and Ervasti (2011) and Grierson et al. (2011). Kwan Cheung and Kor (2018) provided training and support to use smartphone navigation apps for people living with dementia, and their abilities were contrasted with a control group of healthy older adults who did not have dementia; the findings indicated that there were no significant differences between these two groups and that people with dementia could use smartphones for independent wayfinding. The authors called for further research into this form of safer walking technology.

2.4.5 Maintaining personal freedoms

The second theme identified from the recent papers in stage 2 of this literature review explores the use of safer walking technology to maintain personal freedoms. Olssen et al. (2015) describes a trial of GPS technology with three experimental case studies. Within their paper, Olssen et al. (2015) highlight the importance of getting outdoors to maintain ‘self-identity’ (Cohen-Mansfield, Golander and Arnheim 2000), linking the ability to undertake meaningful outdoor occupations to the wellbeing of the person with dementia. In all three case studies, the carer reported a negative impact on the well-being of the person with dementia when their freedom to autonomously go outside and engage in outdoor activities was reduced. The ability to go outside, or not, within this study appears to have also impacted upon the personal freedoms and well-being of the family carer; this is supported by earlier research in this literature review, notably Werner et al. (2012) who founed that increased carer burden was reported by family carers when the person with dementia spent less time in the outdoors. The findings of Olssen et al. (2015) demonstrated that access to GPS tracking technology consistently increased the independent outdoor activities of people living with dementia with a greater percentage of days spent outdoors and an increase in the number of times per day the person with dementia engaged in outdoor occupations.

Within the earlier papers identified in stage 1 of this literature review, ethical concerns for privacy featured heavily within the published literature; discussions about the ethical nature of tracking and privacy also continue in stage 2 of this literature review mirroring what was seen in stage 1 of this literature review with prominent researchers, alongside health and social care professionals highlighting their concerns about privacy. Yet, within the recent papers identified in stage 2, ethical considerations were often discussed in the context of balancing risk with enabling personal freedoms, rather than fundamental issues of privacy. These observations indicate that the discourse in the literature has moved on, with less focus upon issues of control and restraint and a clearer understanding of the need to identify a balance between maintaining the safety of the individual and recognising the importance of getting outdoors to the well-being of people living with dementia. Wherton et al. (2018), describe the in-depth consideration of seven case studies where GPS technology was used to track people with dementia; this study found that families had a sense of responsibility to ensure the person's safety and material comfort while also helping them to achieve fulfilment and happiness, respecting their independence. Wherton et al. (2018) suggested that the driving influence upon how safer walking technology was used was what mattered to the individual person with dementia.

Despite a common reference to their wider body of their work within the literature, the guidelines for ethical use of GPS technology published by Landau and Werner (2012) (Appendix 6) are not discussed by any of the research studies published in subsequent years; it is not clear why this is, but there is some evidence that there has been more of a shift towards an individualised assessment in this field. One recent paper by Wherton et al. (2018) suggests that the current research and debate on the appropriate use of GPS tracking, and the ethical implications of this, are misplaced as they have been considered in isolation from the realities of everyday use.; they acknowledge that the balance between autonomy and safety will be different for each person, influenced by a range of internal and external factors. Thus, suggesting that pre-set principles and standardised procedures are unlikely to succeed for everyone as they do not reflect these individual differences.

2.4.6 Matching the right technology to the person

The third and final theme identified from the papers in stage 2 of this literature review explores the need for individualised matching of technology devices to meet the individual's needs. Evidence to support the need for individualised decision making and the development of a culture of ethical use can also be seen in Øderud et al. (2015), the largest research study found within stage 2 of this literature review -which followed 208 people with dementia, recruited from 19 different municipalities across Norway, for a period of 3 years; the person with dementia and their family carers took part in a range of interviews, surveys and focus groups. This large cohort study provided a professional assessment of users' needs followed by thorough discussions about ethical dilemmas and how to identify the least intrusive intervention. These discussions were reported to be important for successful implementation, and the majority of participants and caregivers reported that they did not experience the person with dementia being monitored or under surveillance. Family carers described only locating a participant when necessary, with one explaining *"I feel like an intruder if I locate without a reason".* Findings from this study echo those of other studies in this literature review, with family carers reporting that safer walking technology increased safety and freedom for the person with dementia, whilst the person with dementia stated that autonomy and freedom to continue outdoor activities were highly valued.

All seven papers in the second stage of this literature review suggested that participants had received training to use safer walking technology within the research studies, with Øderud et al. (2015) acknowledging that the training was crucial to the acceptance and effectiveness of the technology. The level of training provided varied and for some research studies, this involved ongoing training and support to use the devices, whereas in others only initial training was provided. Maze and Hunt (2018) specifically reported on the researcher's experiences of training a person with dementia to use a smartphone in a single case study report; these researchers described a comprehensive cognitive, social and physical assessment undertaken by the occupational therapist in the case study, with the aim of identifying the individual needs of the person with dementia. This is person-centred (Kitwood 1990) in approach and reflects core occupational therapy principles to view the person holistically (Creek et al. 2005). However, the trial of smartphone use was unsuccessful, as the device did not match the skills and abilities of the person with dementia. Although the person's needs were assessed, there was only one form of device, namely a carer's smartphone available to use. Milne et al. (2014) highlights the importance of being able to offer or include a range of technological solutions under the umbrella term of safer walking technology, as not all devices will meet the needs of all individuals. This ‘matching' of the technology to the individual has the potential to both increase usability and improve acceptability of the technology, (Scherer 2002). Several of the recent papers in stage 2 of the review sought to determine the ‘acceptability' of safer walking technology to people with dementia. Milne et al. (2014) and Olsson et al. (2015), sought to determine technology acceptability through family carer interviews or observations. However, findings from Wherton et al. (2018) indicate that the acceptability of safer walking technology is better aligned to the preferences of the person with dementia themselves, especially if used to achieve outcomes that were important to them personally. The technology in Wherton et al.’s study was available in 6 different formats that included items such as keychains, wrist watches and lanyard fobs. These all had the same technological features, but different material properties, which they found to be an important factor in making them acceptable to the user. It is therefore important to ensure both a person-centred assessment of need and an individualised assessment of technological suitability. Wherton et al. (2018) found that the combined work of the individualised assessment process and provision of robust training and support to use technology, was often under-reported and represented ‘hidden work' within the provision of safer waking technology.

2.4.7 Limitations of the literature review

This literature review identified a large amount of published research on the use of safer walking technology in both stages 1 and 2. However, only a small proportion of this was primary research that looked at how the technology was used. Despite this continual discussion and debate within professional literature (Daniels 2008, O’Neil 2013, Gilliard 2001, Sturdy 2005, Wan 2019) there is limited research evidence around the use of safer walking technology; this evidence is also limited by the quality of the design or methods used in available studies. Several studies used survey questionnaires to collect data about participant attitudes and experiences. However, the small sample sizes mean that findings and conclusions drawn through quantitative analysis are of limited transferability. This can be a common problem where quantitative data is collected from a sample too small to produce a statistically significant result, (Kielhofner 2006). It may have been more effective to capture the experiences of these individuals through a more qualitative approach, to ensure a depth of data where a breadth of data was unobtainable.

Interest in this field has grown. In the first literature search several of the primary research studies were from the same research team, but this was not the case in the later review. Within the first review of the literature in stage 2, this re-use of the same data across multiple papers reduced the depth and breadth of data within the earlier findings, as much of the same data was examined and re-examined to find new meaning and potential rather than additional studies with differing populations sought. Most of the early research studies were also small-scale preliminary work or had limited generalisability. Although the number of primary research studies identified in the following 5 years did not increase, the range of international research teams, differing research focus from study to study and the size of some studies did increase. The primary research identified within the second set of searches in stage 2 highlighted several larger studies, (Olsson et al. 2015, Øderud, et al. 2015) with more robust research designs and greater generalisability.

2.5 Recommendations for further research

2.5.1 Recommendations from the literature

This literature review has revealed a growing research interest in, and clinical discussion around, the use of safer walking technology. Whilst there is still a need for more research evidence to support the use of safer walking technology for people living with dementia, existing evidence indicates great potential for its use. If provided in an individualised and person-centred way, with the right support and guidance, safer walking technology has the potential to improve quality of life by increasing the freedom and independence of people living with dementia. Literature discussed within this review suggests that the provision of support during the assessment and decision –making process is key to the effective use of safer walking technology. The reviewed literature recognises the continued dominant voice of professionals and academics within this debate (Bantry White and Montgomery 2014), and yet the research literature contains repeated calls for more primary research in this field (Milne et al. 2014), specifically research that explores the views and experiences of people with dementia and their family carers (Liu, Cruz and Juzwishin 2018) and a person-centred approach to research design and data collection (Øderud et al. 2015). Wherton et al. (2018) call for research with a greater focus on how safer walking technology is used in real-life contexts, arguing that the current research has largely only considered safer walking technology in isolation from its everyday use. It is also clear that a greater breadth and depth of knowledge is needed within this field to develop a clearer understanding of how this technology is perceived and used by all stakeholders concerned. Greater understanding is needed about how the use of safer walking is experienced by the individual; this could then potentially provide insight into the intrinsic motivations and lived experiences associated with the use of safer walking technology.

2.5.2 A new generation of safer walking technology

Safer walking technology has evolved considerably during the period between the two reviews. There is a growing variety of devices designed specifically for the use by people with dementia, each with different functions and purpose. The review illustrates the importance of identifying the right 'fit' between the person's needs and the technology being provided. The findings of stage 2 also highlight that there is also an identified need to understand how smartphones are changing this landscape (Kwan, Cheung and Kor 2018) and how people with dementia are using these to enable wayfind and continued engagement in meaningful outdoor occupations.

2.5.3 The views of people living with dementia

One issue highlighted repeatedly within this literature review is that only a few of the included studies sought the views of people with dementia, yet almost all the studies within stages 1 and 2 of this review called for their greater inclusion. This is not uncommon in dementia research, for instance, Robinson et al. (2007) looked at a range of non-pharmacological interventions to prevent wandering in dementia and found that none of the included papers represented the views of people with dementia. In the following decade, the majority of published literature consists of opinion pieces and reviews, with only a small proportion of the overall research attempted to change this, but of the seven research papers reviewed in stage 2, four attempted to interview or collect data from people living with dementia.

2.5.4 Identifying the different needs of people with dementia

It also became apparent that the research in this literature review often failed to acknowledge the very different needs and experiences of people at different stages of their dementia. For example, someone with moderate dementia who wishes to walk their dog around a familiar local route, but is often disorientated, will have very different needs to someone with early-stage dementia who is seeking to use safer walking technology to continue engaging in regular long distance walking or running activities. Although some of the research studies clearly describe the stage of a person's dementia to be part of the inclusion criteria (e.g. Kwan, Cheng and Kor 2018), others either do not consider this at all (Bantry White and Montgomery 2014) or state that they have included people with all stages of dementia progression (Øderud et al. 2015). This means that, both within research studies themselves and across research within this field, it is hard to determine whom the participants represent. Kontos and Martin (2013) acknowledge this as a common problem in research where people living with dementia are largely represented as a unified category that overlooks important aspects of diversity and social difference. Therefore, future research in this field needs to clearly identify the stages of dementia participants are experiencing at the time of the study, thus enabling a nuanced understanding of how different groups within this field may better use safer walking technology.

2.5.5 Support to use safer walking technology

Almost all the papers identified in both stages of the literature review considered the role of professionals in supporting people to make decisions about the use of safer walking technology. Several papers from both stages of the review indicated that the research demonstrates the need for a more active role to be played by professionals in the decision-making process about the use of safer walking technology. Landau et al. (2012) called for a clearer ‘family decision-making process,’ facilitated by professionals, to protect the person with dementia’s autonomy and independence - a view also supported by the findings of several other studies (Bantry White and Montgomery 2016) (Stupple, Marks-Maran and Morrris-Thompson 2015), in particular Bantry White, Montgomery and McShane (2010) who argue that occupational therapists are well placed to support family carers in assessing the suitability of this technology. Occupational therapy operates within an enabling paradigm that emphasises ability, wellbeing, and quality of life (Moniz-Cook and Vernooij – Dassen

2006, Mountain 2006). (Dunk, Longman and Newton 2010) describe the trial use of GPS location equipment within a Mental Health Trust; this was an occupational therapy led study and one reported to follow person-centred processes for assessment and provision of the technology. The paper concluded that the trial was overwhelmingly positive about the use of safer walking technology for both people with dementia and caregiver participants. However, they also argue that providing the level of support offered in the trial may be challenging, and Øderud et al. (2015) indicate that family carers rate the multi-professional team as the least important figure in the decision-making process around the provision of safer walking technology.

2.6 Key messages from this chapter

- Within the past decade, there has been an increased interest in safer walking technology within the published literature, with research appearing in several different fields including health and social care, and engineering.

- Technology in this field has developed considerably during the period of the literature review, from impractical and potentially stigmatising kits, to small, discreet, wearable devices.

- Safer walking technology has seen a change in use and focus from purely risk management to also include a recognised need to enable independence and support meaningful outdoor occupation.

- Safer walking technology has the potential to support both the needs of family carers and people with dementia, providing both carer reassurance and enabling improved quality of life and wellbeing for people with dementia.

- Although guidance on the ethical use of safer waking technology was published in this field, there is little evidence that it has impacted the research in subsequent years.

- Effective use of safer walking technology requires both person centred assessment of need and an individualised matching of safer walking technology devices, supported by adequate training to use and maintain the technology.

- The voice of people with dementia is largely absent from the early research literature in this field and despite repeated calls for the inclusion of the views and experiences of people with dementia, very few recent research studies sought the views of people with dementia.

The next chapter offers a detailed account of the methods used to undertake research in this thesis - it explores both the theoretical underpinnings of the research approach and the participant recruitment, data collection and data analysis methods undertaken within both study 1 and 2 of this research.

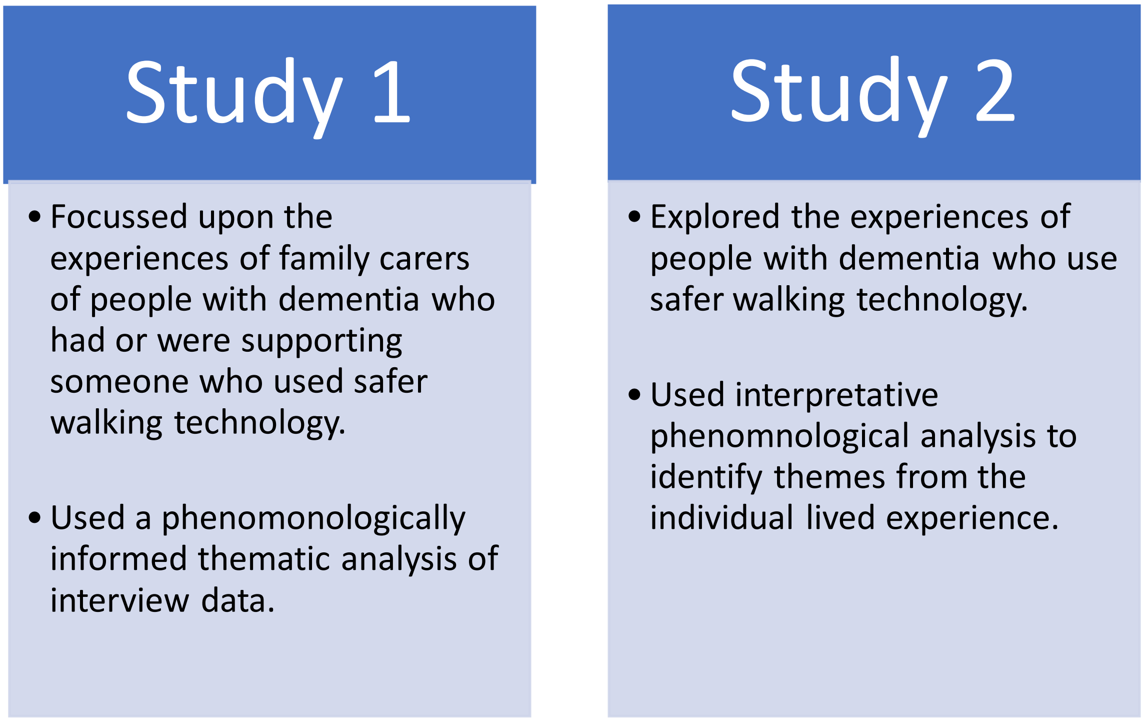
Chapter 3 Methodology

3.1 Introduction

This chapter provides an overview of all methodological decision making and processes used to plan, undertake and analyse the data within this research. The chapter starts with a discussion of the research approach taken, including the theory and ideas underpinning the epistemology of the research. The chosen methodological approach of phenomenology is explored, and a rationale for the analysis processes undertaken is outlined. The findings of the literature review in chapter 2 highlighted that although people with dementia are increasingly using safer walking technology to improve the quality of their own lives, family carers continue to have an important role in choosing and supporting its use. The research literature also indicates that both family carers and people with dementia have different motivations for using the technology and experience it differently. To meet the research aims outlined in the introductory chapter, this research sought to explore the experiences of these two separate groups of people in two different studies. It was envisaged that this would enable a wider picture of the use of safer walking technology to emerge from the combined data and allow a focus on the lived experiences of both family carers and people with dementia who use the technology.

A complete explanation is given of the planning and design stages of the research, including seeking ethical approval and the formation of a stakeholder advisory group. A detailed account of the varied recruitment strategy is also provided, including exploration of the use of both traditional and non-traditional recruitment methods. Data collection and data management strategies are also described and the process of undertaking the participant interviews is discussed. For both studies, the importance of understanding the experiences of the individual led to the use of a phenomenological approach to research design and analysis. Within study one a phenomenologically informed thematic analysis was undertaken, to identify the different themes that arose in interviewing family carers, who discussed both their own experiences and their perceptions of the experiences of the people they cared for. Within study two the use of Interpretative Phenomenological Analysis (IPA) was used to explore the individual lived experiences of the participants living with dementia.

Figure 6 Two phenomenological studies



Study 1

- Focussed upon the experiences of family carers of people with dementia who had or were supporting someone who used safer walking technology.
- Used a phenomonologically informed thematic analysis of interview data.

Study 2

- Explored the experiences of people with dementia who use safer walking technology.
- Used interpretative phenomnological analysis to identify themes from the individual lived experience.

The chapter is then completed by a detailed discussion of the data analysis processes undertaken in each study, including a step-by-step description highlighting the processes of theme formation at both individual participant and whole study level.

3.1.1 Research timeline

This research was conducted part-time over four and a half years of PhD enrolment. The author took two periods of absence from the research for maternity leave and so the total research timeline covers almost seven years. The timeline for undertaking the research also incorporated the need for training, taught university modules and planning in the early stages along with undertaking regular Project Review Panel (PRP) examinations. The initial literature review was undertaken before the research question and aims were formulated in 2013 and then updated after data analysis in 2018. Participant recruitment, data collection, and transcription also occurred within two different time periods during 2016 and 2018; Appendix 7 shows a timeline that illustrates when all of these key activities were undertaken including key research activities such as data collection, data analysis and thesis write up.

3.2 Research Approach

The research question and aims outlined in the introductory chapter of this thesis are addressed within this research by utilisation of qualitative research methods. This qualitative enquiry sought to ensure that the research findings connected to each participant's attempts to make sense of their lives and therefore sought to achieve something which cannot be captured easily in quantitative experimentation. Qualitative research has no theory or paradigm that is distinctly its own (Denzin and Lincoln 2005: 22) but is informed by several philosophical systems such as interpretivism, constructivism, hermeneutics and critical theory (Carpenter and Suto 2008:60). Eatough (2012: 327) argues that it is important that researchers acknowledge their epistemological perspectives and therefore the influence upon both their intellectual and practical approaches to research. Whilst acknowledging the dangers of oversimplification, it should still be recognised that the research question and design are influenced and underpinned by some key philosophical concepts. Therefore, in addition to exploring the research methodology, this chapter also acknowledges the theoretical underpinnings of the qualitative approach taken in this thesis, why they are best suited to answering this question and how they align with the researcher’s core occupational therapy values, described in the introductory chapter.

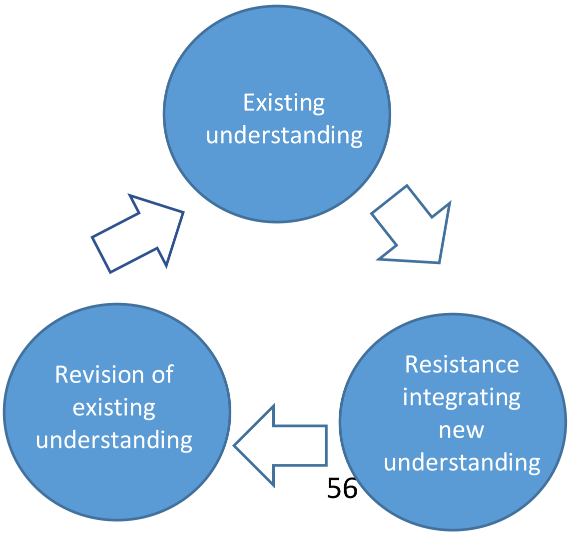
3.2.1 Phenomenology

This research is phenomenological in design and incorporates qualitative research techniques in keeping with this approach. As discussed in Chapter 1 people with dementia have not traditionally been a group given a voice in research and so it was important to the researcher to ensure their voice was heard within this thesis. One key aspect of this was to adopt a methodological approach that empowered them as witnesses, aiming to explore their individual experiences as unique and of value. This is particularly important to the researcher because of her clinical background as an occupational therapist, as occupational therapy is based on Carl Roger’s (1961) client-centred principles. Within her clinical career, the researcher sought to support people with dementia to identify the occupations and activities that held meaning to them as individuals. This client-centred approach informs all aspects of occupational therapy practice from assessment through to intervention and evaluation (Hagedorn 2001:99). These principles are mirrored in this research thesis where the researcher sought to understand how the use of safer walking technology was experienced by those who used it, and how it's impact in their lives can hold meaning for that individual. Phenomenology aims to clarify and illuminate the meaning of people's experiences in the context of their lives, (Eatough 2012: 328). Its purpose is not to categorise or explain behaviour, but to develop an understanding of the human experience. Finlay (2011: 10) argues that phenomenological research is potentially transformative for both researcher and participant, offering individuals the opportunity to be witness to and 'give voice' to their own experiences.

3.2.3 Interpretative Phenomenological Analysis

The basis of descriptive phenomenological research lies in the work of Husserll (1927; cited in Smith, Flowers and Larking 2009: 12) who suggested that researchers should be able to reflect upon their focus, bracketing off their own experiences to ensure a 'pure' understanding of the subject is achieved. However, interpretative phenomenology seeks to acknowledge the impossibility of this, and Heidegger (1987 cited in Finlay 2011: 53) argues that we will always be influenced by the 'lived world' in which we all exist. Within interpretative psychology, a strong emphasis is placed upon the importance of 'hermeneutics', a term used to describe the interpretation of understanding (Eatough 2012: 329.) Heidegger describes the development of knowledge as a hermeneutic learning 'circle', which occurs when our understanding is challenged by new knowledge. We then naturally meet a 'resistance' but through interpretative revision of our original understanding, new knowledge is obtained (Figure 7).

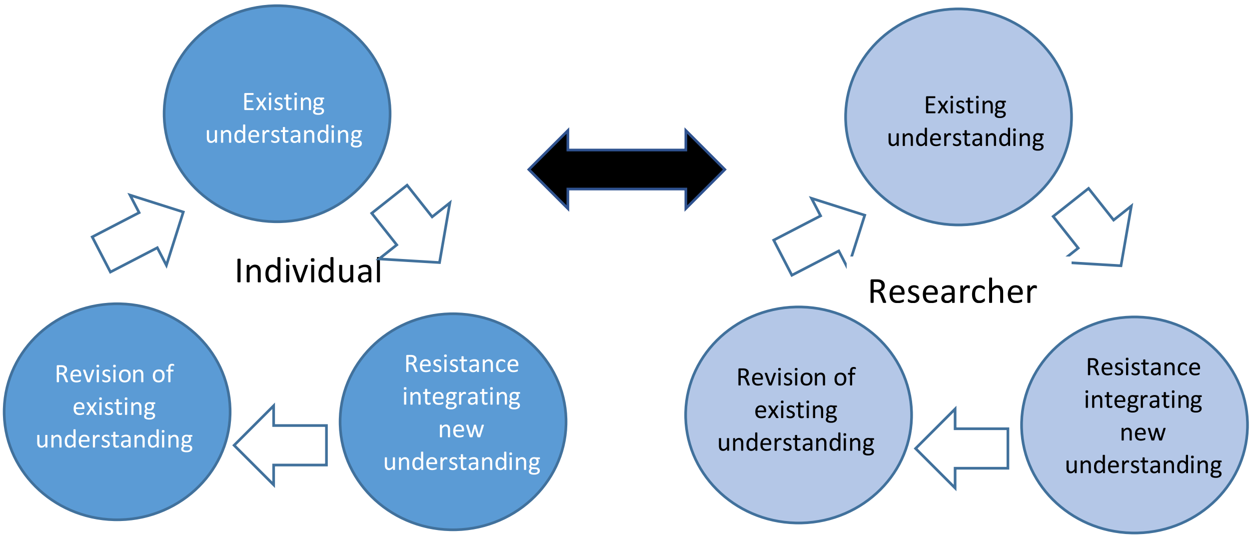
Figure 7 Heidegger's hermeneutic learning circle (adapted from Shaw 2013)



This ‘sense-making’ of the world around underpins analysis within interpretative phenomenology. This approach was selected for the research as it fits well with the desire to not only describe, but also to understand the experiences of people with dementia and family carers of people with dementia. The literature review in Chapter 2 highlighted that there is much written about how safer walking technology is being used and the potential risks and ethical concerns of using it. Yet, very few studies have included the views of participants living with dementia, who have used it themselves and sought to understand that experience.

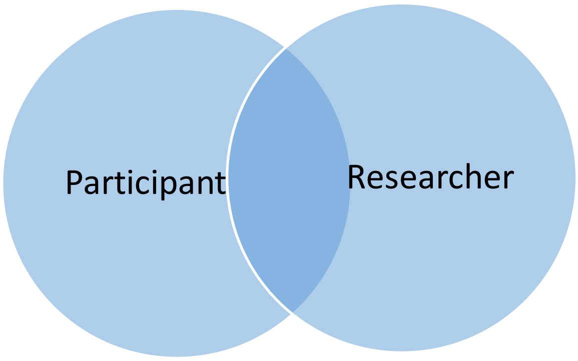
IPA acknowledges the hermeneutic cycle of learning as an individual experience a phenomenon but then goes on to also acknowledge that within the research there is a cycle of hermeneutic learning by the researcher as they ‘make sense' of the individual's ‘sense-making'. This process is known as double hermeneutics; rather than trying to ‘bracket off' their knowledge and experiences of the lived world, interpretative phenomenology recognises the central role of the researcher in the development of new knowledge (Figure 8).

Figure 8 Double hermeneutics (adapted from Shaw 2013)



Within this PhD thesis the researcher is therefore recognised as a clinical specialist in dementia care and occupational therapy, bringing considerable real-world experience to the research analysis process. It has been suggested (Finlay and Evan 2009) that therapists bring valuable professional competencies to phenomenological research as conducting phenomenological research and undertaking clinical practice both involve a journey of self-other understanding and growth, similar skills, values and interests. IPA acknowledges the learning and development of understanding from both the perspective of the participant and the researcher, in a fusion of horizons (Figure 9).

Figure 9 Fusion of Horizons



The fusion of horizons enables the researcher to put the experiences and sense-making of the participant at the heart of the research, whilst also acknowledging the interpretative nature of the data and her role within this, thus increasing the depth of understanding within the analysis and findings. Again, this aligns well with both the core philosophies of occupational therapy and the person-centred approach to dementia care described in Chapter 1. IPA draws heavily on the interpretative approach and Smith (2011) claims it has rapidly become one of the best known and most commonly used qualitative methodologies in psychology research. There is certainly evidence that this methodological approach is increasingly popular within healthcare research (Roberts 2013) as it enables researchers to reach, hear and understand the experiences of participants (Pringle et al. 2011), whilst viewing it through their understanding and lens of experience.

Carpenter and Suto (2008: 23) warn that it is important to ensure that at the core of the interpretative approach is an interest in understanding the complex world of lived experience or lifeworld, and a respect for the perspective of those individuals who live and interact within that world, whilst acknowledging the experience and influence the researcher brings to this process. This can be seen most obviously in the detailed process of analysis undertaken in this research and described later within this chapter. The IPA analysis process involves an in-depth exploration of each data set collected, with a focus on the understanding of the participant's language, meaning and description. The importance of the individual experience is highlighted within this process as the researcher attempts to interpret or make sense of the participant's sense-making of their own experiences.

3.2.2 Interpretivism and critical realism

The phenomenological focus on 'exploration of experiences' lends itself to an interpretivist enquiry, which encourages researchers to concentrate on the human features of experience, the "tangled, messy and multifaceted aspects of experiences" (Martin and Sugarman 2001:196). An interpretivist epistemology draws attention to the way our perceptions and experiences are socially, culturally and historically produced. Commonly referred to as 'naturalistic research' emphasising the importance of understanding experience within the 'lifeworld' (Sokolowski 2000: 147) or the real world. However, Willig (2001: 149) warns against the over-simplification and homogenizing of perspectives as most approaches combine several features that are compatible with more than one epistemological position as can be seen in the approach of 'critical realism'. Contemporary phenomenologists commonly adopt a critical realist position (Finlay and Ballinger 2006: 20), originally advanced by Bhaskar (1989 cited in Barbour 2014: 36) and further developed by Maxwell (2011: 72), critical realism combines realist ontology (the belief that there is a real-world that exists independently of our beliefs and constructions) with a constructivist epistemology (the belief that our knowledge of this world is inevitably our construction, created from a specific vantage point). Willig (2001: 49) also notes that methods often evolve, and researchers must be prepared to modify their epistemological assumptions accordingly. Within this research, an interpretivist qualitative enquiry was used to explore the perceptions and personal meanings within the individual's experience; viewed through a critical realist lens, recognising the subjective nature of the data and supporting the 'untangling' of these complex and multifaceted concepts to promote the development of a greater understanding of the potential of safer walking technology in this area.

3.3 Research Design

This research was designed to incorporate several accessible and person-centred methodological practices. This included the creation of accessible recruitment and study information materials and co-designed with the support of a stakeholder advisory group. To try and capture a wide range of 'voices' from diverse backgrounds within the participant group volunteers were sought by recruiting from a range of places, such as community interest groups and support groups across the West Midlands, alongside online recruitment, social media and an online database.

3.3.1 Ethical approval

Before the stakeholder advisory group was formed or any participants were recruited a detailed research protocol for both studies were submitted to the Coventry University Ethics Committee for review. This provided the committee with information about the overall research design, expected data collection and participant recruitment strategies along with original copies of all consent forms, participant information sheets, and advertising materials to be used (Appendices 8, 9, and 10). This also provided the committee with the rationale for the formation of a stakeholder research group, recruitment strategy for this group and all information, consent forms and planned work to be undertaken by the group. A favourable ethical opinion was given, and the ethics certificate can be seen in Appendix 11. Two dementia charities, The Alzheimer's Society and Dementia Adventure were approached and 'scoped' as gatekeepers who might, in principle, facilitate recruitment; both organisations agreed to support participant recruitment for this research. Both people with dementia and carers were to be recruited at the same time and where possible were identified through the same recruitment venues, strategies, and organisations, although it should be noted that it was not intended that the two different groups would be directly connected e.g. interviewing both carer and person with dementia from the same household. Further ethical approval was also sought, and gained, in 2016 to extend the participant recruitment strategy for both studies to include the use of the 'Join Dementia Research' (JDR) Database (Appendix 12).

3.3.2 Stakeholder advisory group

The research design included the formation of a stakeholder advisory group that recognised the added value and authenticity of consulting a range of other stakeholders as expert advisors, including clinicians from practice, expert academics, older people who regularly engaged in walking as a recreational occupation, family carers and people with dementia. The stakeholder advisory group was used within this research to both support elements of research design and to enhance and explore different views on potentially effective participant recruitment strategies. The importance of patient and public involvement in research is widely acknowledged in the literature (Mockford et al. 2012) and the researcher was guided by a range of resources developed by the National Institute for Health Research (NIHR) available from the INVOLVE website at https://www.invo.org.uk/posttypepublication/ Littlechild et al. (2015) also found that involving the public early on during a project helps researchers to design and conduct their research in a way that potential participants consider to be ethically acceptable. The group was formed by the researcher, recruiting through advertisement to the staff group in Coventry University's School of Health and through the University-run Research Support Volunteer Participants group (RSVP). The RSVP group provides an opportunity for volunteer service users and members of the public to engage with research projects at Coventry University and detailed information about the research's purpose and aims were presented to this group along with a detailed written summary.

Whilst the full impact of engaging in the study for all group members cannot be determined, there is evidence that the involvement in similar research advisory groups can have a positive impact on group members, (Payne, Hull and Woolward 2014). To promote a positive experience for those involved in the group, and anticipate possible difficulties, the researcher provided a detailed information sheet and obtained written consent from all group members before the initial group meeting. The researcher also met with all group members individually (at least 1 week after they had received the information sheet) to offer an opportunity to discuss the research, their role in the research advisory group, answer any questions and discuss any additional needs members had to enable them to take part. In total, the stakeholder group recruited five members who all expressed an interest in supporting the development of the research (Stakeholder group details are shown below in Table 6).

Table 6 Members of the stakeholder advisory group

Group member	Expertise	Recruitment Source
1	Technology user over the age of 65 with an interest in a range of outdoor occupations	RSVP Group
2	Carer for a person with dementia with an interest in rambling	RSVP Group
3	A person living with a diagnosis of vascular dementia who is a keen cyclist	RSVP Group
4	Occupational therapist with extensive experience of working in dementia services	School of Health, Coventry University
5	Occupational therapist and academic lecturer in Assistive Technology	School of Health, Coventry University

This approach reflected the epistemological underpinning of critical relativism – acknowledging the potential varied interpretations which may exist from a single experience. Within this context, the researcher was keen to avoid any potential bias or simply limited depth of data collection; this could arise if the research was designed on the experience and expectations of the researcher alone. The stakeholder advisory group enabled the researcher to seek to explore a range of perspectives, consulting them about several aspects within the research process.

Whilst all members of the stakeholder advisory group brought a unique and valuable set of experiences to the research design, the specific inclusion of people with dementia reflects the cultural shift to include people with dementia in the co-design of research (Tanner 2012; Gove et al. 2018) and in some cases this has elsewhere even been extended to the inclusion of people with dementia in the data analysis stages of research (Stevenson and Taylor 2019) but these cases are rare and pose an additional set of challenges as described by Clarke et al. (2018). A recent review by Miller, Whitlatch, and Lyons (2014) found that people with dementia wanted to participate in service design and research, but the actual level of involvement was limited and declined considerably as dementia progressed beyond mild cognitive impairment; a concern which limits the effectiveness of inclusion and empowerment initiatives considerably, (McConnell et al. 2018). As the target participant group for this research was people living with early-stage dementia, it seemed appropriate to include only stakeholders who did not have dementia or were at the early stage of their dementia. As seen in the literature review in chapter 2, one key flaw in the existing research in this field is an inability to recognise the different experiences and views held by people at different stages of their dementia journey, therefore this study focused on people with early stage dementia.

In total the stakeholder group met with the researcher three times (Table 7) including a final meeting designed to feedback to the stakeholders to show how the work they had undertaken had been incorporated into the studies' design and advertising materials.

Table 7 Purpose of stakeholder advisory group meetings

Meeting	Purpose
1	Review of draft participant information documents
2	Discussion of advertising documents and recruitment strategy
3	Feeding back the final draft of all documents and recruitment video to the group

The initial focus of this group was in designing and evaluating the participant information documents. They also offered advice about overall research design and recruitment. The participant information documents (Appendix 9) were designed in an accessible format, with a large typeface and clear font. Following feedback from the stakeholder group, it was also agreed that all participants would be asked if they would like the researcher to read through the documents with them, in person, if required.

The group also considered the researcher's plans for an advertising leaflet/ poster and recruitment video clip to be used on social media. The group considered both the content and presentation of these documents as well as advising upon how they each felt it would be best to advertise for participants. Following consultation with the group, the researcher then developed a range of visual recruitment adverts including the leaflet/ poster (Appendix 10) and recruitment video. (link in Appendix 13).

3.3.3 Creating advertising materials

Considering their own experiences, the stakeholder advisory group felt that difficulties with processing and retaining written language might deter some potential participants from engaging with written leaflets and posters containing too much text. Research evidence supports their concerns as changes in linguistic skills are commonly reported by people with dementia and can be detectable many years before a typical diagnosis, (Clarke, Barrick and Garrard 2018).

In response to this concern, a range of recruitment advertisements was designed to engage participants. These were developed with input from the stakeholder advisory group and included a leaflet/ poster, a short recruitment video, and a research Facebook page. These can be found in Appendices 10, 13 and 15 respectively. The leaflet/ poster was designed to be eye-catching and give clear concise information about the research; it also featured the web link and a QR code which allowed the direct viewing of the recruitment video on any smartphone or tablet. The same advert was used both as a poster and a leaflet to be handed out and taken away. Consideration was given to the font, colour and size of text included to ensure it was easy to read by potential participants who may have either age-related visual limitations or dementia-related cognitive processing difficulties. The recruitment video was then scripted with the stakeholder advisory group and filmed by the researcher in an 'outdoor location', as this was felt to be more interesting and reflective of the topic being researched. Aiming to enable a greater number of people to engage effectively with the information being provided, the video was made publicly available on the video-sharing platform YouTube. This also enabled it to be played repeatedly if needed and allowed the open sharing of study information across social media platforms including the researcher's own Facebook page. Further details of how the Facebook page was used can be found later in this chapter under the section on Social Media.

3.3.4 Participants

The participants within the research were recruited through a form of volunteer purposive sampling. This has been defined as the selection of individuals or groups of individuals based on specific purposes associated with a research question or aim, (Teddlie and Yu 2007). In this case, participants were sought as volunteers, who might respond to a general call for participants; to be eligible to take part, they had to meet the required research inclusion/ exclusion criteria for their respective participant groups (Tables 8 and 9).

Table 8 Inclusion/ exclusion criteria for study 1

Inclusion	Exclusion
People who have acted as a primary carer for a person with dementia	Wider family and friends who have supported a person with dementia
Family carers who have supported a person with dementia	Family carers who have supported people with other conditions
Family carers who have supported a person who has used a form of safer walking technology in the last 5 years	Family carers who have supported a person with dementia who has not actually used the technology or has used it over 5 years ago.
Family carers who live within the UK	Family carers outside of the UK

Table 9 Inclusion/ exclusion criteria for study 2

Inclusion	Exclusion
The person has a diagnosis of dementia	The person has memory impairment but lacks a diagnosis of dementia
The person has dementia is in the early stages	The person has dementia that has progressed into a moderate or severe stage.
The person can give consent to participate (as determined using the capacity assessment)	The person is unable to give consent to participate (as determined using the capacity assessment)
The person volunteers for the study in response to the recruitment strategy	The person is suggested or put forward for the study by another.
The person has some experience of using a form of safer walking technology currently or in the past.	The person has not used any form of safer walking technology before.
The person is living within the community and has access to the outdoors	The person is living within a secure environment and cannot access outdoors

Volunteer participation ensured that all participants were involved in the study out of choice and because they wanted to contribute in some way to the development of knowledge and understanding in this field; this does have some drawbacks, as this self-selecting group may not be representative of all people living with early-stage dementia and as seen in the discussion of the literature review in chapter 2, the experiences of individuals living with dementia are often unique and as varied as the individuals themselves.

3.4 Participant Recruitment

To recruit participants for this research several strategies were adopted by the researcher and recruitment took place in two different time periods (Appendix 7). The first stage of recruitment was undertaken in 2016 and consisted of reaching out to potential participants in local (West Midlands) community groups and organisations. During this period there was also a social media recruitment strategy online, supported by the gatekeeper organisations. In 2018 the second stage of participant recruitment was also conducted online, using the National Institute of Health Research (NIHR) database 'Join Dementia Research'. The following section details these activities and their effectiveness in recruiting participants for this research.

3.4.1 Gatekeeper organisations

This research approached two national charities and thirty-five smaller organisations to act as gatekeepers to identify potential participants for inclusion within the research. The use of gatekeepers to aid access to research populations is necessary for many studies. However, using gatekeepers can be problematic. According to Green and Thorogood (2009:20), researchers should strive both to ensure that participants are truly voluntary and that the voices of individuals or groups are not being silenced by dependence on gatekeepers for contacts. It is important to consider the issue of power concerning such gatekeeping and ensure appropriate safeguards are in place, (Manthorpe 2011:198). Moriarty and Webb (2000) provide an example of dementia research that sought the views of people with dementia. They describe their experiences of contacting people and found that there was considerable variance in ethical considerations when accessing people with dementia, and much was left to the integrity of the researchers and gatekeepers or those with powers of access. By undertaking a rigorous ethical application process and by establishing a close working relationship between gatekeepers and researchers, many of these potential difficulties were avoided. This equity of access was also supported by the strategy of advertising directly to the members rather than relying on referrals from within the gatekeeper organisations.

The two charities which agreed to act as main gatekeeper organisations, the Alzheimer’s Society and Dementia Adventure; each gave permission and support for the research to recruit participants via direct advertising to their members in person and online. The Alzheimer’s Society is a national charity with a network of local branches, which among other activities host memory cafés to support people with dementia and their family carers. Dementia Adventure is a registered community interest group that facilitates and organises opportunities for people with dementia to engage in outdoor activities. (Further information about the organisations can be found on their websites at www.alzheimers.org.uk and www.dementiaadventure.co.uk.) These two main gatekeeper organisations were asked to advertise the study to potential participants, through two different approaches.

1. To support identification of suitable groups or regular meetings organised by the gatekeepers in the local area at which potential participants are likely to attend. With the gatekeeper organisation's permission, these groups were then approached to gain permission to attend meetings.

2. To allow or support research recruitment by featuring advertisements and the recruitment video on their organisation’s social media streams, such as Facebook and Twitter.

3.4.2 Community groups

With support from The Alzheimer’s Society advertising for participants was conducted in person by the researcher at several of the Alzheimer’s Society Memory Cafés across the region. Over 50 Memory Cafés were approached, but many were reluctant to support the researcher’s attendance, despite the research agreement with the national charity. This was often because they felt they were over-exposed to requests to participate in research or from representatives of companies wishing to promote products. Despite this, between April and August 2016 the researcher attended 7 Memory Cafés across the West Midlands to promote the research and again many enquiries were received, which led to the recruitment of 5 participants. At each café, the researcher was given a 30-minute slot to show the recruitment video and talk to members about the research, answer any questions and provide information packs to any potential participants who came forward. Many of these then contacted the researcher and volunteered to take part in the research. Unfortunately, not all volunteers met the research inclusion/ exclusion criteria and only one was recruited for study 2 from this source, possibly reflecting the lack of representation at memory cafés from people with early-stage dementia.

Sixty smaller gatekeeper organisations were also approached to request direct advertising to their followers or attendees through the provision of posters and leaflets to all members. This approach was intended to capture potential participants who may not have regularly engaged with specific ‘dementia' services in the community but met the research criteria and might be involved in the gatekeeper groups identified. These groups included local Ramblers Associations, Walking4health groups, and other dementia activity groups. In total sixty organisations and groups were approached; of these thirty-seven responded and fourteen agreed to act as a gatekeeper and distributed promotional posters/ flyers to their members. (A full list of all gatekeepers approached, and enquiries received can be found in Appendix 14.) Despite these recruitment activities generating a considerable number of enquiries, no participants were ultimately recruited to either study through the smaller gatekeeper groups. All enquiries were from people who were interested in taking part but did not meet the inclusion/ exclusion criteria. The main reasons for the exclusion of people who enquired about the research were because they lacked experience in using the technology themselves or their dementia was too advanced for them to give informed consent.

3.4.3 Social media

The research was also promoted, and participants sought, by advertising directly to potential participants via social media. Research by Schnitzler et al. (2016) indicates that social media has the potential to enhance the reach of research recruitment to groups that have traditionally been hard to reach. This category could be applied to the potential participants of study 2, as people with early-stage dementia are often diagnosed and then have very little contact with traditional services until a point later in time when their health or other needs change. Direct online advertising to potential participants was undertaken through both the PhD researcher’s own Facebook page and the social media outputs of the two main gatekeeper organisations. In March 2016 the researcher’s Facebook page was launched. (See link in Appendix 15.) This was initially shared with the researcher's professional networks and across several other platforms including Twitter. The page was also shared by several gatekeeper organisations, including the main two gatekeeper organisations and other online dementia networks such as the Stirling Dementia Centre and relevant networks from within the University such as the Coventry University Occupational Therapy and Health Psychology live feeds. Online platforms represent sites at which current discussions surrounding the support and management of health and illness are often constructed and maintained, (Lawless, Augoustinos and LeCouteur 2017).

Social media platforms such as Facebook and Twitter specifically offer researchers a promising method for recruitment in the form of online advertisements, promoted by the platforms to a defined group of its members and paid for by the researcher. Research suggests that online advertisements compare favorably to traditional recruitment methods in terms of direct financial costs (Williams et al. 2012) and the number of labour hours required (Battistella, Kalyan and Prior 2010); often being used to effectively recruit research participants from traditionally difficult to reach populations. This was a relatively untested recruitment strategy for this population and the research design, therefore, faced several possible limitations. Within one similar study, Arcia (2014) highlights a potential drawback to online recruitment, labeled the 'digital divide'—the gap between those actively using the internet and those who are not, because it can be an obstacle to obtaining a socially, geographically, and economically diverse sample. However, the digital divide is narrowing, and the narrowing trend is expected to continue. Roberts (2009) observed within a report for the International Longevity Centre (ICL) that today's adult population will soon be tomorrow's older population and with this transition, they bring both technological expertise and expectation. The report also highlights the increased use and uptake of technology to enable, empower and communicate within the current older population, since the widespread day-to-day use of smartphone technology. This trend has increased considerably since the publication of the ICL report 10 years ago and with the additional popularity of tablet devices in recent years (Delello and McWhoter 2017; Arcury et al. 2018).

As a national charity, Dementia Adventure currently has a strong Facebook presence with over 800 people in the Midlands receiving their daily Facebook posts and there were currently over 108,500 people following the Alzheimer's Society Facebook page at the time of recruitment. Both organisations also have a Twitter presence and users can share or re-tweet postings with a wider audience if they wish. As a result of this many similar Facebook pages such as ‘Alzheimer’s & Dementia Weekly’ often share and re-send information in dementia focused streams to a much wider audience, although it is not clear when these audiences begin to overlap and reach saturation. During the period May to September 2016 the video advert and links to the leaflet appeared regularly on the main two gatekeepers’ social media streams on Facebook and Twitter and it was felt that the use of the video in a more direct form of advertisement would provide less opportunity for gatekeeper selection bias. The video adverts also appeared alongside regular updates about the overall research progress on the researcher’s own Facebook page and Twitter account. The Facebook page gave all interested participants the stakeholder advisory group members, supervisors, and fellow researchers an opportunity to engage with, and view the progress made within the research.

Although initially slow, the enquiries from this form of advertisement increased over time. Many of the responses came from members of the public commenting/ liking and or sharing the research page further across social media. In addition to this, a great number of enquiries were made and the management of this to ensure a prompt and helpful response to these enquiries became a significant part of the daily fieldwork. As a result of this online research promotion, two participants were recruited having either seen the Facebook page themselves or whose family had seen it and shown it to them. Encouraged by this response, a larger scale, more direct form of advertising was adopted in the form of paid advertisements.

Paid adverts were trialed for two months in 2016, using the Facebook paid advert service. This allowed the posts from the Facebook page to appear in the news streams of a selected group of people, previously unconnected to the research or researcher. The adverts were targeted at people over the age of 60, living in the UK and limited only by a budget of £40 per month. A larger budget would reach a larger number of people. Although the recorded reach in audience for these were very favourable, generating significant interest in the research, the additional work it created for the researcher was also considerable and proved a poor way of recruiting participants (Appendix 16).

3.4.4 NIHR ‘Join Dementia Research’ (JDR) database

The second phase of participant recruitment was undertaken in early 2018, using an online research database set up and run jointly by the Alzheimer’s Society and the National Institute for Health Research (NIHR). 'Join dementia research' is an easy-to-use service that allows people with dementia and family carers of people with dementia to register their interest in dementia research, so that they can be contacted about relevant research studies (Join Dementia Research 2017). Further information about the database can be found on their website at https://www.joindementiaresearch.nihr.ac.uk/. The overall aim of the database is to improve and speed up recruitment for dementia research and improve volunteer access to research opportunities. Although previously only available to research with NIHR funding, this was recently opened up to allow a limited number of other research projects with university ethical approval. The use of managed participant databases is not uncommon in research (Helman et al. 2007) and offered an opportunity to advertise the research to a much larger audience of potential participants, all of whom had already demonstrated a willingness to take part in research studies. After a successful application to use the database, approval was gained from the Department of Health to set up a data-sharing agreement with the NIHR funded national JDR database. This was the first such data sharing agreement approved within the 'Coventry University Group'.

Within the JDR system, both research studies were listed and detailed information about each study provided to potential participants. Both studies’ recruitment pages went ‘live’ within the database in February 2018. The studies were matched to any existing members of the database who met the inclusion - exclusion criteria and any new members who joined the database within the live period, February – April 2018. The advantages of using this database were evident in its access to many people who have already expressed a keen interest in taking part as research volunteers. Because of the large number of registered volunteers nationally it was decided to start by matching only with potential participants living within the West Midlands. In addition to the researcher’s convenience of identifying so many participants geographically close to Coventry University, this local grouping allowed for a greater feeling of participant involvement in a research institution with which they could identify. This is a key factor identified by Adamson and Chojenta (2014) in building trusting and open relationships with database participants.

It should be noted, however, that it was not possible to filter the database with all aspects of the studies inclusion/ exclusion criteria and so the initial matches all needed to be contacted and screened to identify those who had direct experience of using safer walking technology. Warner-Smith, Loxton, and Brown (2007) describe how the use of large participant databases requires both a considerable commitment of time and effective working practices, posing a range of practical challenges to researchers. In total, the database matched a potential 376 participants across both studies and the researcher contacted each of these by email, telephone, and if no email was provided, they were contacted by post. Many participants responded positively, and a great number of enquiries were received; these resulted in a further 11 participants being recruited across the two studies. A breakdown of the potential participant numbers, enquiries, and eventual participants can be seen in Appendix 17. Once the target of nine participant interviews had been successfully undertaken for each study the JDR database was closed to new participants. IPA research studies require small sample sizes (Larkin and Thompson 2011: 103) with the quality, rather than quantity of data being collected permitting insightful analyses to be developed.

3.4.5 Recruitment summary

In all instances, it was clear to the researcher that there were a great number of people using safer walking technology, reflected in the public comments on the Facebook page and the anecdotal discussions at memory cafés. However, the period in which the technology is being used to support outdoor mobility appears to be before a likely decline in cognitive skills associated with the person's dementia. Therefore, it proved challenging to identify people with dementia who had experience of using safer walking technology and who continued to have the capacity to take part, this posed participant recruitment challenges. A full breakdown of the mixed recruitment strategies and activities can be seen in Table 10.

Table 10: Overall recruitment

Recruitment activity	**Enquiries**	**Participants recruited to study 1: Family Carers**	**Participants recruited to study 2: People With Dementia**
Poster/Leaflet provision to gatekeeper members of hobby and interest groups	26	0	0
Researcher attendance at Memory Cafés	14	4	1
Online promotion of research through Facebook page	3	2	1
Promotion of research through paid adverts on social media	96	0	0
Contacting volunteers from the JDR database	206	3	9
TOTAL	**345**	**9**	**11** (2 were subsequently excluded after mental capacity assessment)

From the data collected within this research, there was evidence that there are many people engaged in the social media dementia streams and online dementia community, making this an appealing choice for recruitment activities. However, targeted individualized recruitment consistently proved the most successful strategy, whether in person at the dementia cafés or by contacting individuals directly from the online database. The least personal approach of using paid adverts or leaflets sent out to local interest groups to distribute failed to recruit any participants at all.

3.5 Data Collection

All participant interviews were completed by the researcher and took place in the West Midlands. Considerable thought went into ensuring issues of consent and capacity had been addressed appropriately and that the interview process enabled the collection of data that would be both true to the participant's experience and address the research question. The section below details the processes and considerations that were undertaken within this practical stage of the research. When planning and undertaking data collection the researcher sought to ensure the highest standards of ethical practice to maintain confidentiality and secure storage of participant data. Details of these practices are also described below.

3.5.1 Informed consent and capacity

Written consent was gained from all participants at the time of the interview (and a copy of the consent form used can be seen in Appendix 8.) However, dementia is a disease that, as it progresses, can affect an individual's ability to retain or process complex information, (Blossom and Brayne 2008). To ensure the participants could consent to take part the researcher conducted a capacity assessment before starting the interview. This was guided by the two-stage capacity test laid out in the Mental Capacity Act Code of Conduct (The Department of Constitutional Affairs 2005: 41), which provides a statutory framework for people who lack the capacity to make decisions for themselves (For further details see Appendix 19). The researcher was proficient in using the two-stage capacity assessment because of her considerable experience of undertaking such assessments in her clinical role as an occupational therapist in a community dementia service. To ensure the highest standards of practice were maintained, she also attended a training course designed as a 'refresher' for experienced clinicians and researchers working regularly in this field.

In advising researchers about capacity, the guiding principle of the Mental Capacity Act Code of Conduct is that researchers should assume capacity, unless there is evidence, they lack the capacity to make a specific decision. After completion of the two-stage test, if the researcher confirmed that the person did not have the capacity to consent to participate in the study that day, the interview did not go ahead. This occurred within the research on two occasions when meeting with potential participants for study 2. Capacity is not a fixed concept and an individual who lacks the capacity to decide for themselves at a certain time may be able to make that decision at a later date. This is particularly true of people with dementia whose illness is in the early stages. This means that their capacity to make some decisions may change daily; however, neither of the participants excluded from the study were reassessed and so did not ultimately participate.

In addition to ensuring that participants had the capacity to consent, the researcher also had a duty to ensure that the consent was informed. Informed consent is the principle that 'individuals should not be coerced, or persuaded, or induced, into research against their will but that their participation should be voluntary and with a full understanding of the implications of participation', (Green and Thorogood 2009: 69). All participants were provided with a participant information sheet (Appendix 9); this provided an overview of the study's purpose and aims alongside key information about the potential role and demands placed upon participants. It also provided information about confidentiality and the individual's right to withdraw from the study at any time. The Health Research Authority (HRA 2019) advises that participant information sheets should support the consent process by helping to ensure that all those who are invited to take part in a research study have been adequately informed. HRA also advise that in most circumstances it should be used to support conversations with potential participants, rather than being the sole source of information being made available to them. For this research, participant information sheets were provided at least one week before any interviews being conducted and on meeting with the researcher, participants were also offered the opportunity to discuss the information and ask any questions before completing the consent form.

3.5.2 Confidentiality and data management

One important ethical issue within this research concerned the protection of confidential data and the importance of maintaining participant pseudo-anonymity throughout the process and beyond into any dissemination activities that might occur as part of the research. Harding (2013:36) also emphasised the importance of keeping confidential information stored safely. A data management plan was developed and submitted as part of the original 2014 University ethics application; this was then updated in 2018 to ensure compliance with General Data Protection Regulation (GDPR) (Data Protection Act 2018). Any confidential material such as participant names, addresses, and other personal or identifiable information was kept separate from the main research data and destroyed when no longer needed to conduct the research. This was kept initially on the University's secure hard drives, behind the firewalls and then when instructed, in the final stages of the research, moved to an appropriate research repository set up and managed by the University's ethics administrators. All participants were also assigned pseudonyms during transcription, and these were used throughout the transcripts, the analysis and the write-up of the thesis. However, Barbour (2014: 96) states that there is considerably more to preserving anonymity then simply conferring pseudonyms or keeping original contact details under lock and key as names are not the only details which can lead to individuals being identified; it can be difficult to anticipate which aspects of descriptions might give rise to an individual being recognised and so the researcher should be constantly vigilant. To support this, several potential identifiers were removed from the data at the point of transcription.

3.5.3 Participant Interviews

In keeping with the accepted methodological design of IPA studies (Reid, Flowers and Larkin 2005), the researcher carried out one to one in-depth interviews with participants to enable them to describe and explore their experiences of the phenomena being researched. The use of interviews as a qualitative research method has been described as ‘conversation that has structure and purpose’, (Brinkmann and Kvale 2015:5). It is also well recognised that healthcare professionals often ‘take histories’, conducting interviews with their patients within clinical practice. However, Britten (2000:12) argues that there is a substantial difference between clinical and qualitative interviewing. To ensure the interviews conducted for this research collected the right data it was therefore important that the phenomenological theoretical perspectives underpinning the interview were acknowledged, ensuring an emphasis on the meanings that an individual attribute to an experience or situation, (Carpenter and Suto 2008: 82). The use of a semi-structured interview schedule guided the researcher and ensured the interview remained underpinned by both the theoretical and pragmatic aims of the research.

The semi-structured interview schedule contained a mixture of narrative, structural and evaluative questions, with a range of possible prompts. It was used to provide an overall structure, with participants often pre-empting future questions or areas of conversation such that a degree of flexibility was required to enable the interview to run its course. Brinkman and Kvale (2015: 57) argued that the researcher is as “a traveller who wanders together with the participant”, a concept supported by Smith and Eatough (2012: 447) who describe the need for IPA interviews to be participant-led, yet guided by the researcher. The interview schedule started with an advice/reminder section for the researcher which identified the need to vary the describing and labelling words used from those in the script.
The advice read:

"The word service user has been used within some questions and prompts; it is expected that in the initial information gathering this word will be used. However, following that, and wherever possible the interviewer should seek to replace this word with the participant's preferred descriptor (eg. patient, client, etc.) mirroring the language used by the participant."

The interview schedule for this research is longer than recommended by Smith, Flowers, and Larkin (2009: 60). However, not all prompt questions were asked in each interview, but all seven main areas were discussed with every participant. The interview schedule had prompt questions grouped under the following seven main titles; (the full semi-structured interview schedule can be found in Appendix 20), and the main titles are shown below:

1. Initial information gathering
2. Historic relationship with the outdoors
3. Impact of Dementia
4. Attitude towards technology as a supportive tool for people with dementia
5. Use of safer walking technology
6. Looking forward to the future
7. Closing questions

Participant interviews were conducted for both study 1 and study 2 over two data collection periods in 2016 and 2018 (see the research timeline in Appendix 7). All but one of the interviews was conducted in the participant's home. The exception to this was one interview with a carer who didn't wish to speak in front of his wife and so opted to use a quiet room at his local golf club instead. Brinkmann and Kvale (2015: 121) suggested that the environment in which an interview takes place is important, stating that 'being interviewed in one's home, with all of one's private items within the vicinity, can be helpful if the interview topic has to do with the person's biography.' Alternatively, other researchers have found great benefit in conducting 'walking interviews' (Evans and Jones 2011) or 'go-along' interviews, also known as street phenomenology (Kusenbach 2003). This form of 'outdoor' interview was considered by the researcher, but the potential benefit of these has not yet been proven and the increased practical limitations and potential risks and hazards were considered detrimental;

this is supported by advice from the UK Research Integrity Office (UK-RIO), which describes that in promoting good practice, the health and safety of both research participants and researchers should also be considered (UK - RIO 2009).

Interview data were recorded digitally on a portable Dictaphone; this allowed the researcher to concentrate on listening to the participant in the interview and to accurately transcribe verbatim for analysis at a later point in time. The audio recordings were also listened to many times over during the analysis process, described later within this chapter, to enable the researcher to immerse herself in the data. Paulus, Lester, and Dempster (2014: 109) also argue that the ability to synchronize the transcript with the recording when analysing ensures greater transparency and trustworthiness within the research process.

The same interview schedule and process was used for both studies, with one adjustment made for study 2 participants. It was acknowledged by the researcher that participants in study 2, all of whom had a diagnosis of early-stage dementia, were likely to have some (if only minor) difficulties with short term memory loss. This could make engaging in long and in-depth discussions more challenging, as key issues that the person wants to discuss could get missed or when discussing a point in more detail, the main thread of a conversation itself could become lost. To provide support and reassurance to the participants in study 2, the researcher employed a technique that utilised small post-it notes. This technique is guided by the same principles as the ‘talking mats technique’ developed by the University of Stirling to aid communication for people with moderate dementia, (Murphy, Gray and Cox 2007). The post-it notes were placed, with a pen, on a table in front of both the researcher and participant. Throughout the interview, if either person felt that something of significance or meaning was discussed then they jotted it down on a ‘post-it' note. At the end of the interview, the notes were reviewed together. This supported a clear conclusion to the conversations, but also enabled the participant to highlight issues of importance and remember the range of issues they had covered throughout the interview.

In addition to the audio recordings of the interviews, the researcher kept field notes typed up following each interview and an ongoing research diary written throughout the research process including following interviews. Field notes can cover information relating to the environment, the climate and atmosphere under which the interview was conducted, clues about the intent behind the statements and comments on aspects of non-verbal communication as they were deemed relevant to the interview, (Denscombe 2003: 175). This was an essential part of the research process enabling the researcher to also record non-verbal observations and to reflect on her role and the interview experience. The use of reflexivity and reflective diaries to learn and develop is common in occupational therapy practice settings and education (McKay 2009: 55). Such strategies are also well established within the field of phenomenological research (Moon 2006: 12) and within IPA research it supports the researcher's ability to explore the development of the interpretation and sense-making within the data analysis process itself. The use of this diary as a reflective learning tool during data analysis is explored in more detail in the next section of this chapter along with a detailed account of the researcher's reflexive analysis process.

3.6 Analysis of study one

The interview data collected in study one was analysed using a phenomenologically informed thematic process, drawing largely on the methods outlined by Braun and Clarke (2013). This differs to the interpretative phenomenological analysis used within study two and discussed in the next section of this chapter, as it seeks to understand the broader experiences of both the family carer being interviewed and their beliefs about the experiences of the person they care for. This is because much of the data collected within study 1 explored both the individual first-hand experiences of the family carers and, woven within these experiences, also their reflections and interpretations of the experiences of the person they cared for. This mixture of individual sense-making and projected understandings required careful consideration within the formation of themes from within the data. For the analysis of data in study one, Braun and Clarke's (2013) process of thematic analysis was followed; this is less prescriptive than IPA, (described later within study two), but can still be summarised within 4 clear stages. In a clear difference from the process described by Braun and Clarke (2013:202), each interview transcript was analysed individually using stages 1-3 of the above the process before viewing the whole study in stage 4. This maintains its phenomenological grounding in the experience of the individual and borrows much from the individual analysis commonly seen within IPA.

Figure 10 The 4 stages of thematic analysis for study one

Stage 1 Coding
Stage 2 Themes
Stage 3 Production of diagrammatic analysis
} Analysis of individual transcripts

Stage 4 Writing up and finalising analysis } Whole study analysis

3.6.1 Stage 1 Coding

The initial stage of this analysis process involved the identification of codes from within the transcript. Braun and Clarke (2013: 207) describe a code as a word or brief phrase that captures the essence of why a piece of data may be perceived to be useful. Yet, Saldana (2013:38) warns that the process of coding may limit effective data analysis, especially if it is reductionist, distances the researcher from the data or results in nothing more than counting. This could be especially true in selective coding. To avoid these pitfalls the analysis of study one was undertaken using 'complete coding' (Braun and Clarke 2013:206), a process that aims to identify 'everything and anything', within the entire data set and only later in the analytic processes becoming more selective.

3.6.2 Stage 2 Intermediate Themes

Identifying themes from the patterns within coding requires an in-depth understanding of both the interview data being explored and the purpose of the research questions being asked. In working out which patterns are relevant; it is not just a question of which are most frequent. Braun and Clarke (20123: 223) argue that it is also about capturing the different elements that are most meaningful for answering the research question. Within the formation of intermediate themes, the researcher used a practical visual theme development method, writing all identified codes from the individual interview onto 'post-it' notes with the corresponding abstract transcript line numbers noted and available to view easily in a table. These 'post-it' notes were then displayed in a large open area so that the researcher could visually see every code and developing theme. These initial groupings of codes formed the intermediate themes, which could then be viewed more selectively referring to the original research question.

3.6.3 Stage 3 Individual Participant Themes

The formation of the individual participant themes required both a critical and reflective view of the themes emerging, referring back to the original interview transcripts frequently to check participant meaning and researcher perception matched. How themes were grouped depended upon the patterns or connections that were formed from within the interview. The most common process for forming patterns within the analysis was through *abstraction*, putting common ideas together and developing a new name for this cluster, (Smith, Flowers and Larkin 2009: 96). For example, within the data analysis of Emma's interview the new name *'"Better not get back on my bike": A shrinking world*' was allocated to a group of emergent themes which included: parents' isolation, father's decreasing ability to manage technology, cycling accidents, and cessation, impact of not getting outdoors, inability to live at home any more.

In other cases, the analytic process of *'subsumption'* was used where an emergent theme itself was promoted to superordinate status and in doing so brought together a series of other themes to form the superordinate theme (Smith, Flowers and Larkin 2009: 97). A clear example of this can be seen in a theme taken from the data analysis of Annabel's interview. The theme *"People are afraid of it": husband's illness stigmatised them both'*, where the following emergent themes were all incorporated: loss of friends, loss of outdoor occupations and loss of family. Here the emergent theme '*Person's illness causes stigma'* was promoted to a superordinate theme to encapsulate the experiences across all these emergent themes. Occasionally, themes were formed through the identification of opposing themes, known as 'polarisation*'*. (Smith, Flowers and Larkin 2009: 97). This was less common but can be seen in the formation of one of the superordinate themes in the analysis of Francis's interview. Here the emergent themes of 'Wife embraced new technologies as a challenge to be mastered', 'Francis is reluctant to adopt new technologies' and 'They still feel GPS location technology may be helpful' were grouped under the new superordinate theme title *"They are there to be mastered": Differing views on technology.*

Once both the intermediate and individual participant themes were formed, the groupings were translated into 'thematic maps' to create a permanent and visual representation of how the researcher thought the themes fitted together; this was particularly useful as these electronic, yet moveable representations of the groupings could be viewed and revisited flexibly over time as the analysis developed. (An example of the thematic map created for an individual data analysis can be seen in Appendix 22.) The original data extracts were revisited for each of the identified themes to ensure they were true to the groupings and titles allocated. Once set, these were then transposed into individual participant theme tables which illustrated the open coding and focused themes. In the full write up of each participant analysis, the corresponding data extracts were also presented to illustrate the themes.

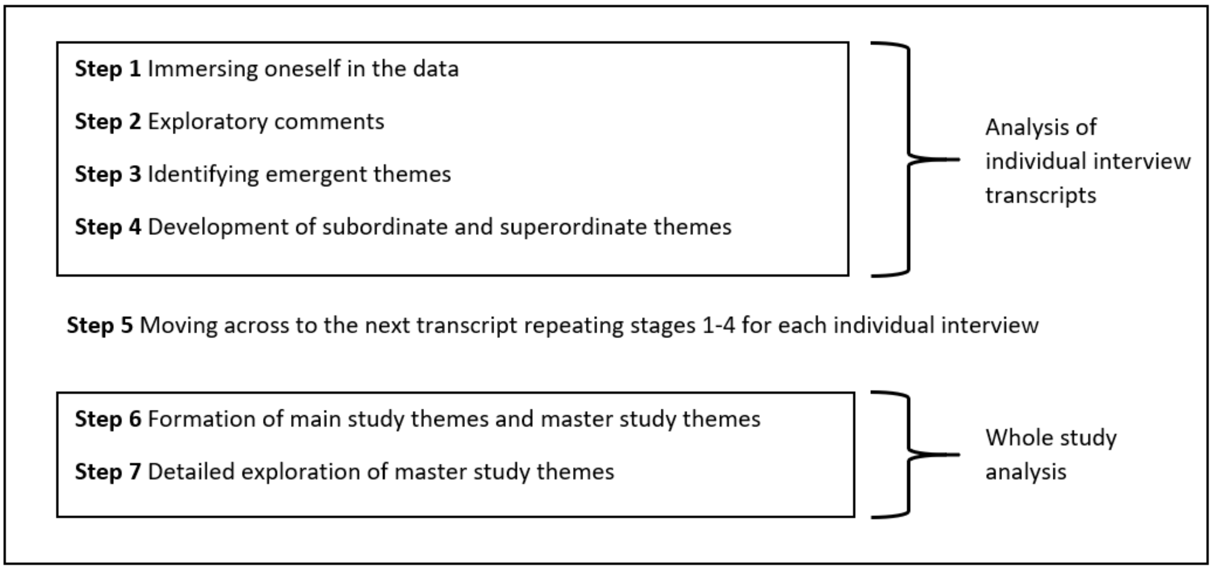
3.6.4 Writing up and finalising analysis

In the fourth and final stage of analysis, the individual data sets were brought together, with themes being combined from across the individual interview data to develop the main sub-themes and main themes. As with stage 2 of this process, a variety of methods were used to group these themes including abstraction and subsumption, with the full list of themes from across the individual participant interviews forming the basis of the creative process. It should be acknowledged that at this stage some common themes identified across the cases were discarded. For example, it was clear that a commonly discussed experience in study 1, amongst the participant family carers, was the stigma and loss they experienced in this role. This information was of great importance to the participants in telling their story and explaining the lived experience of being a carer for someone with dementia and is a commonly featured theme in research with family carers of people with dementia (Enright et al. 2018). The researcher had misgivings about excluding this highly emotive thread and set of codes, However, this thread was not included in the thesis because it was not directly relevant to the research questions.

3.7 Analysis of study two

Interpretative phenomenological analysis (IPA) was the method of data analysis used within study two. As discussed earlier in this chapter, a key feature of the IPA process is the recognition and importance placed upon idiographic experiences unique to the individual, shown in the commitment to understand how a phenomenon is experienced from individuals in a context, (Finlay 2011: 140); it also reflects the importance placed upon understanding the person in context as described by Pentland (2018) and discussed within the chapter 1. This form of data analysis enables exploration of the individual’s sense-making within their own lived experience or life world. One of the popular characteristics of IPA as a research methodology is it’s ‘healthy flexibility' in matters of analytic development, (Roberts 2013). Smith, Flowers, and Larkin (2009: 79) describe the IPA data analysis process in detail but warn that this is a guide to its use, not a single method to be followed prescriptively. In analysing the nine interviews from each study, Smith, Flowers and Larkin’s *6 step* method was followed, but with some minor adaptations appropriate to the data being analysed and the addition of a seventh step which addresses the need to explore the main study themes for each study in greater depth. As such, IPA seeks to explore each participant's experiences separately within their context; so the data analysis process starts with an individual in-depth analysis of each interview transcript, identifying themes from the raw data in a two-stage process enabling the double hermeneutic cycles whereby ‘The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world’, (Smith and Osborn, 2003: 51). The seven steps of this 2-stage data analysis process are shown in Figure 11.

Figure 11 IPA analysis of study two



This seven-step data analysis process was completed separately for: study 1, family carers; and study 2, people with dementia. A detailed description of each step is shown below, and the findings of study 1 and 2 are explored in chapters 4 and 5 respectively.

3.7.1 Step 1 Immersing oneself in the data

Step 1 of this process was undertaken by reading and re-reading the transcripts and listening to the audio recordings of the interviews. This enabled the researcher to re-familiarise themselves with the data. Smith, Flowers, and Larkin (2009: 82) advise that because most people are often used to reading and summarising complex information in very short periods, this part of the process is about slowing down our habitual propensity for 'quick and dirty' reduction and synopsis. To enable a clear picture of the interview narrative to emerge, an interview summary was then written (An example interview summary can be seen in Appendix 21).

3.7.2 Step 2 Exploratory comments

Following on from this, exploratory comments or initial noting were then added to the right-hand margins of the transcripts. This initial level of analysis was the most detailed and time-consuming, examining semantic context and language use on a very exploratory level. The comments were broken down further into three categories:

1. Descriptive comments – these helped the researcher identify facts and describe what is happening within the interview. For example, next to a participant's comments about her daughter's working pattern, the researcher might note 'family routine'.
2. Linguistic comments – these were added where the researcher felt the participant's language might indicate something specific. For example, when a participant described his phone as 'stupid', the researcher highlighted this word and noted the use of language reflects an emotional feeling towards this object, possibly frustration. Was the phone stupid/ or did it make him feel stupid?
3. Conceptual comments – these comments allowed the researcher to note down their initial conceptual ideas, that arose from the transcript in these early readings. For example, the participant might have started talking about how much they love

> the trees in their local woodland and the plants in their garden. If this started to sound like the concept of Biophilia, the researcher might write this as a note.

These comments were added for the researcher to consider in more detail within the later analysis; such comments could stand alone or might start to appear as repeated patterns within the notes. Different coloured pens were used to separate the different types of comments. This simple strategy acted both as a reminder to remain focussed on each aspect in turn and to ensure greater understanding when subsequently re-reading the comments later.

3.7.3 Step 3 Identifying emergent themes

Step 3 then involved analysing the exploratory comments to identify emergent themes. Within this step, there was a focus on discrete sections of the transcript, but it also involved a recall of what was learned through the whole process of initial noting in step 2. The themes reflected not only the participant's original words and thoughts but also the researcher's interpretation. They, therefore, reflected a synergistic process of description and interpretation; the researcher noted this down in the left-hand margin of the original transcript, and a full list of all emergent themes was added to the individual participant analysis alongside the initial narrative interview summary.

3.7.4 Step 4 Development of subordinate and superordinate themes

Step 4 of the data analysis for the individual participant interviews was less prescriptive, with the aim being to draw together the emergent themes to produce clear subordinate and superordinate themes that illustrated the most important and interesting aspects of the participant's experience. This process varies from researcher to researcher and can be both creative and exploratory as the themes are sculpted from both the emergent themes list and reading and re-reading the associated interview abstracts transcript (Smith and Eatough 2012). As with the theme development in study one, and described in 3.6.2, the researcher used a creative 'post it note' based methods to visually see and group the themes together. This method is advocated by Smith Flowers and Larkin (2009: 96) who praise its flexibility, enabling the researcher to explore special representations of how emergent themes relate to each other.

Always working directly with extracts from the transcript, the researcher sought to ground the themes groupings in the individual's lived experience. In a published discussion piece about the use of IPA methodology, Wagstaff et. al. (2014) express concern that at this stage of the process the idiographic focus upon the individual's experience can be lost and describes her experiences of identifying themes as akin to 'drowning in a deep bowl of spaghetti'; to avoid this loss of idiographic focus the authors recommended the use of a relevant, summative quotation from a participant to illustrate each theme and anchor it into the 'real' words of the individual. Larkin and Thompson (2011) argue that the most effective theme labels in IPA studies are usually those that evoke the content of the material within them and the meanings that are attached to that content by the participants. In keeping with the desire to stay true to the 'voice' of the participant, each superordinate theme in this study was given a dual name; half of which was a descriptive label assigned by the researcher and half of which a data extract that it represented from within the individual's narrative. For example, superordinate themes from one participant included:

- “I missed taking him for a walk”: the importance of dog walking
- "I was out of my comfort zone": adapting to change
- “I do all the normal things”: how the technology works for him

Finlay (2011: 229) advises researchers to seek out the themes that resonate or hold clear significance to the individual participant. She suggests that it is important to discard observations or emergent themes that are not relevant to the research focus. In this study, the researcher found that many of the participants wanted to discuss the process and experience of their initial diagnosis. This is not unusual and reflects the natural tendency of people to tell their story from the place they perceive to be 'the beginning'. However, for many of the participants, this information was re-told automatically, and although detailed the researcher did not feel they necessarily held a significant sense-making or relationship to the main research questions or topic. Emergent themes such as these were discarded at this point to allow, what Biggerstaff and Thompson (2008) describe as, a deeper focus on the formation of theme groupings that best demonstrate the person's experience of the phenomena being studied.

Using several different approaches to organise the themes, enabled flexibility to the individual idiographic nature of the data. As identified earlier within this chapter, the author sought to acknowledge her own experiences and sense-making process and influence upon the data analysis process. Throughout these stages, the researcher continued to keep a detailed and reflexive research diary, thus providing a place to allow both reflexive sense-making and reasoning to existing alongside the understanding and notes of the participant's sense-making. This allowed the researcher to acknowledge that grouping these themes was just the initial step in finding sequences for an in-depth analysis, (Finlay 2011: 234). This research diary also served as an audit trail to enable the researcher to check and recheck the formation of groupings and themes. Shaw (2010: 186) advises that keeping a reflexive diary and maintaining an audit trail is essential when undertaking IPA.

As with study one, thematic maps were then formed to create a permanent visual representation of how the researcher thought the themes fitted together and then transposed into individual theme tables. Smith and Eatough (2012: 455) argue that it is important to be disciplined to discern repeating patterns, but also acknowledge new issues emerging as the transcripts are worked through

3.7.5 Step 5 Moving across to the next interview

Step 5 enabled the researcher to move on to the next participant interview transcript, bracketing off previous themes and keeping an open mind to do justice to the individuality of each participant. The process of analysis and theme forming (steps 1-4) was undertaken individually for each of the interviews.

3.7.6 Step 6 Formation of main study themes and master study themes

Step 6 enters into the second stage of analysis which enabled the researcher to begin looking for patterns across the study. Smith Flowers and Larkin (2009: 101) advised that this can often be a particularly creative task, helping the researcher to move to a more theoretical level as it is recognised that themes or superordinate themes which are particular to individuals, also represent instances of higher-order concepts which the participants therefore share. Smith Flowers and Larkin (2009: 106) advise that even where the analysis is at this group level of analysis, the analysis remains true to IPA's idiographic principles because the group level themes are still illustrated with examples directly from the individuals.

As with the earlier step 4 of this data analysis process, the researcher sought to group the themes and used a variety of methods including abstraction and subsumption, with the combined superordinate themes forming the initial basis of the analytical process. Smith and Eatough (2012: 155) acknowledge the need for researchers to adopt various strategies to organise and condense themes, but it is Biggerstaff and Thompson (2008) who most strongly advocate for increased selectivity and rigour in identifying themes. They argue that the frequency of a theme should not necessarily be the deciding factor in progressing a theme, rather a consideration of the richness of the text and how such a theme might inform other parts of an individual's account. This period of in-depth analysis, including analysis of the combined superordinate themes, saw the researcher revisit and explore each section of the interview identified in its original transcript and then in the eventual development of the main sub themes and main themes. Many of the superordinate themes were combined to form the main sub themes, whilst others were renamed to recognise a new feature that emerged from the in-depth analysis. Main theme tables illustrating the main sub- themes and main themes for each study are found in chapter 5 which each explore the findings of study 2.

3.7.7 Step 7 Detailed exploration of main study themes

Although Smith, Flowers, and Larkin (2009) do not specifically describe a step 7 within their agreed 'method' for data analysis, they do suggest that following step 6 the researcher should consider taking the analysis 'deeper.' There are many worked examples of this deeper analysis within the literature, for example, Smith and Osborn (2008: 59), and Brocki and Wearden (2006). Smith and Eatough (2012: 459) describe how IPA's 'iterative' process enables the interpretative levels to acquire more depth as the research moves beyond the descriptive to an interrogation of participant sense-making. Within this PhD thesis, the researcher sought to undertake this final more detailed analysis stage to ensure that despite the larger sample size, the study's findings remain grounded within the detail of the individual and represent the depth of understanding gained through close examination of each participants lived experience. The detail of step 7 of the analysis can be seen within the findings (chapter 5) where each main theme is explored in turn and extracts from individual participant's interviews examined. Understanding where the main themes and main sub-themes occur across all the interviews within a study is important in piecing together a 'whole picture' of the phenomenon being explored but is also balanced out within IPA by the focus on detailed interpretative analysis. This process was started as part of the detailed examination of the data that formed the main sub-themes and main themes. Once these were established, it was continued by looking at how these main themes threaded across both the group and within the individual accounts.

Finlay (2011: 142) also suggests the inclusion of the seventh step of IPA data analysis, but with a different focus. She argues that the seventh step of IPA should be considered to; "Deepen the analysis by utilising the metaphors and temporal referents, and by importing other theories as a lens through which to view the analysis." Such a step is not included in this chapter but can be found in Chapter 7, within the main research discussion. This forms a more complex and combined exploration of the findings from all three areas examined within this research including the findings from studies 1 and 2, and the examination of existing published research literature and theory.

3.8 Reflexivity

The following section of the thesis is written in the first person, from the perspective of the researcher Esme Wood. This enables a clearer understanding of the reflective process and reflective learning.

3.8.1 Using reflection to expand research skills

My clinical background and experience of working as an occupational therapist in dementia care brought many benefits to this research, including a sound clinical knowledge of dementia as a medical condition and an understanding of how it affects people in their day to day lives. Because of this background, I also had experience of visiting people with dementia in their own homes, assessing capacity and conducting one to one interviews to assess their individual needs and therefore had an understanding of some of the challenges presented to people with dementia and their carers. To ensure a smooth transition from clinician to researcher, several reflexive strategies were developed to ensure that the right skills were developed and utilised, particularly in interviewing participants. Newham (2009: 152) argued that clinicians are not novice researchers, due to their experiences of undertaking small scale research at undergraduate and postgraduate level within their qualifying studies. However, in acknowledgment of my limited experience of undertaking research interviews, I sought to develop the required skill set through experiential learning, drawing upon my experience of skill development in practice as a reflective practitioner.

In addition to the audio recordings of the interviews, I kept a reflective learning journal and log of ‘field notes' that were typed up following the interview. The field notes covered information relating to the interview environment, clues about the intent behind the statements and comments on aspects of non-verbal communication that were deemed relevant to the interview. Denscombe (2003: 175) argued that field notes are an essential part of the research process enabling the researcher to also record non-verbal observations and to reflect on their role and the interview experience. A reflective research journal provided a place to record reflections on my role and performance, observations about the use of the semi-structured interview schedule and any other aspects of the interviews that seemed important to reflect upon; this approach supports the process which acknowledges and seeks to understand the researcher’s interpretation of the data based on previous knowledge and experience. According to Gayhe and Lillyman (2006: 38), a reflective learning journal can be a repository for experiences that can then be integrated, deconstructed and re-evaluated to deepen awareness. The use of a reflective learning journal also suited my recognised learning styles (Honey and Mumford: 2000) as a reflector and theorist. The completion of this journal, alongside the opportunity to reflectively review the transcripts of the interviews enabled both reflective and experiential learning to take place, and the development of a more effective researcher-based interview style. It is not uncommon to use reflective learning journals for novice or early-career researchers, and in many fields, it is considered good practice (Bassot 2016: 112).

After completing the first few interviews and reflecting upon the journal and the transcripts, I considered the interviews to be of a good standard, with all of them consistently guided by the semi-structured interview schedule. However, after reflecting and discussing with the supervisory team, there was a recognised need to shift the emphasis from a clinical style of interviews to a research style. Bruton and Ellis-Hill (2009: 62) emphasised the importance of ensuring data collection methods and practices are consistent with underlying methodological and philosophical underpinnings. As with most qualitative research methodologies, IPA requires that participant interviews are conducted with a degree of self-awareness and objectivity (Babour and Schostak 2005: 42). Brinkman and Kvale (2015: 57) argue that the researcher is as “a traveller who wanders together with the participant” a concept supported by Smith and Eatough (2012: 447) who describe the need for IPA interviews to be participant-led, yet guided by the researcher. A reflective review of the initial transcripts revealed some instances identified where I could improve, and it became apparent that my style of research interview was not always in keeping with an IPA approach and was heavily influenced by my previous clinical experience. Several examples were found, where a good question was followed immediately by a leading opener which is not needed and biases the participant's answer. For example.

> ***“I: Yeah and how do you feel about being tracked, is that something that bothers you?” (Interview 1, line 505)***

There were also examples where I did not leave enough space for the participant's reflective thought process and instead, as seen in the following example, I jumped in, closing down the potential conversation about experiences in the scouts and redirecting towards the next question.

P: I used to go out camping with the scouts when I was younger.

I: Did you enjoy that?

P: Yeah, yeah. Good fun. [laughs]
I: Do you know the amount of people who say to me the first time I ever remember going outdoors and doing outdoor things was at the scouts. [Laughs] They did a marvellous thing. Haven't they? Okay so since you have had some memory problems has that affected your… you mention you don't go on holiday anymore has that affected any other aspects of your day to day life would you say?

(Interview 2, lines 163-170)

Smith Flowers and Larkin (2009:63) state that "often the most interesting questions require time for reflection, and richer, fuller answers will be cut short if the interviewer jumps in too quickly." Many examples of good clinical skills were observed, but these often conflicted with my researcher role. In the example below, good rapport building can be seen, but this turns the interview into a conversation, where I show recognition of what is being said and provided a natural conversational style of dialogue.

"I: …because you're listening to you.
P: Yeah.
I: Very clever.
P: And when you've finished you press erase. Now just think how much that would help, not only people with dementia but everybody and I'm sure when you go shopping you forget something…
I: …oh yeah, every time.
P: You know and…
I: …even with a list [laughs].
P: Yeah but if you intend to make a list there's always the times where you don't have it with you because you don't have a piece of paper or you don't have your pencil or whatever,

but you always need have a phone in your pocket, you know, that's it, job is done. They did the searches, there's nothing out there like it. Wouldn't that be amazing?
I: It would yeah. ***(Interview 1 309-322)***

However, this style of dialogue may limit the participant's input and encourage them to also provide brief responses and seek further researcher input. In my clinical role, I was often required to gather detailed information about a person quickly, whilst also developing a therapeutic rapport (Tickle-Degen 2002). This therapeutic rapport can be defined as “A trusting connection and rapport established between therapist and client through collaboration, communication, therapist empathy, and mutual understanding and respect" (Cole and McClean 2003). However, the role of a researcher is different. Whilst Smith, Flowers, and Larkin (2009: 64) stressed the importance of establishing a good rapport, this serves merely as a platform from which to enable the interview to take place; in research it is not essential to promote trust for future therapeutic work, as seen in clinical occupational therapy practice.

Within the transcripts, I also offered praise and examples of positive regard to the participant to highlight an understanding of their strengths. Whilst such an approach is essential to developing a positive rapport and demonstrating positive regard within the developing relationship between occupational therapist and client, it is not necessarily appropriate to the relationship of a researcher and participant. For example:

> ***“I: Yeah, I think you’re a great advocate for the technology and the practical ability to say there might be things that I can’t always do, I can’t do them in the way that I used to but I’ll find a way of making the technology work for me – I think that’s great.”***
>
> ***(Interview 1, 706-708)***

Instead of seeking to invest in the development of a therapeutic relationship based on trust and the demonstration of unconditional positive regard, as seen in therapeutic relationships (Bozarth 2007: 182), Fontana and Frey (2000) argued that the IPA interviewer aims to facilitate the giving and making of an account in a sensitive and empathic manner, recognising that the interview constitutes a human to human relationship.

In the early interviews, I also shared anecdotes from my own experience, which again reflected a more clinical style of interview. The sharing of experiences in a clinical role is important as it reduces barriers and builds trust, but can sidetrack a conversation in an interview, especially for people with dementia. For example:

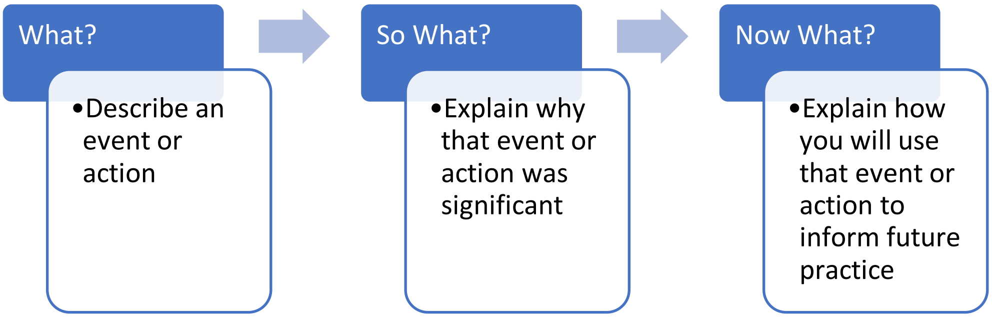
"P: you know, I ended up doing all sorts of things like changing light bulbs, you know, you've got someone living alone they can't go into a room because the light bulbs gone and they can't change it, they can't put their arms above their heads anymore…
I: …I once got in trouble I used to work for a health service for older people in Cheshire cos I regularly used to do things like change the light bulbs or I used to help reorganise people's cupboards for the things they needed down the bottom, what I would see is practical things and I saw it as part of my bonding as well, because I was supposed to be developing a therapeutic rapport, it would help me get to know people and then somebody in our office came across the fact that I was doing all this stuff and got all upset with the health and safety of me going up ladders and it's just really not my job, you know, and I got told off for doing it, I got in a lot of trouble actually for changing light bulbs and things like that.
P: I mean isn't that stupid?
I: I know.
P: I mean that…
I: …you'd do it at home so why can't you do it…"

Interview 1 (948-962)

In addition to changing the conversation, introduction of my anecdote also shifted the attention away from the experience and expertise of the participant. The interview questions should enable the participants to engage in interpreting events, objects and people in their lives, a process known as 'sensemaking', (Smith and Eatough 2012: 441). The double hermeneutic cycle discussed in chapter 3, is important to the principles of IPA and requires that this part of the process involves the researcher becoming immersed in the participant's world (first hermeneutic cycle), not providing anecdotes from their own world experience (second hermeneutic cycle). There is an opportunity to consider the gathered information from my perspective later in the analysis process. Smith and Osborn (2008: 53) describe these two different hermeneutic cycles as "the participants trying to make sense of their world; the researcher trying to make sense of the participants trying to make sense of their world".

To acknowledge these difficulties and develop the researcher style, the first few transcripts were re-read, and I undertook a reflective writing exercise to help identify both the strengths and weaknesses of the initial interview style. Borton's developmental framework (1970 cited in Jasper 2003) was also used to review and reflect upon the identified issues from these interviews. Borton's developmental framework is a straightforward reflective model that promotes reflection on "real-world practice" (Jasper 2003: 99) and is commonly used by healthcare practitioners. The framework consists of asking 3 simple questions, to promote an analytical reflection (Figure 12).

Figure 12 Borton's Developmental Framework



In using Borton's model of reflection, I developed several strategies to improve the way interviews were conducted and promote putting the experiences of the participants at the forefront of the next interviews. These strategies are shown in the completed reflective table in Appendix 23. Reflection upon my role in the initial interviews enabled the development of more research focused interview skills and techniques; this, in turn, ensured the participant interviews stayed true to the theoretical stance of the IPA methodology, and I identified strategies helped to prioritise the participants 'sensemaking', staying true to the idiographic sensibility (Finlay 2011: 140).

3.8.2 Reflexivity within analysis

The potential influence of my experiences and expertise is also a factor to consider within the data analysis process. All phenomenological data analysis methods seek to explore individual experiences within a humanistic context, (Green and Thorogood 2009: 14); yet, they often encourage the researcher to 'bracket off' their own experiences and expertise to increase the rigour and repeatability of the analysis process. Bracketing involves the researcher attempting to separate their assumptions and reactions, placing them aside to focus only upon the expressed views of the participant, (Tufford and Newman 2012). Other forms of qualitative analysis require the researcher to make explicit their position, leaving the reader to decide how this may have influenced the analysis, (Barbour 2014: 37). Although possible within this research, this approach fails to allow a researcher to fully acknowledge or reflect upon how these experiences influence their interpretations. The final approach to this issue as recommended by Parker (2004) is that the researcher works 'with subjectivity rather than against it' in a process sometimes known as 'reflexive accounting', (Altheide and Johnson 1998). This reflexive accounting can commonly be seen within IPA research where, as discussed earlier within this chapter, there is a 'central role for the researcher', recognising their interpretations and acknowledging that without this active involvement research may not fully uncover the meanings the study is seeking to achieve, (Pringle et al. 2011). Shaw (2010) suggests that IPA recognises the significance of the researcher's presuppositions and that they can both hinder and enhance the interpretation of another's lived experience and argues for the embedding of reflexive strategies in qualitative research. To increase the standards of rigour within IPA studies it is therefore essential that researchers engage in 'reflexivity', (Kingdon 2012) and use self-awareness strategies to reduce the potential biases they bring to the research. When undertaking the data analysis for this research I kept a detailed research diary, which recorded both the process of analysis and the thoughts and influences upon the interpretation. The use of research diaries is a well-recognised strategy for both reflective learning and promoting self-awareness within the data analysis process itself, (Moon 2006: 23).

3.9 Conclusion

This methodology chapter provides a detailed account of how this research was designed and undertaken; it explores how its epistemology was influenced by my clinical background and how in turn, that epistemology underpinned the methods adopted within the overall research design and the two individual studies. I made these methodological choices to ensure the best possible data collection to address the specific research question and aims outlined in Chapter 1.

I designed the research with support from a stakeholder advisory group which both promotes patient and public involvement in research and directly involves the inclusion of people with experience of dementia in the design of the research; this recognises the importance of acknowledging and respecting differing perspectives. Participant recruitment strategies, information provision and verification of mental capacity and consent were all carefully constructed to be as inclusive as possible, facilitating engagement of participants from a potentially diverse set of backgrounds and with a differing range of experience.

My adoption of a phenomenological approach kept the research within the client-centred and patient-centred philosophies described in previous chapters; in doing so, this research set out to put the experiences and views of the individual at the heart of the research. My use of Interpretative Phenomenological Analysis in study 2, mandated a focus upon individual experience and gave voice to each participant within the research, whilst also recognising my own lifeworld experiences and their influence upon the analysis process.

3.10 Key Messages from this chapter

- Viewed through a critical realist lens, this phenomenological research utilised an interpretative enquiry to explore the perceptions and personal meanings within the experiences of individual participants.

- This research was designed with the input of a stakeholder advisory group, including older people and people with dementia in co-creation of the research design.

- 2 separate research studies were conducted, both utilising a volunteer purposive sample recruited from both community groups, via online and the JDR database. This included creative recruitment methodologies including the use of social media and development of a recruitment video.

- A 4 step phenomenologically informed thematic analysis was undertaken of the data in study 1, recognising the need to explore the experiences of family carers and their perceptions of the people they care for.

- A 7 step Interpretative phenomenological analysis approach was used to undertake data analysis and explore the lived experience of 9 participants in study 2.

The next chapter presents and discusses the findings from study 1, which explores the experiences of nine family carers who have used safer walking technology to support a person living with dementia to undertake outdoor occupations.

Chapter 4 Findings 1

4.1 Introduction and Rationale

This chapter is the first of two findings chapters: each describing a separate research study. Both focused on the use of safer walking technology by people with dementia but interviewed different groups of people. Study 1, covered in this chapter, explored the views and experiences of family carers who have supported people with dementia to use safer walking technology to access natural outdoor environments. Within this study family carers of people who lived with dementia were interviewed, and the transcripts of these interviews analysed using a phenomenologically informed thematic analysis, as described in the previous methodology chapter. Within this chapter, the data analysis themes for study 1 are identified and mapped across the case studies. These themes are then explored in depth using extensive data extracts to illustrate the analysis.

As discussed in chapter 2, understanding the views of family carers has long been considered important in dementia and assistive technology research, yet this has sometimes been used as a ‘proxy' for research that seeks to understand the needs and experiences of people with dementia (Liu, Cruz, and Juzwishin 2018). In contrast, study 1, like similar research by Hughes et al. (2002), aims to understand family carer’s experiences in their own right, whilst acknowledging the mutually dependent and sometimes symbiotic relationships between a person with dementia and their family carers. To avoid content bias and the potential for data to be influenced in some way by the complex relationships that can form between family members, none of the participants in this study were related to or had any connections with the participants in the second study.

4.2 Participants

Nine participants were interviewed for this study, consisting of five women and four men, all of whom were family carers for people with a diagnosis of dementia. The relationship between the carer and the person they cared for varied, but all the participants cared for a close family member. Six out of the nine participants reported caring for their spouse, with five of these describing marriages of over 45 years. One married couple had met later in life but had still been married for over 12 years. The remaining three participants were all family carers of a parent or parent-in-law. The participants were aged between 45 and 88; the relationship between the participant and the person they cared for and their age can be seen in Table 11.

Table 11 Relationship between the carer and the person with dementia that they supported

	Participant	**Age**	**Relationship to the person they care/ cared for**
A	Annabel	62	Daughter
B	Barbara	66	Wife
C	Carl	88	Husband
D	Diane	74	Wife
E	Emma	45	Daughter
F	Francis	60	Husband
G	Greg	48	Son in Law
H	Helen	74	Wife
I	Ivor	78	Husband

The participants were all interviewed alone, in their own homes, and to protect their confidentiality, real names, names of other people mentioned within the interview and identifying features, such as names of towns, were removed. This is common practice within scientific research, but Brinkman and Kvale (2015: 95) warn that whilst anonymity can protect the participants, it can also deny them the very voice in the research that might originally be claimed as its aim. Therefore, to balance out this risk, each participant was allocated a pseudonym to help identify them individually, improve the readability of the data and remain true to the ideographic nature of each narrative.

4.3 Development of themes

Each participant interview was analysed individually using the methodology outlined in the methodology chapter; the summary of each participant interview can be found in Appendix 24. Multiple codes were identified in the initial reading of the individual transcripts. These were grouped, and a final set of both intermediate and individual participant themes identified for each participant. Theme development across the individual participant interviews can be seen in Table 12. The individual analysis revealed between 4 and 6 individual participant themes each, the mean number of themes per participant was 4.5.

Table 12 Development of Individual themes in study 1 family carers

Participant	A	B	C	D	E	F	G	H	I		
Codes	42	24	27	21	38	38	24	34	23		
Intermediate Themes	18	13	13	16	15	19	14	16	15		
Individual Participant Themes	5	4	4	4	5	6	4	5	4	41	Total Participant Themes

The individual participant themes combine to form the forty-one participant themes; a full table of the participant theme titles from all 9 individual participant interviews can be viewed in full in Appendix 25.

Although each participant's experience was analysed individually, there were many common experiences reported across the interviews, such as acknowledging the health and well-being benefits of supporting someone to get outdoors, a lack of guidance in choosing safer walking technology and an acknowledgment of a ‘useful window of time' during which the technology could be used. From these forty-one participant themes, thirteen sub-themes and five main themes were identified. Again, the process of this theme development is described in detail in the previous methodology chapter but is summarised in Figure 13. The titles of the main themes and sub-themes are then shown in Table 13, along with information about which participant’s interviews the themes are developed from.

Figure 13 Development of study 1 main themes and sub-themes

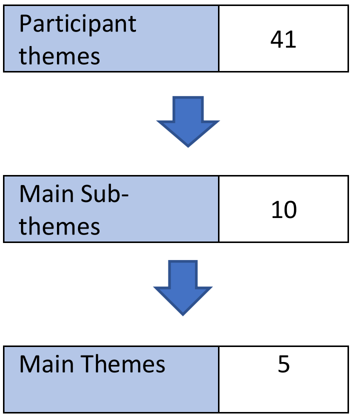


Table 13 Study 1 main themes and subthemes

	Main Themes		Main Sub-themes	From Participants
1	“An active person all his life”: Maintaining self-identity through outdoor occupations	1	“We do a lot of walking together, always have”: Personal identity linked to nature and the outdoors	Annabel, Carl, Diane, Emma, Greg, Helen, Ivor
		2	“Because he can relate to it and not make mistakes”: Feels at home in the outdoors and with nature	Annabel, Carl, Emma, Greg, Helen
2	“We’ll know where he is”: Safer walking technology provides reassurance and confidence	3	“A degree of confidence”: how it helps them as a family	Annabel, Barbara, Emma, Greg, Helen, Ivor
		4	“I know I know you, but I’ve got dementia and I can’t remember your name”: technology gives the person with dementia confidence	Emma, Greg, Helen
3	“It’s got to be given at the right time”: When to introduce the safer walking technology	5	“If you can get used to this, you know for the future”: The importance of developing habits	Barbara, Carl, Diane, Greg, Helen, Ivor
		6	“It’s not as easy to learn now”: Introducing technology at the right time for everyone	Carl, Diane, Emma, Helen, Ivor
4	"Have you thought about a tracking device?" : Support to adopt and choose to locate technology	7	“Do you have to lie to get this stuff?”: poor provision of technology by services	Annabel, Emma, Ivor
		8	“We were given some brochures and some literature”: A lack of professional support or guidance	Annabel, Diane, Francis, Ivor
5	“That was the ideal one”: The right functions and safer walking technology for the right person	9	“We’ve written it off”: when the technology doesn’t work as expected	Carl, Diane, Francis, Ivor
		10	“It might as well have been a banana in his hand”: more harm than good	Diane, Emma, Francis

4.4 Theme 1: “An active person all his life”: Maintaining self-identity through outdoor occupations

When discussing their experiences of caring for a person with dementia, all the participants talked about the important relationship that the person they cared for had with the outdoors. For all, the engagement in outdoor occupations formed an important part of that person's identity before developing dementia. This was, therefore, often the motivating factor in seeking to use safer walking technology to support them to continue to engage with outdoor occupations and maintain that identity. The theme takes its title from the experiences of Annabel who describes the importance her father placed on getting away to green outdoor spaces, whether it be on a family walking holiday or to play golf.

I: Okay well that’s pretty common I would say. Okay so how important do you think it was to your dad personally that he had those opportunities to get away?

P: Oh, he loved it, he loved getting away… He’s been an active person all his life and he gets bored very quickly.
[pause]

P: This is what the problem is now because they were so active and they could get out and about and do what they wanted to spontaneously or planned whereas it’s not so easy for them to do now so it frustrates him.

(Annabel 112-119)

This theme was developed looking across the individual participant analysis of all 9 participant interviews in study 1. Within the theme, two sub-themes were also developed (see Table 13). The sub-themes recognise the shared experiences across the participant group, including the importance of maintaining self –identity through occupational engagement and how these were strengthened by connectedness to nature and natural environments.

4.4.1 Subtheme: “We do a lot of walking together, always have”: Personal identity linked to nature and the outdoors

The first sub-theme looks at the participant's description of how personal identity and the self –identity of the person they cared for was often linked to outdoor occupations. It takes its title from the experiences of Carl, who describes enjoying walking with his wife, who now has dementia.

P: We joined, were forest ramblers and we were very much involved with wild forest, wild forest ramblers, we're still members but XXX can't do the long walking now and I can't get up, well it's changed. I can't get on the walks, anyway so ***we do a lot of walking together, always have.***

I: So, how often do you do that, couple of times a month?

P: Oh every week.

(Carl 284 – 285)

The strong links between outdoor occupations and identity were particularly apparent in Diane's recollections. At the time of the interview Diane's husband had passed away just over 12 months previously, but she was keen to talk about her experiences of caring for him. Her husband spent most of his time in the outdoors and Diane described this as a lifelong interest in a wide range of outdoor occupations.

I: …okay and back in the past was that something he did every day, was he always trying to get out and be an outdoor person?

P: I believe so, I hadn't known him you see cos we only met sort of 20 years ago but ever since I met him yes, **he always wanted to go on the bikes in the canals and you know walks, nature walks, but he told me it had stemmed right from the word go.**

I: Fantastic and how…why do you think it was important to him as a person to be able to get out?

P: He just enjoyed the outdoor life, the birds and the freedom.

(Diane 75-85)

Diane's account of her husband's nature-loving personality was full of pride for the man she had married, and respect for the knowledge he held about the outdoors and nature.

I: had that been from childhood do you know?

P: Yes, he told me so and he said…well he knew nearly every bird and every tree, he used to grow herbs and things and we would go out on our bicycles and collect different things like stinging nettles and he's come back and make stinging nettle soup.

(Diane 59-63)

She spoke of his passion for a wide range of outdoor activities; all of which seemed important to him and therefore her. For example, in the extract below, there was a long pause after she named the river Wye whilst she smiled and appeared to remember him fondly before adding that it was his favourite river.

P: He just enjoyed the outdoor life, the birds and the freedom and the, you know, being able to be his own boss in his own business and, you know, be outside and tend all the animals and help all the animals and birds, he just loved it, it was him and **he loved fishing on the Wye.**

I: Yes, lovely place to fish.

P: Yeah it was his favourite river.

(Diane 88-91)

This aspect of his life was reflected also in his professional working life and identity, as he set up and ran an animal rescue centre in their local town and took animals around the local schools for the children to see.

I: so for example his relationship with the outdoors, was he an outdoorsy person?

*P: Very much so***, he opened up a wildlife centre at xxxxxxx…**

I: …oh wow…

P: …which he built himself and then he used to be called the birdman of xxxxxx [interviewer laughs] and he used to fly birds of prey which he kept in his garden.

I: That's amazing.

P: And ***he used to go around schools showing all the children these spiders and birds and snakes and that was his job. So he was very much an outdoor man****, he knew…*

I: …very much outdoors, had that been from childhood do you know?

P: Yes, he told me so and he said…well he knew nearly every bird and every tree, he used to grow herbs and things and we would go out on our bicycles and collect different things like stinging nettles and he's come back and make stinging nettle soup.

(Diane 45-63)

In these extracts Diane strongly links his identity to these outdoor and nature-based activities, presumably, his title as 'The Birdman of XXXXXXX' was one of which he and she took pride and were, therefore, an important key to his self-identity. In the final extract below she uses the word 'love' to describe his emotional attachment to these activities and states that 'it was him'. Such a final statement of purpose is worth noting and considering as further evidence of the importance of these outdoor activities to the person her husband was.

P: Being able to be his own boss in his own business and, you know, be outside and tend all the animals and help all the animals and birds, ***he just loved it, it was him*** *and he loved fishing on the Wye.*

I: Yes, lovely place to fish.

P: Yeah it was his favourite river.

(Diane 86-91)

Other participants within the study spoke of their relationship with outdoor activities fondly and for one participant Carl, it was clear that walking in rambling association groups was part of the shared identity he and his wife had nurtured throughout their married lives. Their shared enjoyment in the outdoors and walking for pleasure was evident within the interview and represented an occupation that they engaged in together for 60+ years. Carl spoke about their large family of adopted children and his wife's enthusiasm for family life; they looked to the Rambler's Association for a weekly family outdoor outing.

P: we started, the ramblers association in that period were keen on getting family rambling

I: …yeah…

P: …and we were very much involved with family rambling because we had the children.

I: Yes.

P: We had children so we were probably every, every Sunday or every other Sunday that there would be a family ramble, very much part of family life.

(Carl 380-389)

This shared interest initially based upon family life continued past this period and became an established part of their lives for many years more.

I: So, it had more than just the family meaning it had some kind of…

P: …well the family, the family rambling must have ran for something like about 10 years and other families joined but it gradually petered out…

I: …yeah…

P: …they gradually petered out and but the adults side that continued and I led lots of walk up until about 7 years ago, I did 50 walks, 50 Sunday walks in one year.

I: I guess the planning of that would appeal to your organisation.

P: And I led lots of walks so I would lead the walks. I led the walks and yeah, so I've been chairman and secretary and treasurer, walks organiser, walks co-ordinator.

(Carl 400-413)

At the time of the interview, Carl and his wife were in their early 80's and until fairly recently they had been very active in the local rambling association together.

Despite his wife's dementia, this activity continued until Carl's health deteriorated and he had a heart attack. However, as part of his cardiac rehabilitation, they were offered an opportunity to join a smaller rehab focussed health walking group in the local area; and again, they joined the group together.

*P: And, then I had to go to Wolverhampton to have a stent put in cos they didn't do it at Worcester but they do now, I've learnt that and then as a follow up I learnt that **based upon the hospital they had a group called stride and strong and when it started up, it started up from the hospital with senior nurse starting up the walking group and it became a rehab.***

I: Yeah.

P: They have a gym there which you go to and the walking is continuation of that and so I naturally joined that.

I: Of course, yeah.

*P: **And, of course XXX came along and joined that and up until 3, no 4 years ago now XXX was doing 3 miles every Saturday.***

I: Okay, so that was well after diagnosis and still enjoying outdoor activity.

Another participant who described a strong link between the outdoors and occupational identity was Emma, whose father had a lifelong interest in cycling. He had cycled for pleasure and competitively since his adolescence and remained very fit and active until very recently: Emma ascribed his good health to his cycling and time spent outdoors.

*P: …Yeah, I don't think she noticed, I don't think any of us noticed anything I mean **he's always been very fit and active and he was 84 last week he was, he's been a keen cyclist all his life…***

I: …Ok…

P: …and, and he used to live in xxxxxxxx and cycle from xxxxxxx to xxxxxx which is near…

I: …yeah yeah oh wow, that's a real cycle [laughs]…

(Emma 248-257)

However, this passion ultimately led to an accident that triggered a serious deterioration in his overall health and an unexpected move to live in a care home. During the interview, Emma referred several times to a recent event that she felt was important. She described her father being keen to remain outside during an outing.

P: And last week on his birthday we had a taxi over to the local Toby carvery and all the trees opposite are changing…

I: …oh yes, yeah because of the cold snap…

P: …and he said, 'I don't want to go in yet'…

I: …to go have a look at it…

*P: …**he wanted to just stand, he said I wanna have a look at the outside and I thought…***

I: …Yeah…

P: …Yeah, so noticed a different change…

I: …Yeah…

P: …because he can't get out….

(Emma 716 – 726)

The repetition of this story throughout the interview highlighted the importance Emma placed upon this experience and the insight she felt it gave her to her father's current needs and wishes. She reflected upon the limited access he now has to the outdoors and talked about planning to support him to have greater access outside. Her motivation for this was clear as she felt he had lost so much recently and that the opportunity to be outside again would have had a positive impact upon him.

I: Do you think that being able to see the outdoors would work as a substitute for him to be able to get outdoors or do you think the getting outdoors still has a significant importance to him now?

P: ***Getting out would definitely improve his wellbeing*** *looking at his room to one of those that is downstairs and all they are looking at is the fence, dads got the better room of the two but it's still not the same as getting out. I mean we appreciate, and he does but on a wet day or an icy day, you really can't go anywhere…*

I: …Yep…

P: …And that would still be the same at home.

Emma (1512 -1525)

4.4.2 Subtheme: "Because he can relate to it and not make mistakes": Feels at home in the outdoors and with nature

This second sub-theme focuses upon the experiences of several participants who described the relationship their loved ones had with natural environments and what this meant to them. It draws its title from the interview with Helen, who spoke about her experiences of helping her husband access the outdoors.

P: So he still likes to be taken out into the countryside. Taking him shopping is murder, he hates it.

I: Okay, so it's natural environments that are important.

P: Yes.

I: And why do you think it's important to him?

P: Because he can still relate to it and not make mistakes

(Helen 45- 50)

When Helen talked about her husband's outdoor identity she spoke, not only about a lifelong interest in outdoor occupations but also, about the reasons why the outdoors was important to him now that he had dementia. Like Diane's husband, he had a childhood influenced by the outdoors, a personal interest in outdoor hobbies and a professional career based upon outdoor activities.

> *I: What's his relationship with outdoor environments been*
>
> *P: **He was brought up on a farm in xxxx and had his own poultry as a child and he went to xxxx College where he ended up with an MSc in poultry. We've lived at xxxxxx for six years, but then we lived near here with a third of an acre, where he's always almost produced own veg and fruit.***
>
> *I: Sure, so outdoor environments are important?*
>
> *R: Oh yes.*
>
> ***(Helen 21-28)***

Helen's husband has experienced a loss of many cognitive skills and has had to give up several occupations he previously enjoyed since the symptoms of his dementia became more severe. Yet, despite this, spending time in the outdoors still formed most of the structured activity in his typical day.

> *I: And how about now, how often does he engage in any of those activities now?*
>
> *P: Well, he still goes out and feeds the birds nearly every day, unless it's pouring with rain, and he walks the dog every afternoon with a trekker and I think that dog would bring him back anyway. **But the main thing that he still enjoys now is seeing the trees, he doesn't always remember what season it is, but he always comments on the state of the trees and flowers. So he still likes to be taken out into the countryside.** Taking him shopping is murder, he hates it.*
>
> ***(Helen 38-46)***

Much of Helen's interview focussed on the enjoyment her husband gained from these activities and other opportunities to spend time in the outdoors. For example, in the extract below she describes what it is he enjoys about going out together to visit local country parks.

Helen has had to adapt much of their routines to accommodate these activities and the process of preparing for the dog walk could be very time-consuming. When asked why she thinks it is important he continues these activities, her answer was very focussed upon the freedom and space it gave him.

> *P: It works in that it lets him – he doesn’t like being mollycoddled. He doesn’t like me pushing him all the time,* ***he wants to have his freedom, and this gives him his freedom*** *to go off on his own. I don’t always know where he’s been. There’s a lot of people in the area, other dog walkers know the dog and they always chat to him, so he comes back and says, “Somebody spoke to me, I don’t know who it was.”*
>
> ***(Helen 269-273)***

In a world where her husband has lost control of much of the day to day decision making about their lives, this ‘freedom' to roam and ‘freedom' to exist outside of their home as his person still seems to resonate strongly with Helen. Very early in the interview, she was keen to explain that ‘the outdoors' was a place of safety for her husband, where his understanding of nature and the natural environment was reassurance and his increasing difficulties, particularly with cognitive tasks were less obvious.

> *I: And why do you think it’s important to him?*
>
> *P:* ***Because he can still relate to it and not make mistakes and not feel, I think, inadequate. I think he feels more comfortable, more relaxed. I think in crowded situations, especially if he can’t remember or it’s changed a lot since the last time we were there, I think there’s a panic that sets in - or at least anxiety.***
>
> *I: Yes, I can see how that could be.*
>
> ***(Helen 49-55)***

Helen’s use of the word ‘inadequate’ in the above extract hints at the idea that when not in this ‘safe’ outdoor environment her husband does feel inadequate and, in some way, not skilled enough to cope - an emotion that she equates to his experiences of panic and anxiety when faced with challenging situations.

4.4.3 Theme Summary

Theme 1 highlights the importance outdoor occupations in maintaining both the self-identity of the people cared for by the participants, but also frequently the shared and familial identities they hold together. It is also clear that for some people with dementia the outdoors offers a place of relative safety and familiarity, where the challenges of their dementia are less prominent.

4.5 Theme 2: "We'll know where he is": Safer walking technology provides reassurance and confidence

The second theme, identified within this study, highlights a variety of benefits and positive experiences reported by participants when supporting their relatives to use safer walking technology. The theme takes its title from Barbara’s experiences of caring for her husband who often went out for long walks unaccompanied.

> *I: Okay, so having that back-up in place did that give you and your husband more confidence trusting to go out?*
>
> *P: I don’t think, honestly, he realised what it was for, the purpose.*
>
> *I: Okay, so it didn’t necessarily impact on him?*
>
> *P: No, no, no.* ***It did in me because I thought well if he gets lost at least we’ll know where he is.*** *He couldn’t have done it on the computer, actually this problem really didn’t really arise if I must tell you, XXX took it off the minute he walked in, he took it off.*
>
> ***(Barbara 286-287)***

There were many commonalities within the experiences of all participants, but particularly in that the technology offered both reassurance and ‘peace of mind’ for family carers and increased the confidence of the people they cared for. The theme therefore also includes these reported experiences as two sub-themes (See Table 13).

4.5.1 Subtheme 3: “A degree of confidence”: how it helps them as a family

The first of these subthemes identifies the reassurance family carers report safer walking technology offers them. Many participants highlighted this as being the main reason they had sought out safer walking technology and the title of this sub-theme is taken from Ivor's interview to summarise this common experience.

P: I can't say it gives me anything except ***a degree of confidence****.*

I: yes….

P: ***It's enabled me to do more****, to do the things that we would have done with more confidence that I'm not going to lose her."*

(Ivor 373-374)

This was also highlighted by Ivor who reported that his use of the 'tracker expert' tracking device gave him both reassurance and confidence, stating that it enabled him to do more. This confidence also enabled him to allow her to walk more freely when they were out in parks, gardens and other outdoor spaces.

I: Okay sure, so it's got that two-way radio type bit with an SOS button but that's not really the function you use it for?

P: No I can't … Xxxxx is too far down the line now to use that function ***but I can track her on my mobile phone. There's an app which I'm given which I can then see where she is. There's a map and I can see where she's wandering, and I can follow her quite easily.***

(Ivor 263-268)

In addition to supporting Ivor find his wife if she ever did become lost, it also gave him daily reassurance. The safer walking technology gave Ivor confidence to go to busy places, such as an exhibition centre, or remote outdoor locations like their local country park. Having the device in place also enabled Ivor to offer his wife more freedom when they were out. In the extract below he also talks about feeling more confident to leave her with others, again giving her more freedom and independence.

P: Sometimes just things like she goes and gets her hair done or her nails, give me a bit of break, and I go and do a bit of hunting, shooting, fishing; they've got rifles and archery and stuff like that, so that gives me a bit of a break and at least I've got the ability, ***if somebody does lose her, I don't give them the responsibility, I just say "this is Xxxxx, she's got this problem, I'm just going to do some shooting, you cut her hair but I don't expect you to watch over her; if you sit her down there and she starts wandering off, don't worry about it because I've got a device to find her", but they can't get outside; it's very difficult to get outside.***

(Ivor 349-359)

Having the ability to find his wife, even if she were to walk away, gave him the confidence to trust other people more and feel that he is not 'burdening' them with the responsibility of her welfare. This was similar to the experiences reported by Barbara, who used the safer walking technology to monitor her husband, who frequently left their home to go for long walks in the local green spaces. Asked if it provided her with any feelings of security Barbara was confident that it did.

I: Okay, so having that back-up in place did that give you and your husband more confidence trusting to go out?

P: I don't think, honestly, he realised what it was for, the purpose.

I: Okay, so it didn't necessarily impact on him?

P: No, no, no. ***It did in me because I thought well if he gets lost at least we'll know where he is.*** *He couldn't have done it on the computer, actually this problem really didn't really arise if I must tell you, XXX took it off the minute he walked in, he took it off.*

(Barbara 286-287)

Although access to green spaces was a positive experience when engaged in together, his unplanned and unaccompanied walks were a real concern for Barbara, especially after a police helicopter was called to search for him after one such event.

*P: …and although he was in a secure room in the day care centre where the door, you had to put the numbers in the door***, I knew he couldn't get out unless someone left the door open accidentally or whatever, so, so he did have the buddy on then so I knew if he got out where he was at the day centre. If he got out of there at least I'd know where he'd started from.*** *[Laughs]*

I: Absolutely, yeah.

P: And, we could find him… so he never had to do that.

(Barbara 405-409)

An implication of the extract below is that she trusted the safer walking technology to be more reliable than the respite carers provided to support her. It was clear that the safer walking technology offered Barbara an important safety net, right up until her husband stopped going out altogether and moved into a care home.

I: Absolutely, yeah.

P: And, we could find him… so he never had to do that.

I: Okay, but it was a really good back-up reassurance.

P: But at that point the buddy was, I always made sure he got the buddy on and likewise ***I had respite for a couple of hours a week when carers came in to play puzzles or talk to him or just sit and watch the telly with him and I'd made sure he'd got the buddy on then….***

I: …okay, yeah…

P: …and I told the carers he's…make sure he keeps his track on because if he goes off these girls are not going to be able to find him are they?

I: No, no, so it was an extra belt braces…

P: …yes so, so it was in that respect it was and had he been more agreeable to keeping it on [laughs] it would have been even better.

(Barbara 410- 425)

Annabel had similar experiences using the safer walking technology for a period with her father, who wore his tracker when out for walks around the local canals as well as when shopping in town.

I: So what did it bring for you?

P: Piece of mind and I knew I could find him if I needed to.

I: Okay so did it enable your dad to go out more do you feel because you knew where he could get it?

P: Well he was going out all the time anyway, with or without it but the fact he was wearing that made me feel better to him going out even more.

(Annabel 392 – 399)

She had used the system to locate him only a handful of times, to check on his welfare and felt it worked very effectively for them. Annabel's father always carried the safer walking technology because she asked him to, but she never spoke directly to him about the fact she could track and locate him.

I: Okay but he never talked about how it made him feel or any of the…

P: …no.

I: Okay that's fine.

P: He just knew he had to wear it and that's it, he didn't know what it was for.

(Annabel 442-443)

Greg took a more collaborative approach, considering the ethics of tracking his father in law and possible issues of privacy the safer walking technology was purchased after discussion with his father in law and agreement with other family members.

I: So, when it occurred to you that you needed to do something, what made you think of a technological answer?

P: To be honest I'm not sure. I think it was like it was an agreement with everybody...and the fact that he'd lost his phone.

(Greg 166-169)

4.5.2 Subtheme 4: "I know I know you, but I've got dementia and I can't remember your name": technology gives the person with dementia confidence

The second of the two sub-themes explore how family carers felt using safer walking technology gave their relatives confidence when outdoors. It takes its title from Helen's account of her husband's ability to recognise his limitations and how she therefore feels reassured that he had a supportive technology with him to overcome any potential difficulties. She reported how he would often greet their friends and neighbours with confidence.

*P: When he meets people, he will say, "**I know I know you, but I've got dementia and I can't remember your name.**" And he's now confident enough to say that.*

(Helen 460-462)

Helen and her husband jointly purchased a tracker phone and Helen spoke repeatedly in the interview about the impact her husband's awareness of his dementia had on them as a family. She was proud of his confidence to discuss his dementia openly as seen in the extract above.

P: Not sure. Sometimes he just think it's just an awkward lump in his pocket and he could do without it.

I: But he does willingly carry it?

*P: He does, yes, **he does willingly carry it**, because he believes he could use it should he need to. I'm not convinced.*

(Helen 314 – 318)

Helen's husband, therefore, consented to use the tracker phone and was keen to ensure he carried it whenever out on his own. The fact that this device also permitted him to call her if needed, enabled him to feel it was useful to him as well as a reassurance to his wife. When discussing her experiences, Helen described how her husband often wanted to try anything that would help him limit the impact of his dementia in their lives. As part of a post-diagnostic support group they attended together, Helen's husband wrote a note 'to his dementia' that revealed his clear desire to minimise and control his symptoms wherever possible.

> *P: But I was asked to ask him, and he takes his time over things and I think things were churning around in his head and he sometimes takes two or three days, but the answer eventually comes. And he wrote down on a piece of paper for me, I've got it upstairs, actually**, "To dementia, I will endeavour to remain positive, to minimise your effect on my behaviour."** It took him three or four days, because he's said some things and I wrote them down and he says, "No, that's not right." Because that's what he used to do when he wrote research papers, you see. He'd write them and rewrite them and rewrite them until he got it right.*
>
> ***(Helen 103-111)***

This steadfast attitude baffled Helen as her response to the same exercise had been more emotional. Yet because of this pragmatic attitude, Helen felt that knowing he had safer walking technology with him gave her husband a degree of confidence, even after she thought his actual ability to use it effectively had probably deteriorated.

> *I: Okay, and the function as a phone would be important to you, would it, that two-way communication?*
>
> *P: It would be to me. **I think confidence wise, probably to him, because there are a lot of things now that he still thinks he can do, but in practice can't**. But the fact that he thinks that he can ring me possibly helps him, but whether he could actually do it or not, I'm not sure.*
>
> ***(Helen 426-435)***

Helen was keen to discuss the ethical issues surrounding tracking but felt that as her husband didn't mind being tracked there were no concerns for them.

P: The main thing about it is, from my phone I can text this phone, provided I've made sure it's charged and switched on when I go in his pocket. I can text this phone and it will text me back his GPS location.

I: That's brilliant.

P: Which I can then put into my iPad, because I haven't got an iPhone. I haven't got a smartphone, I've just got a phone, but it does send me back the GPS location and I can put that into my iPad and I can see where in this area he is. ***And he doesn't seem to mind. There are people that say that you're taking away their personal freedom or something by tracking them.***

(Helen 229-235)

Far from taking away personal freedoms or privacy, Helen felt that the safer walking technology enhanced her husband's freedom to walk their dog unaccompanied each afternoon. It is clear from the issues explored within this theme that the safer walking technology offered reassurances and improved the confidence of both family carers and, in some cases, the user too. This confidence enabled greater access to outdoor or busy environments that otherwise may have posed a significant potential risk.

4.5.3 Theme 2 Summary

This theme explored the reassurance and confidence safer walking technology provided to the participants within this study. It was clear that both family carers and the people with dementia that they found the safer walking technology helpful. The 'peace of mind' and support provided by the technology promotes greater freedoms and independence for people with dementia.

4.6 Theme 3: "It's got to be given at the right time": When to introduce the safer walking technology

This third theme developed from several of the participants 'dementia bought

desire to talk about when best to introduce safer walking technology. For some of the participants, this issue appears to have been key to the success or failure of the technology. The title of the theme is drawn from Emma's experiences, where she felt her father would have benefited from a much earlier introduction to the safer walking technology.

P: It's got to be given at the right time*…And that is the crux of it, with dad I think it was given too late."*

(Emma 789-792)

Within this theme, two sub-themes were identified from the participant interviews that draw together participant experiences about identifying the right time to introduce safer walking technology to an individual, and the importance of developing habits and routines (Table 13).

4.6.1 Subtheme 5: "If you can get used to this, you know for the future": The importance of developing habits

The first sub-theme within theme 3 focuses upon the importance of developing habits and routine. For people with dementia, the development of habitual routine is often considered key to maintaining skills or abilities. The sub-theme draws its title from Carl's interview where he discusses being given access to safer walking technology to support his wife, so they could get used to using it ready for a time when it may be needed.

I: …so, you were already confident that she was going out and 99% of the time was fine?

P: Yes…

I: …but it was sort of safety precautionary extra.

P: Yes, the sort of suggestion was if you can get used to this, you know for the future…

I: …yes…

P: …because it was clear then obviously, it's not going to get any better

(Carl 790-798)

The timing was discussed by several of the participants in some detail as they reflected upon when was the right time to use safer walking technology for the person with dementia they cared for. Helen felt that her husband's familiarity with similar technology in his mobile phone helped him adopt the location tracker, but that the timing of its introduction was key. She attributed the success they had experienced, with the Doro Tracker phone, was down to the similarity of its appearance and size to her husband's old Nokia mobile phone. She viewed this as a positive discovery, not only for them but, as shown in the extract below she foresaw a time when the use of Smartphones for people with dementia would be more easily adapted to track them. However, reflecting on this Helen also explained how her husband's grasp and understanding of technology he had used previously with success, was now deteriorating.

This seemed to suggest that familiarity with technology is helpful, but that timing can be vital and that there may be a useful window of time for technology of this nature. For participants, Emma and Carl's timing was also a key issue in the relative success of the safer walking technology adopted, although they had contrasting experiences. For Emma, the need for a safer walking or tracking technology did not initially arise, as her father had a very familiar route home. This meant that even when his vascular dementia appeared to impact upon other aspects of his life, he always found his way home.

> *P:* ***For people who’ve had smartphones before they’ve developed the disease, they probably really can track those anyway, can’t they, without. So, I think the next generation of patients with dementia won’t need this sort of thing because they’ll use the phones they’ve always had.***
>
> *I: I see…*
>
> *P:* ***It's nearly 20 years now and he was just starting to have to try and use emails at work and since he's retired because I do it, he's left it to me. So, he doesn't use computers. He doesn't use mobile phones very much, although he's got one. And he's now struggling with the remotes for the television and for which button to press to get the record player and things****.*
>
> ***(Helen 187-196)***

> *P: …I thought, ‘****Oh where’s he going I mean we’ve never stopped him going out for a walk as I say he’s a home-in pigeon, he’s always found his way back home….***
>
> *I: …But heading into town as the shops are shutting doesn’t fit does it?*
>
> *P: No. I thought where’s he off to? I thought perhaps he’s just going for a walk*
>
> ***(Emma 906-908)***

However, the disadvantage of this was that they did not access a safer walking technology until much later than other people Emma met through the local memory café. Within her interview, Emma reflected upon the need to develop routine and habits, which her father never did with wearing or charging his safer walking technology. Yet he had managed to adopt several other new things the previous year.

P: …so when she was in hospital and she was in for virtually a month she had pneumonia herself and that we, the girls could, well the older one XXX the older one, she constructed a chart for him…

I: …Yeah…

P: …and we got him to tick it that he had it…

I: …Yeah that's very OT [laughs]…

P: …Yeah (Laughs)…

I: I'd say (laughs) having talked about…

P: …And with dad, with the repetition he then get, gets into doing it. It becomes second nature

I: …Yeah…

P: …To him. *Then after mum died we then like appointments. We did get a diary for him.*

(Emma 580-591)

Although they initially tried to build the use of the safer walking technology into his routine for him, she felt this was increasingly difficult as his care was being provided by several different providers who did not all share the same understanding of the importance of the building of routines.

P: "Yeah, yeah, so we didn't bother and because ***the carer hadn't reinforced,*** *I mean dad was going to a day centre two days a week and he was with the carer three so it was like Monday, Wednesday, Fridays he was with the carer and then Tuesdays and no…Tuesday and Wednesdays he was at the day centre Mondays and Fridays he was with the carer and then at the time I'd drop Thursday as well."*

(Emma 1385-1397)

At the end of her interview, Emma was asked if there was any issue or topic she had discussed that was particularly important to highlight and she was keen to reinforce that timing of introduction was vital to the use of safer walking technology.

4.6.2 Subtheme 6: "It's not as easy to learn now": Introducing technology at the right time for everyone

Even when technology is provided 'early' to enforce the development of habits and routines, it is not always the 'right time' for everyone involved in its use. Sub-theme 6 addresses the wider experiences of participants who acknowledged that the timing of introducing safer walking technology needed to consider everyone involved in its use. The title takes its wording from Carl's interview where he reflects upon his ability to manage the safer walking technology for his wife.

I: Is it something that you concerned about?

P: Positive, it's positive; ***the dilemma is the amount of time and obviously age. It's not as easy to learn now*** *and I certainly can't keep up with the children, the grandchildren, well the children or grandchildren*

(Carl 634-638)

Carl reported that he and his wife were initially pleased to be provided with the safer walking technology by an early intervention service in preparation for a time when she might become lost in the future.

P: Yes, yes, that would have been, that would have been because we were first involved with, I said we went to Kidderminster and the, the early dementia, the early dementia intervention service we got involved with and because of when I suppose ***we got involved then we were involved with early service probably for over 12 months and so I think it was, it was the nurse whose name I can't remember who probably introduced us because that's why an OT was involved…***

I: …yeah…

P: …so an OT was involved, and I think would that have been when they were trying them out?

(Carl 752-759)

The importance of developing routines and habits was a factor in the early provision of the safer walking technology; they were supported by an occupational therapist to build in the habit of charging and wearing the technology and Carl was taught how to use his computer to look his wife's location up at home. In contrast with Emma's experience, this proactive approach would initially appear to be more effective. Although they did initially build it into their daily routines, it was not needed to maintain Carl's wife's safety and soon became forgotten, sitting on the sideboard charging ‘ready' for when it would be needed. After a while, Carl became concerned that they were taking up valuable resources that could be used by someone else.

P: it may have been cos that was in the early stages…

I: …yes, it would have been…

P: …and because it didn’t work very well and ***we felt or I felt that you know it’s an expensive piece of kit, we’re not making use of this…***

I: …no…

P: …and it needs to go on to somebody else.

I: So, you had your period where you trialled it for its use and it didn’t suit you at the time.

P: No, it didn’t work for us at that time.

I: Yeah, so you gave it back.

(Carl 812 – 822)

Although generous in spirit, this gesture eventually caused difficulties as when they did later want to re-adopt the safer walking technology, they could not arrange to have it. This was due to the prescribing criteria for the technology being adjusted and eventually, the safer walking technology provided by social services was completely stopped. This meant that when Carl’s wife did start getting lost, it was no longer possible to get a new referral for the equipment through social services.

Earlier within this theme, we explored why Carl had returned the safer walking technology before reaching a point where they would have regularly used it. One key factor in Carl's reluctance to keep it was the lack of practice he had in using the safer walking system on his computer. Although the training was provided when he initially adopted the system, over time, he struggled to remember how to do this accurately and felt the system no longer worked well for them.

P: Yeah, as we've just been talking the buddy didn't work at that time, and A, because XXX couldn't cope with it, and B, because of the difficulty in trying to use the system…

I: …yeah…

P: …it didn't seem to work so the technology was not at the stage whereby it was easy for me to interact with and it has presumably moved on a pace from just a few years ago.

(Carl 1205-1211)

Although his wife's ability to learn had been considered in giving the safer walking technology early, the learning capacity of Carl as a carer had not. Carl was in his late 70s at the time of introduction and although he was keen to try the technology, his skills in this area were limited. Carl appears to feel that this, in part, was due to his age. Despite these challenges, when asked how he felt about the use of technology to support people with dementia, he stated his attitude was a positive one.

4.6.3 Theme 3 Summary

It is clear from examining these experiences that the participants had varying degrees of success with using their safer walking technology, and the participants interviewed considered the timing of introduction an important factor in the likely success of adopting the technology into their daily routines. It was also evident that both the carer and the person they cared for needed to be able to use the technology. Irrespective of when the technology was introduced the experience of these participants indicated that there was likely to come a time when the person with dementia's ability to use the technology effectively will diminish, creating a 'useful window' of time for any such technology. This raises questions about the appropriate design for this type of technology and if safer walking technology specifically marketed and provided to people with dementia should be better suited to the changing abilities of those using them.

4.7 Theme 4: "Have you thought about a tracking device?": Support to adopt and choose safer walking technology

Not all participants had their safer walking technology provided through social or healthcare services. This fourth theme looks at the range of support and guidance participants experienced in choosing and adopting their safer walking technology. Although some participants were provided with their technology through social services, many bought them privately after researching them online or seeing demonstrations at an Alzheimer's Society Café. The theme draws its title from Ivor's experience of first hearing about safer walking technology from his local policemen.

> *P: They did ring me back and then the local policeman said, "**have you thought about a tracking device?"** I can't remember how it went, but I think it was the policeman that mentioned it to me but certainly, we exchanged bits of information"*
>
> **(Ivor 231-235)**

Each of the participants appears to have taken a different route to select and adopt a form of safer walking technology; this resulted in a variety of different experiences of receiving (or not receiving) support to choose, acquire or use the technology. A few of these experiences are highlighted here to show the variety of difficulties faced by participants within the study, with the two sub-themes addressing the differences between provision through social services and private purchase (Table 13).

4.7.1 Subtheme 7: "Do you have to lie to get this stuff?": poor provision of technology by services

In the previous theme, Carl talked about receiving help from an occupational therapist to request and learn to use his safer walking technology. He was the only participant who reported having this level of initial support also the only participant who cared for someone involved with the early intervention of dementia services. Subtheme 7 highlights the experiences of participants whose safer walking technology was accessed via local social services. The title of this theme is taken from Emma's interview in which she discussed the challenges of getting safer walking technology for her father. In the following extract, she asked the interviewer incredulously if you needed to lie to services to get access to the right technology. This question was expressed with considerable anger and frustration.

I: Did somebody recommend it?

P: So, I…yes they did and she said I'm not no qualms of XXX going out because I know where he is…

I: …Yeah…

P: …and ***I asked at the doctors and then obviously we got referral through to social services, social services said, 'has he got lost', well, do you have to lie to get this stuff?*** *So of course, you know, you're brought up right and I said well, no he's a home in pigeon….*

(Emma 851 -859)

Emma's father had been diagnosed for several years when she first heard about the safer walking technology from someone she met at an Alzheimer's Café. She asked about it when receiving her own carer's assessment and was very proactive about getting services to support him when needed. Emma had requested her father be assessed, for the provision of this technology, at the time that she felt he would most benefit from its use. However, he did not meet strict eligibility criteria, which stated you need to already have a serious incident of getting lost that required the support of the police to help locate the person. Emma was frustrated by the apparent poor logic of this requirement.

P: …Like we said, it all comes down to money and if you don't know these things are out there, I mean never heard of the buddy system or any other tracking device shall we say…

I: …Yeah…

*P: …**But the council wouldn't give dad a buddy until he got lost….***

I: …Yeah…

P: …well, by the time they got lost, it's too late…

I: …His ability to learn to use it…

P: …Yeah, he didn't know what it was for…

(Emma 794-803)

In theme 3, we saw how important Emma felt it was to get technology to her father early so that he could build it into his routines. Even once the safer walking technology was provided to Emma's father, she found difficulties in encouraging the professional carers to use it. A lack of training meant that the carers involved in his care were not aware of the importance of using it every day and failed to maintain the routines Emma had set up for him.

*P: The original carer had to give up due to ill health, so we then had another one, he was very good, **but he wouldn't enforce dad putting the locating technology on** …well, he's out with me but that's not the point.*

(Emma 827-832)

Again, her frustration was expressed when she stated, 'that's not the point', it is clear that Emma found her dealings with services extremely difficult and the lack of 'joined-up' professional guidance on the provision and use of the safer walking technology left her father struggling to get or use the safer walking technology at the right time for him. Unfortunately, she was not the only participant who had a difficult experience when dealing with social services in adoption of safer walking technology. Annabel cared for her father and, although she eventually moved into his home to support him, in the early days she had serious communication difficulties with the professionals involved with her father's care.

P: I come up the one day and there was a lady sat and I said "and who are you" she said "I'm one of dad's carers" I said "since when?" and they'd be coming…

I: …so who was…

P: …doctors…

I: …as his main carer at the time?

P: No-one.

I: Oh really, that's unusual

P: Well I was not impressed because I came up the one day to visit him and he said "oh my god I've had loads of people in this house today", I'm like "who would you have in the house" he's like "I don't know but he's asking me lots of questions" and it's only after I started pried and prodding I found out it was…well the 'side by side team' because their envelope…their file sorry was there and I rang them and said what's this all about, so obviously…

I: …it's unusual for them to do…to put care in without consulting family, if there is family, I mean for some people there isn't.

P: Well according to a solicitor I spoke to they don't have to.

(Annabel 301 – 322)

As the main carer for her father she found being excluded from the care planning very upsetting and the strength of feeling about this issue when interviewed several years later can still be seen in the below extract.

P: And I sound very negative because I am angry that they actually put care into this house without my knowledge.

I: Oh really?

P: I come up the one day and there was a lady sat and I said "and who are you" she said "I'm one of dad's carers" I said "since when?" and they'd be coming…

I: …so who was…

P: …doctors…

I: …as his main carer at the time?

P: No-one.

(Annabel 297-304)

Unfortunately, the same difficulties were experienced when safer walking technology was provided to her father. Annabel was not aware of its existence or that it had been issued to him.

I: Okay and what prompted you to get that in the first place?

P: I didn't ask for it, they gave it to him.

I: Okay, so…

P: …I came up one day and said "what on earths that round your neck" [interviewer laughs] didn't even know.

I: So this is when you weren't living here?

P: Yeah.

(Annabel 280 – 288)

Although this comment was said humorously during the interview, the shock and confusion at finding her father wearing a tracking device were still evident. Annabel was not provided with advice or training on how to track her father using the safer walking technology and found this information out independently.

4.7.2 Subtheme 8: “We were given some brochures and some literature”: A lack of professional support or guidance

For other participants, safer walking technology was purchased privately and the support and guidance for this process appeared to be limited. This sub-theme takes its title from the interview with Francis, who bought his safer walking technology privately without any support from services. He was interviewed for this study in the weeks following his wife's diagnosis of dementia. The diagnosis was sought after she had become lost in what should have been a very familiar place near to where they lived. Francis was keen to ensure they had everything they needed to help her stay as active as possible and ordered a small clip-on tracking device from a disability catalogue.

> *P: It was just --- on the initial diagnosis of dementia, I thought it would be useful* ***--- we obviously were given some brochures and some literature,*** *and I thought it would be useful to try something like that.*
>
> ***(Francis 357-360)***

The leaflets and brochures were handed to him by the GP receptionist when he asked if there was anything he could read. Following the diagnosis, they have not had any further contact or support from services and, as a family, Francis reported they had been struggling to adapt to his wife’s changing needs.

> *I: Yes, I can imagine so. So, in terms of the adoption of technology, gadgets, computers, that kind of thing, would you say that your wife has always engaged with those or not?*
>
> *P: To a certain extent.* ***Her confidence with, for instance, doing things on a computer or accessing things online, so for her bank account and other things has deteriorated markedly.*** *But then to be quite honest, to a certain extent so has mine as well.*
>
> ***(Francis 249-257)***

However, Francis was keen to minimise the impact of these changes. It was unclear if he knew about possible avenues of support or guidance because throughout the interview Francis seemed reluctant to imply that they were not managing.

Other participants in the study reported similar experiences, with Ivor and Greg both seeking out their information online.

> *P: Well because* ***I read it on the reviews and I went to the web page and actually went through it, I actually read through the whole lot before I actually purchased it.*** *I looked at the others that were a bit cheaper, but they didn't do half as what this one does.*
>
> ***(Greg 178-184)***

Notably, none of the participants were provided with guidance and advice on private purchase of such technology from any of the professionals involved in their care.

4.7.3 Theme 4 Summary

It is clear from the experiences of participants discussed within this theme that the advice and guidance available to people wanting to access or use safer walking technology was variable. In particular, there were several barriers to accessing technology through social services. However, for those who bought their technology privately there appeared to be little or no professional support available. Professionals involved failed to signpost participants to possible guidance and very little choice was given as to which technology to adopt.

4.8 Theme 5: "That was the ideal one": The right functions and safer walking technology for the right person

The final theme identified in the participant interviews acknowledged the importance of getting the right technology for the right person. The title of this theme is taken from Greg's interview where he reflected on his experiences of trying to find the right type of safer walking technology for his father-in-law to use.

> *P: And I was looking for something that I could communicate with dad just in case and* ***that was the ideal one,*** *so beforehand was studying it and looking at which one was the best out of all of them, even though it wasn't cheap, I couldn't go for a cheaper one because it didn't do half of what that one did.*
>
> **(Greg 185-190)**

With such a wide variety of safer walking technology available to consumers, and the individual nature of dementia as a progressive illness, many of the participants wanted to explore their experiences of getting the wrong match in the technology they used. This theme is therefore explored within two subthemes, the first identifies the need to get the right technology for the individual and the second explores the potential harm that having the wrong technology brings (Table 13).

4.8.1 Subtheme 9: “We’ve written it off”: when the technology doesn’t work as expected

This first sub-theme recognises that for some participants the safer walking technology they purchased or were provided with did not meet the needs of the person they cared for. After Francis’ wife’s recent diagnosis of dementia, that they bought a small tracking device from an equipment catalogue. However, he quickly found that the tracker he had bought did not provide the kind of functions they had hoped for. Sub-theme 9 takes its title from Francis's experiences.

> *I: Okay, I see. So, do you think that when you first got it, it improved her ability to go out in any way?*
>
> *P: **I think it improved her confidence initially, but the last time we tried to use it, it wouldn't work, so we've written it off.***
>
> ***(Francis 416-417)***

Though purchased to help his wife feel confident and enable him to find her if she got lost again, the tracker initially seemed to help a little, but after a short time, they became disillusioned. The tracker they bought was the simplest and cheapest device seen within this study and although advertised as being helpful to support ‘people with dementia who wander' it does not appear to have the practical functions necessary to fulfil this promise.

> *I: Were also hoping it would give that ability to find your wife, or at least know that she could be found when out and about.*
>
> *R: **The thing only has a practical range of a few metres, so it's not going to find her if she's got on the wrong bus,** for example*
>
> ***(Francis 408-411)***

All the family carers interviewed in the study felt it their responsibility as the main family carer to decide upon, or request access to, the right safer walking technology. As part of the interview, they were asked about their own experience and attitude towards technology and how this influenced their decision to adopt safer walking technology. One participant, Ivor, was very keen to discuss the wide range of new technology he incorporated into his life, including his smartphone and smart home set up and other digital devices. He took pride in his ability to master new technology.

> *I: Are you someone who's able to use technology and gadgets and things?*
>
> *R: No**, I am teaching myself as fast as I can. I'm quite … when I learn to use things I'm quite au fait with them,** and I haven't avoided it, I've just not made probably the most of technology.*
>
> ***(Ivor 162 – 165)***

Ivor cares for his wife without support from other family or outside services. After an incident where she went missing from their home, he was advised by the police to consider using a tracking device. He was referred to the social services safer walking technology scheme but did not feel the technology was right for them.

> P: I was recommended to start looking for it when Xxxxx went AWOL for a couple of hours, I reported her to the police and then the police rang me back**, I can't remember the connection, but they did ring me back and then the local policeman said "have you thought about a tracking device?" I can't remember how it went, but I think it was the policeman that mentioned it to me but certainly we exchanged bits of information and then I … he showed me one bit of kit which I wasn't that impressed with,** and then I passed the one back to him, because he wanted something for his young grandson.
>
> ***(Ivor 231-238)***

As there was no further support available to him to look at other types of technology, he could purchase himself, he decided to undertake his internet search for suitable technology. The tracking device he chose is currently the most expensive tracker used by participants in this study and has the widest range of functions.

But **eventually I sourced two or three of them and this one appeared to be the one that would do the job for me, and I think to be fair, used correctly, it will be okay**; it's just that it requires you to reset it to the place you're in every time you move. So, if we go away, I've got to set it again or I've just got to let it ring once and then just keep an eye on it, you know. So, it doesn't have to ring me, but if I lose Xxxxx I can look at it and see where she is.

(Ivor 238-245)

However, when reflecting upon his experiences of setting up and using the 'Tracker Expert' device, Ivor acknowledged that he had found several aspects of the set up difficult and has therefore not used many of the functions that he had hoped to. For example, the geofencing option.

I: Okay. So, what were you hoping to get from this when you bought it, what were you hoping it would give you?

*P: **I was hoping it would be a little less complicated** and in a way because I have to … every time I use it, I either have to allow it to ring me once, right, and it's a cost element I suppose,*

(Ivor 290 - 194)

It is possible that because Ivor was keen on technology in his own life and felt confident about adopting new technology he wanted to get 'the best' safer walking technology available. However, this had not necessarily resulted in the best technology for them, because of its complexity. Ivor was particularly keen on the 2-way radio function of the tracker as he felt that he would be able to use it to give his wife clear instructions to stay where she was and wait for him if she were to become lost. However, in the extract below it can be seen that they have never been able to use this function because the controls were too complicated for his wife to understand. This is something that may have been picked up in a detailed assessment of her needs.

I: So, we were mentioning earlier that, again for the recording, this has seven functions doesn't it?

P: Yes, there's an SOS button, so if somebody … if a person gets lost they can press the button and it immediately rings my telephone and it sounds the phone, and I can speak to the person on the end. ***I've told Xxxxx about it, but she can't remember to press it, and we've never had to use it in anger yet. I've tried it with her, and I've said, "that's yours, press it and let's have a chat, and I'm going to go in the other room", and she follows me.***

(Ivor 301– 309)

Having the wrong technology left Ivor feeling disappointed, not with the tracker, but with himself. In the extract below you can see the negative impact this experience has had on his confidence and abilities.

P: Once I've done it once or twice it shouldn't be too complicated, but it's just doing that

I: It's new isn't it?

P: Yes, it's just a new thing. ***I'm very disappointed in my lack of ability to master it. So, I rate myself reasonably clever but, you know, technology is sort of … anyway.***

(Ivor 316-320)

4.8.2 Subtheme 10: "It might as well have been a banana in his hand": more harm than good

Ivor was not the only participant who had a negative experience of using safer walking technology. Sub-theme 10 identifies examples of where participants felt that the introduction of safer walking technology was harmful to them or the person they cared for. For example, Diane was also hoping that using technology would support her husband to have more independence and go out more. She did not feel herself to be a particularly confident technology user but was persuaded to try a technological solution by a speaker at the local Alzheimer's Café that she and her husband attended.

I: So, what made you…just going back so the binatone that you're using is a two-way radio and what made you think to use that in particular?

P: ***Well it was a gentleman that came to the dementia café and the carers meeting who got all these items from the technology department*** *and he said I think this would be helpful, so he came to the house and he brought all this stuff and said, you know, would you like to try it so he showed me how to do it, there and then, and I thought that will be good*

(Diane 305-313)

From this presentation, she signed up to trial several assistive technologies from social services, including a falls detector, door alarm and the Binatone mobile radio. However, the radio was very complicated to operate and neither Diane nor her husband were able to master it. Although advised that the radio could be used to support people with dementia, it was not specifically designed for this purpose.

I: So, what was his expectation of it, did he, at that time you had it did he understand it was for and what…

P: …yes he did understand….

I: …and was he hoping…

*P: …and he tried and tried and in the end he just cried. He said I can't go out now. He just cried cos it was too complicated [laughs*___]. It was, it was too many buttons, you still got your push to talk button, up and down buttons to change the channels, speakers, you've got all your core buttons, you're transmit buttons and microphone, it was all just too much for him___ *and then he couldn't even find which pocket it was in, in the end.*

(Diane 360-371)

In the extract below Diane expresses her frustration and anger at the complicated nature of this technology. The final comment about it 'might as well have been a banana', could be a humorous aside, but was said with real bitterness.

I: So from your general experience do you think that technology and gadgets is a helpful thing for people with dementia?

P: It depends what it is ***. This in particular one the binatone mobile radio was of no help whatsoever and had I had purchased it I would have very angry because it was so complicated and a gentleman like XXX with dementia he had no idea when he was out how to work this thing, it might as well have been a banana in his hand,*** *because he hasn't got a clue, if I said "you've got to press just this button here when you're out" no way, he'd be holding it upside down, back to front…*

(Diane 282-292)

Such bitterness and strong emotions initially could appear disproportionate to the nature of the experience. Diane felt that trialling a new technology like this could be a reasonably risk-free venture. However, in the following two extracts, we can see that the bitterness she felt was because the expectations that she and her husband had placed upon the use of the technology.

P: And then when he came back to talk to me about this, he said there's 38 channels and I said that's just no good.

I: No that's very complicated device isn't it?

P: And then if you've got between buildings that were tall it would cut off. ***So, I was really disappointed because I thought it would give XXX the freedom.***

I: And that's what you'd want…

P: …in the beginning yes…

(Diane 324-330)

The extracts above illustrate that the false hope created by trialling the radio caused real emotional distress to both Diane and her husband. Such experiences were reported by several participants and highlight the very real difficulties caused by adopting the wrong form of technology. In this extract, the inability to use the radio signified a turning point for Diane's husband where he felt now unable to go out. For a man whom we have seen in previous themes held such a significant part of his identity with the outdoors; so the impact of this must have been devastating.

Barbara also described her experiences of using the safer walking technology with her husband and how she too had expectations about it keeping him safe. Her husband, however, did not choose to wear the safer walking technology often and this led to several difficulties. However, she persevered, especially as this followed a pattern of difficult experiences all rooted in her husband's inability to recognise her as his wife, or their home as his home. In the extract below she recalls a frequent occurrence where her husband would walk out of the house unexpectedly, usually not wearing the safer walking technology.

P: …and I was looking after him as well and I was sort of curled up on the settee cos I couldn't' stay in bed or anything cos of him and ***he said, 'I'm ever so sorry. I've just got to go home' and he just walked out.*** *I'd not locked the place up I think at that time. It was prior to that and he ended up…have you come across the new bridge down the motorway?*

I: Yes.

P: Well, when you go actually across the river if you turn about 4 miles up the road, that's where he walked to. He walked from here, which is fair old walk.

(Barbara 459 - 465)

In these instances, he always reported trying to get 'home' as he was concerned that his wife and children would be worried about where he was. Barbara found these experiences very challenging, partly because of the emotional upset they caused and partly because she was unable to go with him when he left.

P: Well, like eventually I got the police involved obviously and then the police helicopter at one point so.

I: Oh God that must have very stressful.

P: Well, this was the problem. He could, if he got out of the house he was off [laughs] you know the sister encourage walking and…this was the opposite side of all of this really where you know ***for him to be a little bit less mobile would have been a blessing….***

I: …yeah…

P: …because I couldn't keep up with him if he went off.

(Barbara 367-370)

Her husband was very vulnerable when out alone and she was very keen to try any way possible to track or locate him. Therefore, she continued to try and get him to wear this technology as often as possible. The very real risk posed to him is highlighted in the extract below, where she recounts an incident in which police and police helicopters were used in the local area to try and locate him.

*P: No, I used it right up to the time he went into a nursing home 2013. That was in the November, the few months leading up to the, this in November were just horrendous****. I mean in February, he'd taken off, he got out and taken off. It was cold, wet and horrible and I think he was out for about 5 hours and that was when we had the police here*** *and the helicopter and then I started thinking between that in the February towards the November and I thought I can't cope with this. He's getting aggressive as well which was not nice, and I did use the buddy up to the point of him going into the nursing home because XXX attended day care…*

(Barbara 393- 396)

The safer walking technology was not always as effective at tracking Barbara's husband as he was sometimes reluctant to wear it. She reflected in the interview that something more discreet, than he wore, might have worked better, but at the time she was unaware of any other products available or where to look for them.

4.8.3 Theme Summary

Theme 5 highlights the need to find the right technological solution for each person to be identified individually. The experiences of the participants demonstrate how the functional requirements for the specific technology and the abilities of those operating it should be considered carefully when choosing a safer walking technology to adopt. It is also clear from these experiences that using safer walking technology, that does not suit the needs of the people involved, can be emotionally harmful and have the potential to leave them vulnerable and at risk.

4.9 Conclusion

The findings above explore a broad range of experiences and information about how safer walking technology used by participants within this study have been used to support people with dementia to access the outdoors. A range of experiences was discussed by participants within study 1 and clear themes emerged from the data. The study's themes highlight the opportunities and difficulties faced by a small group of family carers when using safer walking technology to support their relative with dementia to access the outdoors.

4.9.1 Barriers encountered in using safer walking technology

Lack of information on availability of safer walking technology, and advice on how and when to use them, appeared to feature in almost every participant experience within study 1. In some cases, family carers felt responsible for the selection, organisation, and management of safer walking technology, with a mixed market of private purchase and social services provision making this a complicated role to undertake. For those accessing technology through adult social services, information and advice also appeared very variable, with Carl describing being provided with safer walking technology by an early onset dementia team long before his wife needed it, yet Emma found it almost impossible to get the same technology provided in the same county because of what appeared to be short-sighted prescribing criteria in the main social services team. This seemingly ‘unfair’ system may create even more potential for harm as participants within the study reported that they felt their relatives were ‘set up to fail’. As discussed within the literature review chapter, there is an ongoing discussion within the professional and research literature about the ethics of using safer walking technology and their potential to invade the privacy and autonomy of those being tracked (Bantry-White 2018). None of the participants in the study expressed concerns about the ethical issues arising from monitoring their relatives, but many had considered this as an important issue and had made the decision to take on the technology collaboratively with the person they cared for. Once safer walking technology was introduced, participants reported that as family carers of people with dementia the responsibility for maintaining the safer walking technology often fell to them; this included daily activities such as charging batteries and setting up systems and routines for the person with dementia to follow. It also involved more complex roles, such as using computer software or applications (apps) to log in and track the person if needed. Several of the participants reported that the safer walking technology was difficult for them to manage and build into their routines.

Within the study, several participants identified a ‘useful window' of time where the safer walking technology appeared a good match to the needs of the person with dementia. As well as identifying the right time to introduce such technology, participants also talked about their experiences of ‘giving up’ or naturally abandoning the safer walking technology as it no longer served a useful purpose; this appears logical given the inevitable deterioration in cognition and sensibility arising from dementia and its gradual impact upon the functional abilities of the person using it. Yet, again there is no identified literature to support the transition to ‘giving up’ the technology or identifying where the ‘useful window’ ends; this leads to a potential period of transition where the once useful technology no longer worked for the person as desired. This was seen within the participant experiences in this study where Emma, Greg, and Helen all describe how the person they cared for began to struggle to use the safer walking technology. These barriers to the effective use of safer walking technology are discussed in more depth within Chapter 7.

4.9.2 Benefits experienced using safer walking technology

The main reason that participants within the study held a positive view about the use of safer walking technology for people with dementia, was because of the benefits they observed at the time when they felt the technology was ‘right’ for them and the person they cared for. Within this study, this positive view was discussed in some detail by the participants and came from several different benefits experienced when using the safer walking technology. For most participants, the reassurance was that they could locate their relatives in the unlikely event that they became lost and disorientated when away from the family home.

The desire to maintain a connection with, and monitor the safety of, the person they cared whilst they were engaging in outdoor activities that carried some risks, such as walking along the canal towpaths, was a common experience within the study. For example, Helen was reassured by the ability to stay in touch with and check on her husband on his daily walks, as she could not accompany him due to her own poor health. This appeared to be a recurrent factor in the spousal carers within the study, since many of the family carers were less mobile than the person they cared for or had other health conditions of their own to manage alongside their caring role. All 9 of the participants in the study discussed the importance they placed on enabling the person they cared for to maintain regular access to the outdoors. For many, this was framed specifically in discussions about the health and wellbeing benefits of getting out into green outdoor spaces. The findings, within the present study, indicate that the participants saw the safer walking technology as key to enabling them to support these outdoor activities. Participants largely discussed the potential benefits to the person's health and well-being through enabling connectedness to nature and maintaining meaningful occupations.

For many of the participants, safer walking technology held the key to them maintaining lifelong occupational identities. Annabel felt it was important to her husband’s wellbeing for him to be able to maintain this occupational identity. Annabel was not alone in seeking to maintain the occupational identity of her husband; other participants within the study also reported outdoor occupations as key to the well-being and identity of the people they cared for. For example: Helen’s husband’s career in poultry farming and lifelong commitment to edible gardening meant he was rarely comfortable inside; Emma’s father had been an active member of a cycling club for over 40 years. The participants were very keen to adopt any strategies or technology that could enable their relatives to maintain these occupations despite their dementia. These were also occupations that could easily be replicated within inside environments, instead relying upon access to the outdoors. For participants within the study, the use of safer walking technology was introduced as practical support to enable the person they cared for to continue meaningful outdoor occupations for longer, maintaining their occupational identity and sense of personal freedoms. These benefits of using safer walking technology are discussed in more depth within Chapter 7.

4.10 Key Messages from this chapter

- Phenomenologically informed thematic analysis was used to explore the experiences of nine family carers who have used safer walking technology to support a person with dementia to undertake outdoor occupations.

- Five main study themes were identified from looking across the participant group, illustrating similarities and connections between their experiences.

- Insufficient support and guidance made using the safer walking technology particularly difficult for the family carers interviewed and there was the potential for considerable psychological harm and distress to both family carers and people with dementia when technology was incorrectly selected or provided.

- Despite these difficulties, a unanimous overall positive view was still held by participants about the use of safer walking technology for people with dementia. Family carers reported benefiting from the increased reassurance and peace of mind that the technology gave to them.

- Carers also identified real benefits to the people they cared for, through both enabling connectedness to nature and maintenance of meaningful occupations key to the person’s identity.

In the next chapter, the findings of study 2 will be outlined and discussed. Study 2 interviewed people with dementia who used safer walking technology themselves.

Chapter 5 Findings 2

5.1 Introduction and Rationale

Chapter 3 highlighted that, within safer walking studies, only a small amount of the published research explored the views and experiences of people with dementia. Most research was found to either focus on the experience of family carers and professionals (Oliviera et al. 2018), or the use of family carers responses as a proxy for the views of the people with dementia they cared for (Liu et al. 2018). This PhD thesis sought to include and focus equally on both the views and experiences of people with dementia and family carers. This chapter presents the second study, which analyses the interviews of nine people with dementia who had experience of using safer walking technology. The theme development is described, and the themes identified within the data analysis are discussed.

Data analysis was undertaken as described in the methodology chapter (Chapter 3). Although each participant's experience was analysed individually, there were many common experiences reported across the interviews, such as the use of safer walking technology independent of a family carer, the use of safer walking technology to maintain engagement with natural outdoor environments and an awareness of the health and well-being benefits of getting outdoors. This chapter describes how 16 main sub-themes and 5 main themes were identified from looking across the nine interviews. The themes are mapped across the nine case studies and then explored in some depth using extensive data quotations to illustrate the findings.

5.2 Participants

Of the nine participants interviewed, each with a diagnosis of dementia, there were two women and seven men. The participants were aged between 57 and 88, with a mean age of 66.6. The participants were all interviewed, one to one, in their own homes; to protect their confidentiality, real names, names of other people mentioned within the interview and identifying features, such as names of towns were removed from all transcripts and quotations. As seen in the previous chapter, each participant was allocated a pseudonym to help identify them individually, improve the readability of the text and remain true to the ideographic nature of each narrative. Participant demographics are shown in Table 14.

Table 14 Study 2 participant demographics

	Participant	**Gender**	**Age**
A	Adrian	Male	57
B	Brian	Male	72
C	Cynthia	Female	88
D	David	Male	73
E	Edward	Male	71

	Participant	**Gender**	**Age**
F	Fiona	Female	62
G	Gary	Male	60
H	Hugo	Male	64
I	Ian	Male	53

5.3 Development of Themes

As with study 1, each of the participant interviews was analysed using the methods outlined in the methodology chapter (and a summary of each participant interview can be found in Appendix 26.) A large number of emergent themes were identified in the initial reading of the individual transcripts. Using the methodologies described in Chapter 3, these were grouped, and a final set of subordinate and superordinate themes identified for each participant. Theme development across the individual participant interviews can be seen in Table 15 below.

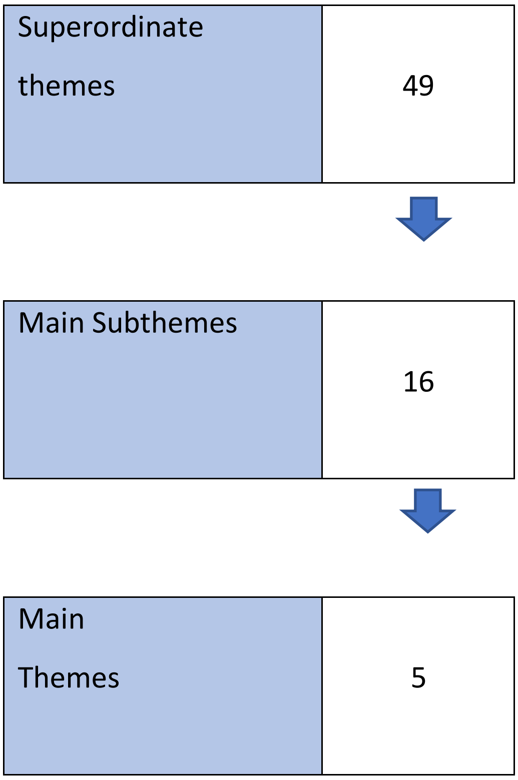
Table 15: Development of individual themes in study 2

Participant	A	B	C	D	E	F	G	H	I		
Emergent Themes	36	32	42	22	43	17	22	33	24		
Subordinate Themes	22	22	24	19	26	17	22	33	24		
Superordinate Themes	5	5	6	5	6	4	6	7	5	49	Total Superordinate Themes

Each participant had between 4 and 7 superordinate themes, which are also described in Appendix 26, with the mean number of themes per participant being 5.4. In total there were 49 superordinate themes; a full table of these superordinate theme titles from all 9 participant interviews can be viewed in Appendix 27.

Step 6 of the analysis process described in Chapter 3 required the researcher to look across all participant interviews and the 49 superordinate themes; from these, the main sub-themes were developed. For study 2, 16 main subthemes were identified, and these were then grouped into 5 main themes. The detailed process of theme development at this step was also described in the methodology chapter, but a summary of the theme development for study 2 can be seen in Figure 14.

Figure 14 Development of main study themes in study 2



The main sub-themes and main theme titles are shown in detail in Table 16. also identifies from which individual participant's the themes are drawn.

Table 16: Main study themes in study 2

	Main Themes		Main sub-themes	From participants
1	"What makes me, me": Identity linked to the outdoors	**1**	"Countryside has always been a part of me": rural identities	Adrian, Cynthia, David, Fiona, Gary
		2	"I just like being outside": a love of the outdoors	Adrian, Brian, David, Edward, Fiona, Gary, Hugo, Ian
		3	"It's all the little things that are really important": outdoor occupations	Adrian, Brian, Cynthia, Edward, Fiona, Gary, Hugo
2	"You tend to do things to help": Getting outdoors for health and well-being	**4**	"Doing whatever I need to do": personal responsibility for maintaining health	Adrian, Brian, Cynthia, Fiona, Hugo
		5	"I made a point of going out and not vegetating": indoor vs outdoors	Adrian, Cynthia, Edward, Hugo, Ian
		6	"Lets you connect with stuff that's really important": outdoors as a place of restoration and reflection	Adrian, Cynthia, Edward, David, Hugo
3	"I know what can happen": Impact on family carers	**7**	"I've seen both sides of the coin": experiences of caring for others with dementia	Adrian, Brian, David, Fiona, Hugo
		8	"She actually bought this tracker": reducing stress for family carers	Adrian
		9	"I'm not going anywhere that's secret": the ethical nature of tracking	Adrian, Gary
4	"Technology is the key": Technological challenges and opportunities	**10**	"Glued to my hand": technology is essential to daily life	Adrian, Brian, David, Fiona, Hugo, Ian
		11	"Changing habits becomes harder": adopting new technology	Adrian, David, Fiona, Ian
		12	"Start using it before they have to": timing of introduction	Adrian, Edward, Gary
		13	"Not a gadget person": support to use technology	Fiona
5	"Just be confident where I am": Overcoming fears and maintaining freedoms	**14**	"There might be something wrong": experiences of getting lost	David, Edward, Gary, Hugo
		15	"I can find out a lot about what's around where I am": uses safer walking technology for planning and reassurance	Adrian, Cynthia, Edward, Gary, Ian
		16	"It's all about empowering people": independence, autonomy and positive risk-taking	Adrian, David, Fiona, Edward

Each of the main themes and main subthemes is discussed in detail below.

5.4 Theme 1 -"What makes me me": Identity linked to the outdoors

All participants talked about how their identity or past experiences linked them to the outdoors. This theme ran throughout all of the participant interviews within this study and was key to understanding the experiences of getting outdoors to engage in occupations that held meaning to the participants as individuals. The title of the theme is taken from the experiences described by Fiona, who described why she felt it was important to maintain engagement in those meaningful activities, because they formed an important part of her identity.

I: But those activities you have been describing to me, do you think that your dementia is going to impact upon that at all?

P: R:I think inevitably it will, but I will cross that bridge when I come to it, or rather we will, because it's a bit of a team effort, yes. And as I say I tend not to think too much about the future because it's so uncertain, sorry that sounds a bit emotional, but that's the reality of it. ***But whilst I can still do those things, I want to do them, because they're part of what makes me me if that makes sense?***

I: Yes. And that leads very nicely into what I was going to say is the importance of being able to continue to get out for you.

(Fiona 500-510)

This theme was developed looking across the individual participant analysis of all 9 participant interviews in study 2. Within it, three sub-themes were also identified (Table 16). The sub-themes recognise the shared experiences highlighted within the participant group and seeks to explore these experiences which include the importance of maintaining meaningful occupations and occupational identity. Outdoor occupations and natural environments offered meaningful connections; these were often built from childhood experiences, which offered reassurance in the connections they felt with nature in the present.

5.4.1 Subtheme 1: “Countryside has always been a part of me”: rural identities

The title of this subtheme is also drawn from the experiences of Fiona, who discussed her childhood experiences of visiting the countryside with her family. Sub-theme 1 explores the importance participants placed on their childhood experiences in shaping their identity and relationship with the outdoors. In her interview, Fiona stated that ‘the countryside’ had always been ‘a part of her’, implying that her relationship with rural outdoor settings is a key component to her identity.

> *P: As a child my parents used to encourage us. We used to go for walks a lot or the Sunday drive and then there would be a walk at the end of it, and a love of sort of nature and* ***countryside has always been part of me.*** *But it has come to the fore again since I’ve been retired and since we’ve lived here and it’s on the doorstep.*
>
> ***(Fiona 127-131)***

Within her interview, she also described her engagement with outdoor environments and described how throughout her life she has sought out occupations that enabled her to maintain this identity as a person who engaged with the outdoors, even when living in an inner-city home.

For many other participants, their connectedness with the outdoors also came from childhoods spent in the countryside or exploring green open spaces. As highlighted in the experiences of Gary who, when reflecting upon his childhood experiences of attending a rural boarding school, observed that these were happy times.

> *P: When I was at home, which wasn’t very often, we didn’t go out. my mother then got MS and, in those days, there weren’t services, you were stuck at home, so we didn’t go out very much and I didn’t. But actually, at school I went to a boarding school, a grammar school and it was for kids who would benefit from being taken away from their home environment in Ipswich. So,* ***I used to love going out, we used to go out in the fields and wander around, we were outside in the country and that was lovely. So, I’ve always liked being out and I used to here actually go out a lot****, now I can’t be bothered. But I don’t think that’s Alzheimer’s, I just think I can’t be bothered. And XXXXXX you have to drive for miles to find some countryside to walk in which is my excuse.*
>
> ***(Gary 164 – 177)***

Not all participants had rural upbringings, within his interview David discussed his past experiences of engaging with outdoor environments: initially also describing the green open spaces he played in as a child. Having grown up in a post-war inner-city, these were old bomb sites where the buildings had come down, but where large green spaces had temporarily emerged.

I: So, have you always enjoyed getting outdoors, like from childhood?

*P:**Yes, absolutely. I would say childhood, it was after the war and stuff and kids running round wild the whole times, it was smashing.** I don't do that anymore but yes, I've always gone out a lot. I've often had to but now I do it out of choice.*

I:Okay and did you grow up in the city or in the countryside?

P:A small city.

I:A small city, so did you have access to green spaces?

P:Oh yes, everywhere to do most things.

I:Everywhere to do most things, okay, sure.

P:Bomb sites and those kinds of things.

(David 58-69)

David has spent his whole life living in the same large city and throughout the interview, his only reference to green or natural spaces are those found within cities, such as informal green spaces as seen in the above quotation and informal parks and gardens. For all of the above participants, these childhood experiences shaped their relationship with the outdoors and influenced both their emotional engagement with the outdoors and their occupational identity, as seen in the following two sub-themes.

5.4.2 Subtheme 2: "I just like being outside": a love of the outdoors

The second sub-theme combines the participants' expressions of enjoyment, pleasure, and love for spending time in the outdoors; it acquires its title from Edward, who when asked why he spent so much time outdoors spoke passionately in his interview of the pleasure he gained from being in the outdoors.

P: Actually, I would say from April to September I'll be out every day. If I'm not doing something else elsewhere, I'll be outside either sitting in the sun or gardening.

I: Okay, that's very good. And why is this important to you personally, why does it matter?

P: It just gives me pleasure. I love seeing things grow, I love trees. I love growing things from seed. It's difficult to say, really. I love birds, I do a lot of birdwatching. ***I just like being outside.***

(Edward 191-200)

For Edward, the pleasure of being in a natural environment alone seemed to be motivation enough to get out. The different occupations he engaged in are as a method to get outside, rather than getting outside to engage in the occupations. When asked why it was important to him now, he thought for around 12 seconds before answering:

P: I think that ***the outdoors in any and every form is really important to people with dementia, because it's too easy and it too often happens, I'm sure, for people to just withdraw.*** *I mean, here are my living in the middle of a lovely area and I've got a big garden. I could become quite lonely out here. Equally, I could be living in XXXXXX or XXXXXX or somewhere on a street and I could be very lonely because I'm just sitting inside because I don't go out for various reasons.*

(Edward 663-671)

In this quotation he appeared to be thinking more widely than just his own experiences, but also to those of others he knew, considering why the outdoors is so appealing to people with dementia. His statement implies that it is easy or common for people with dementia to 'withdraw' from the outdoors. This issue was referred to several times within the interview, indicating the significance he felt it had. This led to his consideration of the importance of maintaining confidence in one's ability to go outside.

> *P: I am involved in a project to do with sand dunes run by a lady called XXX XXXX. And we're looking at just this sort of thing. And I would say because I think* ***the biggest issue for people with dementia in getting out is losing confidence,*** *to be sure you'll be safe, in your own terms, I don't mean not taking risks, but you'll be able to get home, you'll be able to remember to buy what you want to buy or go where you want to go – catch the right bus, etc.*
>
> ***(Edward 593 – 601)***

It is within this context that Edward framed all his discussions around safer walking technology and the importance to him personally of getting into green outdoor environments.

5.4.3 Subtheme 3: "It's all the little things that are really important": outdoor occupations

The title of this subtheme is derived from a direct quotation from the interview with Adrian; it captures the importance of continuing outdoor activities to carry on the familiar pattern of everyday life. When asked about the importance of his everyday regular, 'sedate' outdoor occupations Adrian talked about how for him, the 'bigger picture' didn't matter and that the importance of engaging in the 'little things' was key to him.

> *P: Because I mean what I personally wanted to know after my diagnosis was, you know, will I be able to do stuff with the family, will I still be able to ride a bike, can I go for a pint, can I go on holiday, can we go shopping. This is what's really important on a day to day basis. The big picture doesn't really matter,* ***it's all the little things that are really important*** *to you that matter.*
>
> ***(Adrian 505-511)***

Adrian describes being able to do these 'little things' or mundane, 'sedate' occupations regularly as important in maintaining his sense of self, day to day. Being able to continue doing these things was what he wanted after his diagnosis.

P: I loved the bike. I love history, go to…I mean one of the things I used to do with my family when I was very young is used to go to Scotland and we'd brought a book, pre-historic sites in Scotland and we set out to visit them all in the Highlands, so we loved going to incredibly remote places and, you know, we'd make stories up about what was happening in the place to educate the kids and make them think about things and so yeah ***we've always been very outdoor in a sedate way and never been into mountain climbing or anything like that****, you know, up until my diagnosis I was relatively fit and used to go to the gym quite often.*

(Adrian 228-238)

This sentiment was echoed in several other interviews. For example, it featured prominently in Fiona's discussion of her reasons for enjoying the outdoors and the importance of her outdoor occupations. During the interview, Fiona often expressed the pleasure she gained from being in the outdoors and her love of nature and the countryside. For example, where she talked about the enjoyment she gained when using her ride-on mower.

P: If I get stressed, going and mowing is a really good way. And ***it's such a beautiful environment, I can just sit on the mower and look at the beauty all around me****, which sounds a bit wanky but do you know what I mean?*

I: Yes I know exactly what you mean.

(Fiona 143-147)

But, as already discussed, this appreciation of the outdoors was also a significant part of her identity, stemming back to her early childhood. It was more than just a lifetime of outdoor experiences that make up this identity, it was also the importance of the occupations she undertook in the outdoors, such as playing hockey, running and dog walking.

I: But those activities you have been describing to me, do you think that your dementia is going to impact upon that at all?

P: R: I think inevitably it will, but I will cross that bridge when I come to it, or rather we will, because it's a bit of a team effort, yes. And as I say I tend not to think too much about the future because it's so uncertain, sorry that sounds a bit emotional, but that's the reality of it. ***But whilst I can still do those things, I want to do them, because they're part of what makes me me if that makes sense?***

I: Yes. And that leads very nicely into what I was going to say is the importance of being able to continue to get out for you.

(Fiona 500-510)

These occupations helped to define her as an individual and made up her occupational identity, as defined previously in the introductory chapter; how she orchestrates her time, reflecting and defining her identity and personality. She talked about both her long-term involvement with outdoor hockey and many years of dog walking.

R: As a child my parents used to encourage us. We used to go for walks a lot or the Sunday drive and then there would be a walk at the end of it, and a love of sort of nature and countryside has always been part of me. But it has come to the fore again since I've been retired and since we've lived here and it's on the doorstep. But before moving here XXXXX and I lived in XXXX, but again there was countryside on the doorstep there, you didn't have to go far. ***And dog walking, because we've had dogs, we've been together 25 years, and we've had dogs, so we've always done dog walking, which again is getting outdoors. So yes, it has always been part but it's more so now probably than ever****.*

(Fiona 127-136)

From engaging in these occupations, she gained a sense of enjoyment and freedom that she felt it was important. For Fiona it was not simply about being in outdoor environments, but about doing something purposeful and meaningful in them.

I: Okay. And why is it important to you personally to be able to get outdoors?

*R:**The fresh air, the freedom, the nature that's out there, the things that you can experience, and it's doing something**, it's not just sitting indoors in front of the box, which is another temptation, you know? Very easy to just think oh I'll just lie here on the sofa and watch TV; I haven't got to work.*

(Fiona 178-183)

Dog walking featured prominently in five of the participant experiences, where they all reported engaging in this occupation daily. Hugo talked about how he walked daily, regardless of the weather. He described walking for pleasure, for occupations of daily living, in social groups and as part of a volunteer role at a greyhound rescue charity. It appears that walking is an occupation that he enjoyed. He was quick to clarify that he was a 'walker' and not a 'runner' or a 'jogger', thus ensuring that the interviewer got a clear understanding of his identity in this role.

I: And have you always enjoyed going out?

R: Walking, yes. I've never been into running or jogging, that's not my scene at all.

I: What about when you were growing up when you were a youngster, did you spend lots of time outdoors?

R: Not so much as in very young but teens, yes

(Hugo 129- 134)

For Hugo this is a historic occupation, walking and dog walking appears to have importance to him, as he has spent considerable time walking with his own dog/s over the years. Reflecting on his memories of walking, he stated:

> *P: I'm also involved in re-homing greyhounds, which keeps me walking quite a lot. I do go up there, there's some kennels which is a mile away basically; when I actually went there we used to have our own pet dog who died 3-4 years ago. We didn't want another one because we felt it was restricting our lifestyle because we go away quite a lot to be honest, we've got a caravan in Cornwall, we go down there a lot and we also go wherever we want to be honest and if you've got pets, we've always had pets and the dog died about 3 years ago, and we had a cat which died last year, and all of them have been elderly; we've only had 2 dogs during the course of our marriage, one lived to 17 and the other dog lived until he was 15 so that's 32 years, we've been married 47, so it isn't a bad innings really. But generally speaking,* ***walking with the dog was the main activity, and I do miss that, and that's one of the reasons why I got involved with the greyhound re-homing, because at least I can go out and get some exercise and I can have some time with the dogs.***
>
> ***(Hugo 100-118)***

5.4.4 Theme Summary

The first theme illustrates that the relationship the participants had with the outdoors was often complicated, built on their childhood experiences, but often part of the personal identity they express through the occupations they engage with. For some, participants, these occupations gave them purpose, for others they gave them pleasure or a sense of self.

5.5 Theme 2 – "You tend to do things to help": Getting outdoors for health and well-being

The safer walking technology was universally used by participants in this study to support them to get out into outdoor environments for active leisure occupations. One commonality across many participants was the belief that these outdoor occupations would promote or maintain their health. Therefore, this theme explores the experiences of participants who sought to use their engagement in the outdoors to support their health and wellbeing. The title of this theme was developed from the experiences of Hugo, who described his efforts to help maintain his health and well-being more, since receiving a diagnosis of dementia.

> *P: Because I'm aware of the problem I have, or potentially have,* ***you tend to do things to help****, right, you get more exercise, you do more brain work"*
>
> *(Hugo 61-63)*

This theme was developed by looking across the individual participant analysis of all 9 participant interviews in study 2; within it, three sub-themes were also identified Table 16.

5.5.1 Subtheme 4: "Doing whatever I need to do": personal responsibility for maintaining health

This sub-theme takes its title from a quotation within Fiona's interview, where she explored the different motivations behind her outdoor occupations, which included both training for a marathon and using her ride-on mower.

> *P: And the only thing that I can do in terms of my health and wellbeing is keep running and keep going outside and keep being healthy, you know? A healthy mind, healthy body, what's good for the heart is good for the head, all that sort of cliched stuff, but that's true. So, I think now I'm accepting it if you like, I am definitely going back out again and getting on with the mower and doing* ***whatever I need to do****.*
>
> *(Fiona 294-299)*

For many of the participants within this study, it was evident that they felt a degree of personal responsibility for maintaining their health. This is illustrated in Fiona's attitude towards her mental health and physical fitness. Fiona was very aware of the risk of her vascular dementia deteriorating or taking another 'step' down as she describes it and felt obligated to do all she could to reduce the chances of this.

I: So, what would it mean to you if you had to stop engaging in running, dog walking, things like that?

P: Oh gosh. I think I could very easily get very depressed. And I think I might have said before, one of the things I have to be careful about is my stress levels, because my frontal … hang on, I've got ischaemia, chronic something ischaemia, I can't remember what sort it is, but it's these here, and that's not going to change, so there's nothing I can do that will make the blood flow increase. ***So I have to keep exercising and doing these outdoor things otherwise it means that the likelihood of me getting another episode and then a step, so it's vital for my health that I keep doing those things, and that's a bloody good reason to be doing it.*** *Sorry I swore.*

I: No that's totally fine.

(Fiona 519-530)

As well as this focus on maintaining her physical health with outdoor exercise, Fiona was keen to explain the positive impact that living in the countryside and getting outdoors also had for her wellbeing and mental health.

I: Are you out every day or some days?

P: Pretty much every day at the moment. If you took the marathon out of the equation then it wouldn't be every day but it would be most days, especially in the nicer weather, when you want to have the doors open and get outside, less so obviously in the winter. I'm not a great walker, especially now I run, I don't want to walk, I want to get there quickly, so yes. But yes, most days**, especially living somewhere like this, yes. I think that also adds to my wellbeing, you know. I think if I was cooped up in a flat in a town I think that would not help my mental state, I'm pretty sure of that, so I do count my blessings that we live somewhere so good**, yes.

(Fiona 168-177)

5.5.2 Subtheme 5: "I made a point of going out and not vegetating": indoors vs outdoors

Other participants were keen to draw parallels between both getting outdoors and being well, as well as those between staying indoors and being unwell. The title of sub-theme 5 is drawn from the interview with Hugo. Hugo returned several times to discussing both outdoor and indoor environments and their impact upon him. In the below quotation he described 'going stale' inside:

I: How important is it to you personally to be able to get out and walk the dogs?

R: ***Oh, that's important; I mean otherwise you're sort of in here and stale, aren't you?*** *I mean I have a lot of activities in here, I do lots of things in here, and it doesn't bother me the fact that it's raining, I've got lots of things to do that will keep me occupied; I managed to keep this going. But especially when the sun comes out then that's a different atmosphere altogether.*

(Hugo 170-178)

'Stale' is a term associated with the deterioration of food that is 'past it's best'. A notion that is often identified in the dementia literature, where many express concerns about the lack of value society place upon people with dementia in their communities. This sentiment is echoed again in the following quotation, where Hugo also associates staying indoors with 'vegetating'.

P: No, I mean I still remain fairly active, and as I mentioned, it's quite the opposite, because of this problem **I made a point of going out and not vegetating,** *mainly to keep active….*
(Hugo 221-225)

Despite acknowledging that he had many indoor occupations to engage with Hugo seemed keen to explain his need to get outdoors. Although this could be considered part of his proactive response to the diagnosis of dementia – keeping brain and body active, it is also clear from the following quotation that this was not a new pattern of behaviour.

I: It sounds like you do quite a lot of walking one way or the other.

P: Yes, over a period of time, because you wouldn't do that all in one week sort of thing, but that's not unheard of, I mean particularly when we had the animals, we had the dogs, I always used to, because I used to do a lot of travelling, going on different sites around the country, I used to take the dog with me, she travelled beautifully, you never knew she was in the car and ***every time I went somewhere I would always go and find either on the way there or on the way back, a National Trust property or what have you and just walk the dog for a couple of hours, spend the entire day out, otherwise I had to get back to the office!*** *That was always with the dog and I really enjoyed that as well, I mean I used to spend hours walking.*

(Hugo 199 -214)

In the quotation above, Hugo discusses his working days many years ago – often spent visiting different sites around the UK. During this travelling, he would take his dog and used the opportunity to get out into a variety of natural environments. He joked about the alternative – returning to the office with mock horror. This theme returns within the interview again when Hugo went on to describe a period of ill health where he was unable to get outside and walk regularly. Hugo went on to discuss his experiences of recovery from nerve pain in his leg further, describing the impact this had on both his physical and mental health.

I: I don't have that problem now, that's gone, I've got over that, but that activity I thought brought me down mentally significantly, ***and it took a long time, it took months to get past that, and one of the benefits or one of the things which got me past that was actually walking the dogs****; I found it difficult to walk on uneven ground, actually where we walk the dogs is on uneven ground, so that I had to do a walk, which was on even ground, and everybody would go that way and I'd say, "I'm going this way."*

(Hugo 428 -436)

It appears that his time walking the dogs in his volunteer role was a vital part of his recovery. The impact of this was a period of illness for him, that was quite severe, and he describes this in terms of his mental health, confidence and general well-being.

"Last year I obviously had very limited activity, walking activity until I got this back and really was a downside, not only medically for that, but it also affected everything else, because you couldn't walk ***… I lost confidence*** *even just walking to the village. I don't have that problem now, that's gone, I've got over that, but that activity I* ***thought brought me down mentally significantly,*** *and it took a long time, it took months to get past that"*

(Hugo 423 – 431)

This seems to illustrate the importance that accessing the outdoors and dog walking has for him as an individual and the real loss experienced when unable to continue with it. This loss appeared to affect Hugo considerably – and might be described as occupational deprivation (Whiteford 2000) as defined in the introductory chapter, and is a well-recognised experience, with serious implications for the individual's health and well-being. Imagining a future where he would no longer be able to go out and walk provoked an even stronger statement from Hugo:

> *P: So I would imagine to answer your question: what effect would lack of walking be?* ***I think it would be a deterioration in quality of life all-round, just not the activity of walking, it would affect everything to be honest, because that actually is the basis of life, being able to walk isn't it?***
>
> ***(Hugo 442-447)***

By choosing to quantify his response in such black and white terms 'the basis of life' he is demonstrating the emotional significance of this to him personally.

5.5.3 Subtheme 6: "Lets you connect with stuff that's really important": outdoors as a place of restoration and reflection

Sub-theme 6 explores the restorative and spiritual connections that contribute to the health and wellbeing of the participants. Its title is derived from Adrian's quotation, below, which explores how he finds dog walking in the woods calming. Dog walking in natural environments also appears to hold a significant role in Adrian's life. In the following quotation, he explained how he found these experiences impacted his mental health and well-being. Highlighting that these outdoor occupations allowed him to 'connect with something important'.

> *P: Behind where we live we have a small wood, so I was advised a long time ago for stress you should meditate and I've never been able to work out how you meditate but I honestly think walking in the woods with the dogs, listening the birds, watching the squirrels…made me feel…it's absolutely fantastic, calms you down, makes you feel good,* ***let's you connect with stuff that's really important****. I do that twice every day, which is great.*
>
> ***(Adrian 301-307)***

Adrian was not the only participant to talk about the restorative nature of outdoor environments. Several other participants also spoke about the benefits of natural environments to their spiritual well-being. This was most prominent in the oldest participant in the study, Cynthia, who had several serious physical health difficulties which limited her ability to get outside further than her garden.

P: ***I don't like doing exercise, walking around but I did go down as long as its fine or even if it isn't, I go outside, walk up the drive or whatever that's almost every day.***

I: Oh okay so you're walking in the outdoors on a good day is, is good exercise…

P: …and that's much more often than not walking but in the meantime, I've put these sandbags on my feet.

(Cynthia 691-697)

Cynthia reflected on the role spending time walking in her garden had in helping her manage the 'upsets' of daily life.

I: Do you go in your garden most days or do you go for walks?

P: Oh, every day.

I: Every day.

P: At least once a day and if ever anything upsets me it will be several times a day. I just go and walk round the little garden you know, little things…

I: …so why is it important to you to been if you've been upset to get out? What is it about the outdoors?

P: [pause] it's difficult to say.

(Cynthia 341-349)

For Cynthia, this restorative effect resonated with her religious and spiritual identity. She talked of the spiritual connection she felt with her God when spending time in her garden and the importance she placed on being able to do this:

I: …so why is it important to you to been if you've been upset to get out? What is it about the outdoors?

P: [pause] it's difficult to say. ***I'm quite religious and there's a biblical sentimental poem but there's a line which says you're nearer Gods heart in a garden than any place that's on earth****. That's biblically…*

I: …so it has a spiritual connection for you?

P: Yeah, not consciously so but I've looked at it over the time and yes it does and there's an entry which wasn't so big one when I first came here and now is ***and its sort of a sign of permanency or no matter what happens to me or around me things will go on****…*

I: …yeah.

P: ***We're only part of a continuum*** *I think….*

I: …and that feels very important to you as a person…

P: …yeah…

(Cynthia 347-361)

Spending time in the garden that she had nurtured for over 60 years gave her both a sense of familiarity and reassurance, but also an understanding of the natural cycles of life. In the following quotation from the interview, she appeared to reflect upon her own life and how she fitted into the wider context of the spiritual and natural environment she experienced in her garden.

5.5.4 Theme Summary

Theme 2 identifies a willingness in participants to take responsibility for their health and well-being and that engagement in outdoor occupations can play a significant role in that; it also illustrated that when experiencing periods without access to the outdoors participants have felt a negative impact on their well-being. Therefore, many participants view their ability to access the outdoors, and associated occupations, as essential to remaining well. Being outdoors appeared to have the potential to contribute to both the general wellbeing and spiritual identity of participants and reflects the deeper meanings participants often associated with engaging in occupations in natural outdoor environments.

5.6 Theme 3 - "I know what can happen": Impact on family carers

The third theme identified from study 2 focuses on the participants' consideration of the impact on family carers. The title of this theme is drawn from a quotation in David's interview where David talked about how his understanding of dementia was drawn from personal experience, both within his family and with friends of his family.

> *My father had senile dementia, it was called then and was in a lunatic asylum as they called it in those days - for the last four or five years of his life, **so I know what can happen.** And of course, we have lots nowadays, I think three friends we've had who have developed dementia in the last year or so, so we see it around us. My wife also does a lot of work in dementia*
>
> ***. (David 143-149)***

This theme was developed looking across the individual participant analysis of all 9 participant interviews in study 2, although not all participants chose to discuss this aspect of their experience in depth. Within the theme, three sub-themes were also identified (Table 16).

The sub-themes recognise how participants' experience of caring for a family member had influenced their expectations and understanding of their dementia; there is a limited consideration of the impact using safer walking technology had on family carers and some consideration of the ethics of being tracked by a family carer. For many this consideration of the family carer experience initially developed from their own experience of caring for a relative with dementia.

5.6.1 Subtheme 7: "I've seen both sides of the coin": experiences of caring for others with dementia

The first sub-theme within this theme draws upon the experiences of participants as family carers themselves and how this may have influenced their current perceptions of their family carers. The title of this sub-theme is taken from Adrian's account of why he feels safer walking technology is important. He previously cared for both his father and mother who both had dementia in later life.

> *P: But if I'd have had a tracker and slipped it in his pocket there would have been no problem so I think…**cos I've seen both sides of the coin, from** the point of view having somebody you care about deeply and not, you know, losing them, the very small inconvenience of having somebody find out…I mean it doesn't matter, I'm not going to go anywhere that's secret, I mean what's the point?*
>
> ***(Adrian 679 -685)***

Many other participants also discussed their experiences of dementia in a relative; for some this brought with it negative emotions and concerns about their futures. For David, it is possible this was because of the difficult associations and stigma attached to the term dementia. He described how he felt about his condition in different terms. Whilst acknowledging the diagnostic label of dementia, he was also keen to offer a different view of his condition:

> *I: how did you find that developing those difficulties affected your identity at all, who you are?*
>
> *R:That's an interesting question, I do a lot of work with Alzheimer's Society and some of the senior people there know that I've been diagnosed, the sort of work I do, they want people with dementia as well and carers as well as human beings. So, some of them do know, one or two of them quite often ask how I'm feeling and if it's making any difference and I tend to answer, no not as far as I know**. I believe, as I have age-related slowing down of mind and body,** I'm pretty sure it takes me longer to do things, like (inaudible 00:07:35) or whatever it might be than it used to, and it probably takes me … I guess it takes me longer to answer questions, as I'm just doing now, hesitating more, perhaps.*
>
> ***(David 105-118).***

By reframing his dementia in this way, he was able to accept some day to day changes in his abilities and cognitive skills without having to face the full prospect of 'dementia'.

P: *So, that to me, is just general age-related decline and the usual things about coming into a room and not remember why or coming into a room with two jobs do to and only doing one and walking out without doing the other one.*

I: *I still do that already*

.

P: *I think everybody does to an extent, yes.* ***All those cognitive things do they gently deteriorate.***

I: *Has it had any impact on your life as such, in terms of your ability to do practical things?*

P: *What the cognitive decline?*

I: *Yes.*

(David 119 - 129)

This ‘gentle deterioration' is possibly more acceptable to him personally, especially as he had a family history of dementia. His father had what was then labelled ‘Senile Dementia' and spent the final years of his life in what David described as a ‘lunatic asylum'. This experience must have been distressing for him, at the time, and whilst early diagnosis, care, and treatment for dementia has moved on considerably since then, it appeared David did not want to be categorised as having dementia in the same way as his father. This reframing of his condition allowed him to keep moving forward with his life, whilst also acknowledging small changes and developing coping strategies for these.

Not all experiences of participants who had relatives with dementia were negative. Brian talked openly about how both of his parents had dementia before they died.

I: So, you have an open manner about it.

P: That's right and if they think I'm struggling they tell me it's amazing. It's amazing. It really is amazing, and I've been positive about it all along. There's no point in ***being Both my mum and dad passed away with the disease. My mum had vascular. My dad had Alzheimer's and they've given me a bit of both [laughs] in the genes and they don't…it runs in the family [laughs].***

(Brian 230 – 237)

His positive outlook and openness about his dementia may have been partly because of his parents being very 'happy' during their illnesses and although they both lived with advanced dementia for some time, they retained a good quality of life and he had mainly positive experiences.

P: So in the home she was doing these lists and the lady at the home said what's going on and I said well…I explained what I've explained to you, she said 'oh no we understand that'. So they went into that and asked her what party she'd been doing [laughs].

I: Yeah that's really good. That's really good.

P: Yeah.

I: So in terms of…

*P: …****and my dad was in a different world but he was happy.***

I: Well that's a very good thing.

*P****: I mean my mum was happy and every way so I've got no qualms providing they've given me that [laughs].***

(Brian 430 – 441)

This, in turn, seems to have enabled Brian to adopt a very pragmatic and optimistic view of his current situation and the potential changes he might face in the future.

5.6.2 Subtheme 8: "She actually bought this tracker": reducing stress for family carers

Sub-theme 8 focused upon the notable absence of discussion around the role of safer walking technology to support the needs of family carers. Reflecting upon the past experiences of family members did not always lead to the consideration of issues faced by current family carers. All the participants interviewed for this study lived with a family member who cared for them. Although they often explained their carer's role, briefly in response to an opening question about their support network, most of the participants chose not to talk about the impact their dementia had on the person they lived with. Nor did they choose to directly discuss how the safer walking technology being discussed could be helpful or reassuring to their family carers. The only exception to this was when Adrian briefly mentioned that the location tracker in his car was purchased by his wife.

> *P: She bought…**she actually bought this tracker** and said will you put this in your car, but I found out it's actually…it is a…you can leave it in the car but you can take it off and put it in your pocket and I think that for, you know, your partner, your supportive, whoever is quite useful.*
>
> *(Adrian 654-658**)***

This is the only real mention he made of the benefits of having the safer walking technology to family carers. This omission is notable when considering that six of the nine participants were carrying safer walking technology that would allow their family carer to track them, but none chose to discuss this. They chose instead to focus upon the benefits they gained as an individual and the confidence or practical assistance the safer walking technology provided to them alone.

5.6.3 Subtheme 9: "I'm not going to go anywhere that's secret": the ethical nature of tracking

Sub-theme 9 examines the ethical considerations of using safer walking technology to track people with dementia. Within each participants' interview, there was some limited discussion of the ethical implications of using safer walking technology. The title of this sub-theme is drawn from the following quotation within Adrian's interview.

> *"The very small inconvenience of having somebody find out…I mean it doesn't matter, **I'm not going to go anywhere that's secret,** I mean what's the point?"*
>
> *(Adrian 678 – 682)*

Again, this subtheme was notable in its near absence. Although the impact on their family carers was not discussed directly, a small number of the participants did consider the ethical implications of being tracked and in doing so showed some indirect awareness of the theoretical benefit such technology may have to family carers. Adrian openly considered the perspective of a potential carer when thinking about the use of safer walking technology to track a person with dementia.

> *I: So you use all kinds of technology then, you use a satnav satnav, you use a mobile phone, apps and it's connectivity to other things, you use GPS trackers [laughs]…*
> *P: …yes [laughs] well, you know,* ***we live in a modern world and the only people that would find this technology invasive I think are people who have something to hide.***
> *I: Yeah, totally.*
> *P: You know and fine, if that's what they want, if that's there bag that's there bag*
>
> ***(Adrian 703-711)***

It appeared that, concerns about privacy and the use of safer walking technology were almost a 'non-issue' for the participants. This may in part have been because very few of the participants used their safer walking technology for this purpose and were not frequently getting 'lost'.

5.6.6 Theme Summary

Theme 3 highlights how many of the participants had past experiences of being a family carer for someone with dementia; these experiences impacted how they viewed their diagnosis. Yet, there was very little consideration of how the condition then impacted the family carers in their lives, or how the safer walking technology could be used to support family carers. There was also a notable lack of concern about privacy and the ethics of tracking with safer walking technology. These issues couldn't, therefore, be easily discussed from the perspective of the participants in this study and may be a potential area for future research.

5.7 Theme 4 - "Technology is the key": Technological challenges and opportunities

The fourth theme from this study identifies the variety of experiences participants had using safer walking technology. The title of the theme is taken from Adrian's quotation below, in which he identifies how such technology is both challenging and helpful.

*P: I mean and so **yeah technology is the key**, I mean…and the problem is initially it takes time to set something up and it takes time and peoples time to help people organise it and get into the groove so to speak, but then that time is reduced**.***

(Adrian 761-765).

At the time of the interview, all the participants were actively using safer walking technology to support them to get outdoors. The experiences of all nine participants were explored and four sub-themes identified within this theme (Table 16).

5.7.1 Subtheme 10: "Glued to my hand": technology is essential to daily life

For most of the participants, technology was an everyday tool, used in a range of different ways to support their daily activities. This use of universal 'everyday technology' not designed specifically for people with dementia was seen, throughout the interviews, with participants who had dementia. The title of this sub-theme is extracted from a statement by Fiona, who used a range of everyday technology to support her in her daily life; she felt that this was normal and that it enhanced her ability to do things. She was particularly keen on her smartphone, stating that:

P: I'm slightly scared of technology, but I'm getting better if you like.

I: Okay. And do you generally find it helpful?

*R: Oh gosh yes. **My phone is usually glued to my hand.** And now, yesterday for example, when I was driving to XXXXXXX, I used to look at a map and be able to remember the route and go, but now I have to rely on perhaps stopping and getting the map up.*

(Fiona 325 - 331)

Adrian too was keen to explain that his smartphone was essential to him because of the difficulties he faced because of his dementia. Highlighting the practical importance of his phone Adrian makes a comparison between the use of his smartphone to support cognitive skills and the use of a walking stick to support someone with ‘a bad leg’.

> *I: How do you feel about technology being able to support people with memory problems in general, do you think it’s…*
> *P: …**essential, it’s absolutely essential. I mean, you know, [pause] if you can have this and it’s going to help you to live a proper life isn’t that as useful as a stick to somebody who has a bad leg?***
> *I: Yeah.*
> *P: So, what’s the difference? Sorry it’s a ridiculous question, somebody who needs a stick would never be asked ‘well, do you really need that?’.*
> ***(Adrian 325-331)***

Adrian clarified that the technology supported and enabled him to "live a proper life", going on later within the interview to discuss a wide variety of functional uses for his smartphone and highlighting the independence and autonomy this gives him. For Adrian it appears that this independence equates to ‘a proper life’, highlighting the value he places upon his freedoms.

This attitude was common and supported by other participants including Hugo, who when asked about his general attitude towards technology, was clear that he also felt it ‘essential’ in his life.

I: And do you generally find technology helpful in your life?

R: ***It's essential, it is life to be honest now; you can't separate one from the other, it is part of life and if you don't accept it you're in the last century and not this one to be honest.*** *I have battles with my wife over this because she's got an absolute fear of technology, I mean she just said she got a, I don't know what phone it is, but basically it is what it is: a phone, I can communicate with her and that is its sole purpose. But anything, even this, bog-standard-*

I:That's a smart phone isn't it?

R: Yes; S4 I think it is.

(Hugo 237-248)

Hugo had adopted navigational apps such as 'google maps' and 'map my walk' for everyday tasks, such as going to the shops, long before starting to use them to support his dog walking or within his walking group. He continued to use them for these purposes too and in the below quotation describes how he used the apps daily.

"The apps that I use are obviously Google Maps, I mean I use it probably most like you, getting here today, as a sat-nav system, if I wanted to go to XXXXXXX or whatever then I would plonk that in and then off we go." (Hugo 269-272)

Within the interview, the researcher did not state that she had used any form of sat nav or GPS device to get to the interview – this was just assumed by the participant. This indicates the extent to which he believed society has come to accept the use of GPS location tracking and wayfinding as a whole. Hugo used the word *'obviously',* but although 'Google Maps' dominates the app market in this technology there are several other apps available. The assumed 'understanding' between participant and researcher, here, reflected the participant's perception of assumed knowledge and, possibly, enthusiasm to show his competency and own knowledge in this area.

5.7.2 Subtheme 11: "Changing habits becomes harder": adopting new technology

Sub-theme 11 explored the difficulties that some participants had experienced in adopting new safer walking technology. It takes its title from the quotation below from David, in which he acknowledges that changing habits can be increasingly difficult, especially with the expectation of 'life-changing' results.

> *"**Changing habits become harder and harder**, getting into new habits gets harder and harder and therefore adopting new approaches to life and technology could totally change your life, so it's not like getting a posher television or something like that. It's potentially a total change of life that people are expecting, and I imagine that might be difficult."*
>
> ***(David 225-231)***

Despite his past experiences of being a technology 'expert' and the enthusiastic tone to his discussion of the potential benefits of technology, David showed only limited enthusiasm for the locating app he used on his phone. The tracking technology he used when walking was located on his blackberry phone, but he did not feel it was very good. This appeared to be mainly because of the integration of this technology within his phone. In the following quotation he expressed strong feeling about his phone:

> *P: I don't think I'm an early adopter now, but I have got a smart phone, I don't use apps, partly because it's a Blackberry and so there's not many apps anyway. **I use what I use, I don't use it as a phone very much, I don't make many phone calls, I hate the phone, so I don't think I'm a fast adopter, if a new smart phone comes out, a new Blackberry comes out, I don't rush out and get it.***
>
> *I: No, but you were once an early adopter and you still obviously use technology?*
>
> *R: In the case of IT yes and I use technology all that time.*
>
> ***(David 167 – 176)***

This strong statement appears to come from a disillusionment that new technology was no longer easy for him to adopt. He goes on to state that:

P: So, if people are unused to technology, that sort of technology, then they won't probably won't be able to train themselves to get into the mindset that's important. They may be able to train themselves to do this, that and the other but it won't be automatic, like I automatically word process, always have done, since computers came out in the late 1970s. So, ***word processing to me is second nature, totally second nature but if I had to do that, if I was encouraged to do that, as something totally new, I'm sure I would find that very difficult. Like if someone gave me an iPhone and I said, right well I'm going to use this, I'm not sure how well I could do that. I'm used to smart phones.***

(David 196-207)

This acknowledgment of being 'left behind' left him both angry and reflective. He then began to justify the decision not to engage with the new technology because of his dementia, telling the researcher that:

P: Yes, I know people, for example, who have never got into using microwave cookers and they don't like them.

I: Yes, because my grandmother was the same, she would not have one.

R: Yes, I think we're probably on our tenth by now, we were a very early adopter of microwave cookers, I think they're fantastic. My wife isn't so keen on them but yes, that's right and as much ***as people do find new kinds of things difficult and then with dementia, people are encouraged to keep the person concerned in a familiar surroundings****. In fact, in the papers, they say dogs with dementia are best kept in familiar surroundings (laughter).*

I: Oh, it is a strange world.

(David 212-224)

He was careful to attribute this advice to 'the person' rather than himself. His fear of not managing the potential changes had inhibited his desire to take on or adopt the new technology. Although this may have been a protective strategy, it may also have come from an aspect of trial and error with his blackberry phone, itself somewhat outdated at the time of the interview.

5.7.3 Subtheme 12: “Start using it before they have to”: keen to adopt new safer walking technology

Several of the participants were keen to discuss the importance of timing; both issues of when safer walking technology was introduced and when they might be discarded, were discussed. The title of this subtheme is drawn from Edward's quotation below.

> *P: I think people should **start using it before they have to** because the sooner you get used to using it. I remember reading someone's blog some time about it and it makes perfect sense. If you try to introduce, I don't know, some whizzy reminder system when someone actually can't remember to set the damn thing or whatever, then it's too late*
>
> *(Edward 341-346***)**

When discussing his experiences of using technology since developing dementia, Edward was keen to express his views on when best to introduce safer walking technology. He was also well informed about the experiences of others. Within the ‘dementia community' on Twitter, he has a prominent voice, publishing a monthly blog and tweeting regularly to over 2,000 followers. He was also aware of a first-hand observation about the tendency for people with deteriorating dementia to stop using the technology they have previously found helpful and easy to use. In the quotation below he discussed his observations of peers who attend the Dementia Empowerment and Engagement Project (DEEP) group in his local town.

> *“I mean, it’s interesting that, in these DEEP groups that we have, peer groups, there are people who are further on than me and it’s quite evident that they, and I will, eventually struggle with working out what to do with a smartphone, just as much as anything else.* ***So when I say I will continue to use it, I’ll continue to use it for as long as I can.*** *But I can see other people becoming less confident and less able and therefore putting it aside because they think, “Oh, it’s too much hassle, I don’t want to do it anymore.”*
>
> ***(Edward 549-557)***

5.7.4 Subtheme 13: “Not a gadget person”: support to use technology

Sub-theme 13 identifies, that for one of the participants, adopting new technology required some support from those around her, even if though she previously adopted technology readily. The sub-theme takes its title from Fiona's quotation below.

> *"I did get a mobile phone before all my friends, back in the days when they were a brick,* ***but I'm not a gadget person really"***
>
> *(Fiona 316-317)*

Fiona was keen to stress that she was only able to manage setting up and the ongoing management of the technology with the help of her partner and nieces and nephews. She describes it as "a bit of a team effort".

Although Fiona felt she utilised this technology effectively, she required ongoing support from others to keep using it. This support was vital, as without it she may not have been able to continue using the technology and therefore might also have to adapt or give up some of the outdoor occupations she engaged in.

> *P: When I was first training I actually took the Garmin to … we went to New Zealand, we were away for five weeks, and I had to run, so I was mapping places that I didn't think I'd ever be mapping, so there's an interest in that as well, to be able to pinpoint where I was doing my 2 or 3K or whatever it was, so I can see that continuing. I'm less sure about the Google maps, but partly because* ***I'm fortunate to be in a relationship with somebody who can do that for me, so I don't rely on it. If I was on my own, it would be very different, but then I think this would all be very different if I was on my own, if I hadn't got the support.*** *But as I say I don't see the Google maps use increasing particularly for me.*
>
> ***(Fiona 546 -555)***

> *I: I also have an MP3 player, I could use my phone, but I wanted separate music and I didn't want to take my phone running because it's quite bulky compared to the MP3 player. I use the computer for … well XXXX will tell you that I play Jewel Blitz all day. It's not all day, but I do play it quite a lot, and I enjoy it. It's mindless, but it's fine, mindless, but not Candy Crush, definitely not.*
>
> *I:- Of course, got to draw a line?*
>
> *R:Exactly.* ***But I'm slightly scared of technology, but I'm getting better if you like.***
>
> *I:Okay. And do you generally find it helpful?*
>
> *R:Oh gosh yes*
>
> ***(Fiona 318 – 328).***

Fiona was the only participant who acknowledged needing support from her family carer to manage the setup or running of the technology.

5.7.5 Theme Summary

Theme four demonstrates the essential role that safer walking technology played in the lives of the participants interviewed; even those who perceive themselves to have limited skills in this area were keen to adopt technology to assist them to engage in occupations in the outdoors. A key consideration in the use of safer walking technology, for some participants, appeared to be in the timing. Some of the participants were aware of the importance of adopting technology early, whilst others foresaw a time where they may no longer be able to easily utilise the technology that had become so essential. Consideration of support to continue using safer walking technology was only identified by one of the participants.

5.8 Theme 5 – “Just be confident where I am": Overcoming fears and maintaining freedoms

The experience of getting lost and the fear of getting lost were often cited as factors in why many participants decided to use or try safer walking technology; these experiences could be very frightening or represent key changes in a person’s life. This theme takes its title from the following quotation from Edward, who explains how using his safer walking technology helps him feel confident when outdoors.

> *P: I will find where I'm going on the Google Map just because I feel happier, I know where I am. So, it's just going to there because (a) I'll avoid going round in circles and not getting to the right place and (b) I want to know how far I can go without having to retrace steps or whatever else.* ***And just be confident where I am,*** *simple as that.*
>
> ***(Edward 431-436)***

Three sub-themes were identified within this theme (Table 16). This theme explores how safer walking technology was used by the participants to increase confidence, provide support or overcome the practical difficulties they faced, because of their dementia, when getting outdoors.

5.8.1 Subtheme 14: “There might be something wrong”: experiences of getting lost

For many of the participants, the prospect of getting lost or being unable to find their way worried them. This sub-theme explores how participants’ experiences of getting lost were discussed in the interviews. For two of the participants, these worries were rooted in an experience of being lost that led them to seek help and support which ultimately ended with a diagnosis of dementia. The first of these participants was Gary, who had lived in the same area of a busy city for all his adult life and recounted his experiences of becoming lost just streets away from his home. This sub-theme also takes its title from this quotation:

> *P: "And I was coming down from a side road and I got to the junction and I looked, and I had not a clue where I was…. and I thought. blimey……. So that's when we thought whoops* ***there might be something wrong.***
>
> *(Gary 69-73***)**

Throughout his interview Gary was reluctant to talk about his feelings, preferring to state facts and carefully worded accounts of his experiences. When asked prompting questions such as 'how did you feel?' he simply shrugged. However, in recounting the quotation above about becoming lost, he became visibly agitated and tearful. This experience had a significant impact on him and represents a turning point in his life. Edward also found himself lost in his local supermarket.

At the time of the incident (and at the time of interview), Edward was a very independent man, driving himself around and representing the 'voice' of people with dementia on several committees and panels for his local health commissioning service. In the following quotation, he explained how he found himself temporarily lost:

> *"I remember I had a 10 or 15 second period of total disorientation in a supermarket, which was the thing that probably was the first major episode, where I just didn't know where the hell I was, what I was doing there and so on – it was disconcerting rather than worrying but it came back after about 15 seconds or so, but it was a blank."*
>
> *(Edward 228-234)*

Several other participants recounted experiences of getting lost and described the associated fear and bewilderment that these experiences brought.

5.8.2 Subtheme 15: “I can find out a lot about what’s around where I am”: uses safer walking technology for planning and reassurance

Sub-theme 15 focuses on how safer walking technology benefited the participants, in particular in offering the opportunity to plan and give reassurance. Its title is taken from the below quotation, in which Ian describes the usefulness of the safer walking technology.

> *“I find it useful in as much as **I can find out a lot about what’s around where I am”***
>
> ***(Ian 342)***

For Ian, Edward, and Gary the use of safer walking technology was strongly linked to avoiding getting lost. Despite his difficult experience in the supermarket, Edward felt that planning and preparedness helped him to avoid difficult situations and always carried a smartphone to ensure he could orientate himself, if necessary. In the following quotation, he described how he uses this to plan the dog walks he undertook in the local area near to his home:

> *I: You talked before about it being a reassurance to have it?*
>
> *R:Yes. If I took the dog for a walk in, I don’t know, let’s say XXXXXX just up the road, ten miles away, and I do sometimes. I will find where I’m going on the Google Map just because I feel happier, I know where I am. So it’s just going to there, because (a) I’ll avoid going round in circles and not getting to the right place and (b) I want to know how far I can go without having to retrace steps or whatever else.* ***And just be confident where I am, simple as that.***
>
> ***(Edward 428-436)***

For other participants, the use of safer walking technology offered them reassurance or confidence. Although Cynthia didn't go further than her garden, it was quite large and she had concerns about becoming lost if unable to see her house. In the following quotation she referred to the pendant alarm she wore around her neck, this has an emergency button that she could use if she wished to summon help.

P: I'm not the least bit worried about being on my own…..I am [pause] I was quite careful if I went down the garden I took a walking stick or something, as you can see I always wear this…

(Cynthia 289-294)

5.8.3 Subtheme 16: "It's all about empowering people": independence, autonomy, and positive risk-taking

Sub-theme 16 identifies how the use of safer walking technology by the participants supports their independence by promoting autonomy and independence. The title of the sub-theme is taken from Adrian's interview and is seen in the quotation below:

P: you always need have a phone in your pocket, you know, that's it, job done. They did the searches, there's nothing out there like it. Wouldn't that be amazing?

I: It would yeah.

P: I mean…and ***it's all about empowering people isn't it****. And so, if you get to Tesco's and you can play this…nothing sophisticated, nothing complicated*

(Adrian 416 - 420)

Adrian used his smartphone for a range of supportive functions but felt that the use of 'Google maps' was key to his ability to go out independently and live his 'own' life. Fiona too used her smartphone every day and in addition to the usual phone functions, she also used the navigational application Google Maps on this to locate herself, when out and about walking the dogs. She also used a specific 'running watch', which could track and monitor her progress when out running. At the time of the interview, Fiona was in training to run the London marathon. Her running watch could also be linked to her computer at home and allowed Fiona to review the runs she has already completed and plan future runs. When asked what prompted her to start using this type of technology, she initially cited both it's accuracy and ease of use.

I: So, thinking about the Garmin watch, what made you think to use it?

R: The other girls in the running group had one and because I'm competitive I needed to be able to challenge myself. ***And some people use their phones, but this is much more accurate and it's much easier to look at while you're running, and if you're a proper runner you have one, okay?***

I: Yes, that's fair enough.

(Fiona 379-382)

She used both devices when running, but stated she was reliant upon the watch and couldn't run without it.

I: And how did you expect it would help you particularly? What were you wanting to get from it?

P: I wanted to be able to see where I had been, what distances I had covered and what that was in reality. So I could say to you oh well I run from XXXXX to XXXXX, and that means nothing to you, but if you looked at it on a map, you can then see that's a long way. ***It also helps me because when I was trying to increase my distances, I would look at where I had already run, and then I could plot where the next run would be to take me however many more kilometres I needed to go.***

(Fiona 384-392)

Fiona was clear that, because of her dementia, she needed to use this technology to be able to participate in running.

Now I don't know whether other runners could do that without, but I absolutely couldn't because of the dementia. ***And I do sometimes try, when I'm looking at the watch, I try to predict things, like oh well if I'm doing this at the moment, and I have to stop doing that because I can't, whereas I think for other runners they can***, *they can look at the watch and say 'Oh well I've already done such and such and I'm going to be doing such and such, so I'll carry on at this pace'. I just plod on at the same pace and get there when I get there.*

(Fiona 413-420)

In the quotation above, it was clear she felt her dementia would make running long distances and training for a marathon impossible without the support of this technology; the watch also serves a different purpose, as a safeguarding device. When training for a marathon it is not unusual to be out running for very long periods and over large distances; that for Fiona was across the very remote and rural countryside. The watch also enabled others to locate her as described in the quotation below.

> *P: So now it's basically just telling … I'm not really looking at the pace anymore, I'm looking at how far I have run, and then when I get home, I will look at the detail of it.* ***And one of the things it tells me is the … I think cadence is the word, but my feet. And I'm terribly predictable, I always run at the same pace, which is great for anyone who's coming out to meet me or find me, they know exactly where I will be, and I couldn't have done any of that without that watch.***
>
> ***(Fiona 406-412)***

Fiona felt that this was important and went on to discuss the security it brought her and why it was essential to her participation in this occupation.

> *I: And it might seem like a strange question but how does having the watch make you feel? Does it have an emotional dimension for you?*
>
> *P:* ***It's more about if I didn't have it, I would feel, not naked, but I would feel I couldn't have a proper run. It's part of my equipment, it's part of what I need to have a good run. So, it gives me some sort of a security actually.***
>
> ***(Fiona 447-452)***

5.8.4 Theme 5 Summary

Theme 5 identifies the very real concerns the participants had about getting lost and the potential impact of that in their lives. Participants describe using safer walking technology to both plan for and orientate themselves when outdoors. Participant experiences within this theme indicated that a strong sense of reassurance and confidence is sought and often achieved whilst using safer walking technology. This confidence, in turn, empowers the participants to continue engaging in their outdoor occupations independently.

5.9 Conclusion

5.9.1 Barriers encountered in using safer walking technology

Of the nine participants, six had previously become temporarily lost or disorientated in a familiar place. The fear of getting lost, or negative associations with the previous experiences of getting lost, seemed to play a significant role in the decision to seek out and use safer walking technology. However, very little of their discussion was focussed upon these experiences or the anxieties created by them. Whilst acknowledging the risks of getting lost within this study, participants chose to spend significantly more time on discussing the empowering uses of safer walking technology to way-find, locate or navigate themselves independently when outdoors. For all nine of the participants the technology was used independently of their family carers and as a tool to enable them to feel reassured or reduce anxiety about the potential for getting lost.

Within the participant interviews for study 2, there was also some limited evidence to suggest that people with dementia were reluctant to adopt what they saw as potentially stigmatising technology designed specifically for the needs of people with dementia and therefore reject these kinds of specifically marketed assistive technology in favour of everyday technology. Several of the participants within study 2 used navigation apps on their smartphones, with participants describing this as both ‘normal’ and an ‘everyday’ use of navigational technology. Within this study, the majority of participants used their safer walking technology without assistance or support from others. However, for other participants, the role of family carers in setting up and ongoing ‘tech support' was vital to their use.

The challenges of learning new skills because of their dementia were acknowledged by some participants in this study who reported finding it harder to adopt new habits and technologies. The current nature of assistive technology, as an ever developing and changing tool, makes this a particularly challenging issue for people with dementia. Within this study, some of the participants were also keen to reflect upon the ‘right time' to introduce safer walking technology to enable the development of habits and routines. There was also discussion of a ‘useful window’ of time where the technology could be adopted and used easily by people with dementia, whilst acknowledging that it would at some point no longer be of help.

Another challenge faced by participants within this study was the limitations of the safer walking technology they used. For many, the technology did not provide the exact combination of functions that they needed or was limited to use for only one aspect of their needs. Participants within study 2 demonstrated several innovative ways in which they used their safer walking technology to compensate for the difficulties they experienced because of their dementia. This process is what Greenhalgh et al. (2013) refer to as ‘bricolage', in which people create new uses for devices, in conjunction with other products, according to their own needs, often in ways not specified in their designed purpose. The concept of bricolage and its role in wider assistive technology literature is discussed in chapter 7, along with an in-depth consideration of the barriers to using safer walking technology identified in this study.

5.9.2 Benefits experienced when using safer walking technology

Within the individual interviews, all 9 participants spent time considering the value and meaning that getting outdoors held for them. Several were keen to identify their responsibility for maintaining their health and well-being, describing the outdoor occupations they undertook as crucial to how they maintained their well-being. Within this study, participants made links between getting outdoors and remaining well and contrasted these with staying indoors and poor physical and mental health. Several participants described periods of occupational disruption and their fears about the impact of possible occupational deprivation. As discussed in the introductory chapter, occupational disruption and deprivation can impact a person’s health and well-being and have the potential to also undermine their occupational identity and sense of self. For many of the participants, their connections to nature and outdoor focussed occupational identity stemmed from childhood experiences, with many describing patterns of occupation, such as dog walking, that have been maintained throughout their entire lives. The importance of maintaining these meaningful occupations was highlighted by many of the participants, who described both their individual meaning, but also the importance of the outdoor environment. For all participants, some form of connection to nature was highlighted as holding importance to them as individuals, but for some, this also had a spiritual dimension, where outdoor environments, and the occupations engaged in within them, offered opportunity for both restoration and reflection. These benefits of using safer walking technology are discussed in more depth within chapter 7.

5.10 Key Messages from this chapter

- Interpretative phenomenological analysis was used to explore the experiences of nine people with dementia who had used safer walking technology to undertake outdoor occupations.

- Five main study themes were identified from looking across the participant group, identifying similarities and connections between their experiences.

- Several of the themes highlight that the participants have a complex relationship with the outdoors, which often stems from childhood experiences and is key to their identities.

- It also appeared that engaging in outdoor occupations had a role in the ongoing health and wellbeing of participants, which often contributed to their physical health, mental health, and spiritual well-being.

- Study two's findings also indicated that participants used the safer walking technology to maintain their autonomy, empowering them to continue engaging in these outdoor occupations by using the technology to plan for and orientate themselves when outdoors.

- Findings from this study also noted an absence of participant accounts of how the safer walking technology might be used by family carers to track or find them, with only a passing consideration of the ethical issues surrounding such possibilities.

- Overall, the findings highlight the essential nature of safer walking technology in the everyday lives of this small group of people with dementia.

The next chapter presents and discusses additional findings from studies 1 and 2, which identified a range of different data about how safer walking technology was used and what outdoor occupations it was used for.

Chapter 6 Findings 3

6.1 Introduction

Chapter 6 presents an overview of this additional data enabling an overview of the technology used in both studies, its functions, use, and purpose.

6.2 Which safer walking technology was used?

All participants in study 1 currently used or had previously used some form of safer walking technology to support the person they cared for to gain greater access to the outdoors. Within study 2 all the participants were currently using a form of safer walking technology to engage in outdoor occupations themselves. The family carers in study 1 identified five different forms of safer walking technology and people with dementia in study 2 identified nine. The types of technology used by participants in both studies 1 and 2 varied considerably as can be seen in Appendix 26, along with a detailed description of each device.

Within study 1 all participants used just one form of safer walking technology. None used multiple forms of technology and the majority (4 out of 9) used the Buddi system, which was the only system available via adult social services in the local authority areas in which participants lived. At the time of the research, the Buddi system was not available in all areas and the eligibility criteria for social care provision was restrictive, which excluded some participants from obtaining it through a public source. The other forms of safer walking technology were purchased privately by the participants and all participants had been using their devices for at least 6 months before agreeing to take part in the study. Table 17 below identifies which participants used which technology in study 1, highlighting the popularity of the Buddi system with family carers.

Table 17 Safer walking technology used by family carers in study 1

Safer walking Technology	Participants	Total
Buddi tracker system	Annabel Barbara Carl Emma	4
Doro Phone Tracker	Greg Helen	2
Bina tone 2-way radio	Diane	1
Small clip on Tracker	Francis	1
Tracker Expert	Ivor	1

Within study 2, only one participant used just one form of safer walking technology, whereas the others all used several, but often for slightly different purposes. For example, one participant, Brian, used the Google maps app on his iPad to plan walks and his sat nav to locate himself when outdoors.

Table 18 shows which safer walking technology was used by the participants living with dementia in study 2; and where they were using multiple technologies together. The most commonly used technology was the ‘Google maps’ smartphone app, with seven out of nine participants using this. This is followed by GPS on a satellite navigation device and the ‘find my iPhone' tracking function on Apple devices. These findings demonstrate that the people with dementia in study 2 had a preference to use ‘everyday’ smart technology, rather than ‘assistive technology’ designed specifically for them as an identified demographic group.

Table 18 Safer walking Technology used by people with dementia in study 2

	Adrian	**Brian**	**Cynthia**	**David**	**Edward**	**Fiona**	**Gary**	**Hugo**	**Ian**	**No. of participants using this safer walking technology**
iPhone App Google maps	YES			YES	YES	YES	YES	YES	YES	**7**
Find my iPhone	YES			YES	YES	YES	YES			**5**
GPS Sat Nav system	YES	YES		YES	YES				YES	**5**
Ipad App Google maps		YES			YES					**2**
Ipad App Google Earth					YES			YES		**2**
iPhone app- Map my walk								YES		**1**
Garmin running watch						YES				**1**
Pendant alarm system			YES							**1**
Small tracking device	YES									**1**
Number of safer walking technology devices used by each participant	**4**	**2**	**1**	**3**	**5**	**3**	**2**	**3**	**2**	

6.3 How does use of safer walking technology differ between studies, participants and devices?

Within study 1, all of the technology was identified as a recognised form of 'assistive technology' being used by family carers to track or locate a person. The different types of technology used reflected the differing needs of the participants, the availability of devices in their local area, and their financial situation. In addition to the difference in purchase cost, there was considerable variation in ongoing service charges, size and weight. Some of the safer walking technology used had many different functions, whilst others had just one. However, just because a range of functions were available, it did not necessarily mean that all were used. For example, Ivor used the Tracker expert, which had many different functions, but he only used the GPS safer walking function of the device. His wife was unable to use, for example the SOS button or understand how to use the two-way conversation.

> ***I've told Xxxxx about it but she can't remember to press it, and we've never had to use it in anger yet. I've tried it with her, and I've said "that's yours, press it and let's have a chat, and I'm going to go in the other room", and she follows me. (Ivor 254-258)***

Each piece of technology used in study 1 had a different set of functions (Table 19).

Table 19 Function of safer walking technology in study 1

Function	Buddi tracker system	Bina tone 2-way radio	Small clip-on tracker	Doro Tracker Phone	Tracker Expert
Can track the person over a small area	YES		YES	YES	YES
Can track the person over a large area	YES			YES	YES
Can call the person and have a 2-way conversation		YES		YES	YES
Emergency SOS button for the person to press	YES			YES	YES
Gives off an alarm beep sound to help with safer walking			YES		
Geo-fencing can be set up to alert if a person leaves a set area					YES

In contrast to study 1, just one technological device identified in study 2 was a recognised form of assistive technology and none of the safer walking technology was designed specifically for use by people with dementia. The safer walking technology used by the participants in study 2 had a range of possible functions (Table 20). One participant, Cynthia, in study 2 used a pendant alarm, which is a type of in-home telecare device, but her use of this to enable her to continue engaging in outdoor activities was innovative and not necessarily as originally envisaged by product designers and manufacturers. Cynthia described how she had adapted this in-home alert device to enable her to access her garden, marking very clear boundaries from the signal limitations. All other safer walking technologies used within study 2 were ‘everyday’ technologies, easily available and commonly used by the general public.

Table 20 Functions of safer walking technology in study 2

Function	Phone App Google maps	Tablet App Google maps	Tablet App Google Earth	Phone App Map my walk	GPS Sat Nav system	Garmin running watch	Pendant alarm system	Small tracking device	Find my iPhone
Independent way finding	YES	YES	YES	YES	YES				YES
Plan a route	YES	YES	YES	YES	YES				
Find a person	YES	YES	YES		YES				
Smart device	YES	YES	YES	YES					
Locate another person							YES	YES	YES
Record a route				YES		YES		YES	
Record performance data				YES		YES			
Emergency call button							YES		
Direct call to 24-hour call center							YES		

The safer walking technology chosen by the participants in study 2 appeared to place greater emphasis on enabling independence rather than enabling others to track and find them. The devices more commonly used were those which allowed the participants to locate themselves, plan a route or find a specific place.

> ***"Well, well I would say, my schedules, where I'm going next if I've got 2 appointments like I got today I've got that and I can click into it to just remind myself where I'm going and why." (Brian 541-544)***

For many people with dementia, the ability to plan effectively is impaired by reduced sequencing skills and poor short-term memory, even in the early stages when many other cognitive functions are unaffected. The findings in study 2 appear to indicate that for Brian the use of his iPad and the smart capability it had to connect his calendar and apps such as Google maps enabled him to overcome many of these difficulties. The safer walking technology was often adapted to be used in different ways to meet individual needs; sometimes in conjunction with other smart devices or digital planning aids such as iPad calendars. He was happy to demonstrate how he used his iPad during the interview,

> ***"When we're going on holiday or something like that or if I'm visiting somewhere, I've never been before and I'm, I know but I don't know the address where I'm going so I'll put that into Google to see where it is. I probably put it in there, but I will also put my Tom-Tom up to take me there." (Brian 383-387)***

Brian reported using his iPad to plan both the routes to and from these appointments, but also to schedule in and plan the routes for his daily dog walking, family walking holidays and visiting friends. It was clear that Brian used his iPad continuously throughout the day to check and recheck his plans and to guide him when out on his daily walks. In the car, he switched to a sat nav device as well but appeared less confident with using that because it didn't link back to the iPad and his calendar.

A similar preference for a smart device was reported by Ian, who was the youngest participant in the study in his early 50's and living with a recent diagnosis of early-onset dementia. He had access to several potentially helpful safer walking devices but found his phone to be most useful because of its immediate proximity.

> ***"I have got a sat nav but I don't tend to use the sat nav quite as much. Not that I couldn't use it, I just don't find it very much good so I don't tend to use it. But because I've got a phone on me all the time, I find that more useful." (Ian 315-321)***

Ian reported using his phone out of 'necessity' and often used it when walking in a large and remote country park near to where he lived.

> ***"It's quite a big open area and you do sort of need to know your orientation." (Ian 409-410)***

Brian and Ian both used the same safer walking technology to support them when outdoors; yet, they used it in very different ways, demonstrating the need for the technology to be adaptable to the different needs of each individual.

> ***"I find it useful in as much as I can find out a lot about what's around where I am." (Ian 342-343)***

> ***"I like to look at the bigger picture, where I am" (Ian 382-383)***

6.4 What was the safer walking technology used for?

Participants in both studies said they relied on the technology to plan and engage in outdoor occupations that held meaning to them or their loved ones. Many of the participants in study 2 described technology as essential to their ability to continue engaging in those occupations. Participants across both studies described engaging in a range of outdoor occupations from dog walking to marathon training, with 14 occupations identified in total (Table 21).

Table 21 Outdoor occupations supported by the use of safer walking technology

Outdoor Occupation	Participants from study 1	Participants from study 2	Total number of participants
Walking for pleasure	Annabel Barbara Diane Emma Francis Helen Ivor	Edward Hugo Ian	10
Walking with dogs	Barbara Francis Greg Helen	Adrian Brian Edward Fiona Hugo	9
Walking with groups	Barbara Carl	Adrian Fiona Gary Hugo	6
Walking holidays	Annabel Ivor	Adrian Fiona Gary	5
Gardening	Barbara Ivor	Cynthia Edward	4
Walking for fitness	Carl	David Gary	3
Cycling	Emma		2
Bird Watching	Diane Helen		2
Fly Fishing	Diane Greg		2
Golf	Helen Ivor		2
Foraging	Diane		1
Wildlife Rescue	Diane		1
Marathon Training		Fiona	1
Mowing grass meadows		Fiona	1

Many of the occupations identified were undertaken by people with dementia in both studies, with some form of walking as the most popular occupation undertaken by all but one of the participants when using the safer walking technology.

6.5 Key messages from this chapter

- From the interview data in both studies, a range of additional data was identified that was not searched for within the IPA studies, but which highlight several important factors to consider when seeking to understand the use of safer walking technology by people with dementia and family carers;

- A wide range of outdoor occupations were identified by participants within both studies, but by far the most common was walking, including walking for leisure, and dog walking.

- Many people with dementia used their GPS technology in combination with other technology to co-produce the technology that best suited their needs.

The next chapter discusses the key findings from the three studies and how these findings compare to other research within this field.

Chapter 7 Discussion

7.1 Introduction

This PhD thesis aimed to identify how safer walking technology is currently being used and the potential it has for supporting occupational identity and well-being through enabling access to meaningful outdoor occupations for people living with early-stage dementia. The research methodology promoted the collection of findings of an idiographic nature and these represent an in-depth analysis of detailed and wide-ranging interviews with 2 small homogenous groups, exploring the lived experiences of both family carers and people with dementia.

This discussion chapter draws the findings from the previous three chapters and discusses them in the context of the current research and clinical practice in this field. New and original findings are highlighted, and the influence of the research design is discussed. The discussion is then structured around the three research objectives, first set out in Chapter 1, these were:

1. To understand the experience of using safer walking technology from both the perspective of people with early-stage dementia and family carers.

2. To identify which forms of safer walking technology are being used and what barriers and enablers users experienced.

3. To determine the potential role of safer walking technology in supporting occupational identity and well-being through outdoor occupations for people living with early-stage dementia.

7.2 New and original findings

The literature review, described and discussed in chapter 2, highlighted that there is still only a small amount of research on safer walking technology encompassed by the objectives of this thesis, although this appears to be changing rapidly; it also acknowledges that technology reported in the published research is continually developing. Within this thesis, several new findings were identified that have not been reported in previous research studies (Table 22), and that is in part because of the rapidly changing way in which people with dementia are adopting and adapting the way they use this technology. However, this is also because of the unique perspective of this research study, looking at the lived experiences of those who use safer walking technology to engage in outdoor occupations. The new findings in Table 22 are discussed in detail within this chapter, exploring their meaning and implications in the context of the overall research question and objectives.

Table 22 New Findings

	New Findings
1	Safer walking technology has a role in maintaining occupational identity and well-being for some people with dementia through enabling access to meaningful outdoor occupations.
2	The type of technology used depends upon who is the greatest advocate for the adoption of safer walking technology. Family carers and people with dementia appeared to choose very different forms of safer walking technology, as they use the technology differently. Family carers are more likely to choose a specialist tracking device, whereas, people with dementia are more likely to use their smart phones and other mainstream GPS technology.
3	Some people with dementia are creating their own technology solutions by combining safer walking technology with other technology to meet their individual needs.
4	The increased acceptability of wearable technologies and tracking devices, in general, appears to have reduced the ethical concerns and potential stigma associated with wearing and using trackable technologies.
5	There is a need to provide ongoing support whilst a person is adopting and using safer walking technology. Family carers, in particular, identified that the transition point of giving up the technology, creates a particular period of difficulty and feelings of failure.

7.3 The influence of the research design

Within the conclusion of the literature review in chapter 2, several recommendations were made about further research in this field, by identification of gaps in the current research knowledge. This PhD thesis incorporated many of these recommendations and the research design has some influence on the type of findings identified in studies 1 and 2.

7.3.1 Understanding different perspectives

The literature review also recognised a dominant voice of professionals and academics within the existing literature (Bantry White and Montgomery 2014), with only a small proportion of the available literature having consulted people who have used safer walking technology themselves. Studies that focus upon the experience of family carers were present (Liu et al. 2017) but continue to call for a greater evidence base with more empirical research to support the use of safer walking technology. Studies that included the voice of people with dementia were rarer and there were repeated calls for research that sought the views of people with dementia (Liu, Cruz and Juzwishin 2018). In response to these calls, and acknowledging that both people with dementia and family carers were commonly the users of safer walking technology, the studies in this PhD were designed to capture the voices of people with dementia and family carers separately, to understand the different experiences these two groups of people have of using safer walking technology.

Previous research studies, identified in the literature review, have mainly described observational studies (Kwan, Cheung and Kor 2018), or used repeat questionnaires/ surveys (Olssen et al. 2015) with only a few interviewing users directly about their experiences (Oderud et al. 2015). Findings from the studies in the review called for a greater understanding of the needs and barriers to the use of safer walking technology. Both studies in this PhD used in-depth interviews, encouraging the participant to lead the direction of the conversation and using post-it prompts, for the people with dementia, to support short term memory difficulties. The interviews explored these issues from the individual's perspective, providing evidence to confirm the need for greater support to adopt and use safer walking technology. The in-depth interviews also identified a new area of currently unacknowledged need around providing support to give up or stop using safer walking technology. This was recognised in the individual participant analysis and was revealed because of the participant-led interviews and the research focus on the ‘lived experience' of users.

7.3.2 Using safer walking technology in everyday lives

Wherton et al. (2018) called for research to focus on how safer walking technology is used in real-life contexts; Wherton et al. (2018) explored the use of safer walking technology as part of a small technology trial or specific local provision, where the technology used was predetermined by the researchers. Both studies 1 and 2 of this PhD recruited participants who were already using a form of safer walking technology and consequently saw a diverse group of participants from a wide range of socio-economic backgrounds, urban and rural settings, and with differing access to locally provided services. This thesis differs from the previous research identified in Wherton et al.'s review as it did not start by designing the research around the technology, but instead focussed on the people who used it. By designing research that was less prescriptive about the safer walking technology, a more varied picture emerged in this PhD, giving a contemporary overview of the types of safer walking technology being used; and this revealed new information about the use of safer walking technology. For example, within the existing research, reviewed in chapter 2, only one study identified that every day smartphones could be used by people with dementia as safer walking technology and yet this PhD identified that this smartphones are already being widely used by people with dementia in this study.

7.3.3 A person-centred design

Within the literature review, Oderud et al. (2015) identified the need for research in this field with a more person-centred design. The studies within the PhD were therefore incorporated a person-centred approach within their design; this included the formation of a 'Stakeholder Advisory Group' (SAG) to co-design aspects of the research, including data collection tools and advertising materials. One key outcome of the SAG involvement was the creation of accessible advertising materials. Consideration was given to how people with dementia process written and oral information. Even in the early stages of dementia, many people report difficulties with reading and retaining information from written documents (Gold et al. 2004). To ensure the research study information in this PhD was accessible to all potential participants, a recruitment video was created for use across multiple platforms, (Appendix 13). The use of a recruitment video proved to be extremely popular with participants, with all but one of the participants stating that watching the video had a significant impact on their decision to volunteer to take part in the research. Within the video the researcher appealed to people who regularly engaged in outdoor occupations using their safer walking technology to volunteer and therefore influenced the type of person recruited. Heath, Hindmarsh, and Luff (2010: 109) argued that, when used within social research, video can be highly engaging and is often underused. This innovative recruitment strategy also enabled greater sharing of the research information across digital platforms including both social media and the JDR database.

7.4 The experiences of using safer walking technology

The first objective of this research sought to gain a general understanding of how safer walking technology is used and experienced: To understand the experience of using safer walking technology from both the perspective of people with early-stage dementia and family carers.

Each interview analysed as part of this research expressed the complex and often unique experiences of the participants, as they sought to use safer walking technology to enable meaningful outdoor occupations. The types of technology and range of occupations engaged in varied from person to person, but some patterns and similarities emerged from the data within the analysis. The two different participant groups interviewed in studies 1 and 2 described very different experiences of using safer walking technology and it became apparent that there were notable differences. Key differences are discussed in the following section, which is divided into three main areas of discussion:

- Motivations to use safer walking technology.
- Different types of safer walking technology.
- Use of bricolage.

7.4.1 Motivations to use safer walking technology

Despite the evolving technology in this field, the findings from this research indicate that the main motivators to initially adopt safer walking technology remain the same as those seen in the existing literature. For all the people with dementia interviewed in study 2, and most of the family carers in study 1, the decision to start using safer walking technology was undertaken following an incident where the person with dementia became lost in a normally familiar environment. The findings of study 1 indicate that carer reassurance also remained a significant factor in the decision to use safer walking technology and illustrates the importance carer participants placed upon the reassurance this gave them as family carers.

The literature review, in chapter 2 indicated that the two most common reasons for considering safer walking technology were to reduce the risk of a person getting lost (Pulido 2017) and to improve the wellbeing of the carer (Bantry White and Montgomery 2014); he use of safer walking technology to offer reassurance to family carers featured prominently as a reason for adopting it (Neubauer et al. 2018) and for its continued use (Dale 2010). Within study 1, most participants felt such reassurance as they could locate their relatives in the unlikely event that they became lost and disorientated when away from the family home. Although these ‘getting lost' instances are reported to be rare (Pulido 2017), the potential harm and risk to the person with dementia was considered high by the family carers in study 1. Some participants in study 1, (Ivor and Francis), describe the reduced personal anxiety and reassurance they experienced, even though neither participant had ever actually had to use the safer walking technology to find their relative when lost. For other participants in study 1, (Helen and Barbara), they were reassured by their regular use of the technology to ‘check-up' on and communicate with their relatives whilst that person was out on their own. However, Gabriels (2016) described how electronic monitoring has the potential to erode family carer's time and through electronic monitoring, family carers can be continuously responsible for the safety of their relatives. Bantry White (2018) therefore warns that safer walking technology also has the potential to increase the ‘burden of responsibility' on family carers, as they feel an additional responsibility for their family member, even when they are not physically with them. Research by Oliveira, Sousa, and Aubeeluck (2018) indicates that having time away from their role as a carer is an important factor in maintaining a good quality of life for family carers of people with dementia. Barbara and Helen both reported that they were keen to have some time away from the person they cared for but felt more willing to monitor their relative using the safer walking technology than to leave them with respite carers. Barbara doubted the carer's ability to maintain her husband's safety and preferred to hold responsibility for his whereabouts, yet also highly valued the opportunity to have time to herself. Understanding how family carers experience safer walking technology promotes a greater understanding of how they manage their own personal challenges and the benefits derived from the safer walking technology, adapting and using the technology to meet their individual needs. This is in keeping with Hill, Yeats and Donovan’s (2018) call for a greater understanding of the challenges to partners of people with dementia - they argued that there is a greater need to recognise the relational challenges of ‘couplehood’ in dementia and advocate for a more joined-up approach to supporting people with dementia and their family carers, acknowledging both their needs as individuals and the needs of their relationship.

Of the nine people with dementia interviewed in study 2, six had previously become temporarily lost or disorientated in a familiar place. The fear of getting lost or negative associations with the previous experiences of getting lost seemed to play a significant role in the decision to seek out and use safer walking technology. However, very little of their discussion was focussed upon these experiences or the anxieties created by them. Study 2 also found a notable absence of discussion by people with dementia around the benefits of using safer walking technology for family carers. People with dementia within study 2 used safer walking technology to locate themselves, and to find their way around, rather than the traditional role of family carers using it to track them. All but one of the participants in study 2 omitted to talk about the technologies potential to be used as a tracking device for others to use. This is in contrast to the current narrative in the research literature which repeatedly identifies the role of technology in providing carer reassurance and peace of mind to the family carer using the tracking function (Bantry White and Montgomery 2014). Whilst acknowledging the risks of getting lost, the people with dementia interviewed in study 2 chose to spend significantly more time on discussing the empowering uses of safer walking technology to way-find, locate or navigate themselves independently when outdoors.

For all nine of the participants in study 2, the technology was used independently of their family carers and as a tool to enable them to feel reassured or reduce their anxiety about the potential for getting lost. This suggests that some people with early-stage dementia are using safer walking technology to take responsibility for independently managing their health and well-being. For some people with dementia, safer walking technology also gives them the opportunity to self-manage some of the risks associated with successfully navigating outdoors. The emphasis within all the interviews in study 2 was around ‘self-management' and people with dementia being responsible for safeguarding against ‘getting lost' incidents themselves. Participants wanted to be able to find their way, and the safer walking technology they used offered them both a practical ability to do this and an increase in overall confidence when outdoors. Within the literature review in Chapter 2, only one research study (Kwan, Cheung and Kerr 2018) explored the potential for safer walking technology to be used to ‘way-find', and none of the literature explored the independent management of risk by people with dementia themselves. However, the findings of this PhD do echo the findings of Bartlett and Brannelly (2019) who sought to understand how people with dementia experienced and dealt with vulnerability when outdoors. In their research, Bartlett and Brannelly (2019) describe how people with dementia attempt to independently manage anxieties and risks when outdoors, to avoid carer burden. It appears that independence and autonomy when going out are important factors for some people with dementia and demonstrate why some of the alternative risk management strategies identified in the literature, such as accompanied walking groups (MacAndrew et al. 2019) would be unsuitable for these individuals.

For many of the people with dementia interviewed, engaging in outdoor occupations was crucial to how they maintained their well-being. Although it should be acknowledged that the recruitment video used to recruit some participants intentionally sought out people who engaged regularly in outdoor occupations. Personal narratives and first-hand accounts of living with dementia, such as blogs (e.g. Mitchell 2019 available at www.whichmeamitoday.wordpress.com), often identify a desire to 'live well' with their dementia Carers and health professionals are also encouraged to promote healthier lifestyles; this is seen in both government strategies, such as 'Living well with dementia: a national dementia strategy' (Department of Health and Social Care 2009) and The Alzheimer's Society guidance 'Staying healthy with dementia' (Alzheimer's Society 2019). Although the provision of assistive technologies to increase independence, choice and autonomy have featured in the wider literature and policy for some time, the literature review in chapter 2 demonstrated that, only recently has this been framed within the discussions around safer walking technology. Alongside the introduction of a more person-centred approach to dementia care, there is also a wider policy narrative around 'responsibilisation' associated with some assistive technology provision. This is in part a shift in public health and social care policy that revolves around the notion of 'choice', which appeals to citizens' free will to make healthier and safer choices, reducing their own risks and therefore the need for increased state provision of health and social care services (Peeters 2013). The benefits of this movement, incorporating the provision of assistive technologies in the wider context, are to give greater choice and so ultimately more control to people with disabilities. People with dementia interviewed in study 2 repeatedly emphasised their desire to access outdoor occupations to maintain their own health and well-being, often describing the physical, mental and spiritual benefits of getting outdoors; they articulated a need to take responsibility for their own health and argued that safer walking technology gave them the tools to do this independently, placing significant importance on the health and wellbeing benefits they gained from using their safer walking technology. Yet a representation of people with dementia using assistive technology to take responsibility for their own health and well-being is absent from the research literature reviewed in chapter 2. The same can be argued for the notion of self-managing potential risks associated with dementia, despite the policy shift towards greater consumer ‘choice'. More traditional viewpoints in this field often assume a lack of awareness or understanding about risk-taking, even in people with early-stage dementia (Paillard-Borg et al. 2009,) or a lack of insight into the potential dangers that outdoor occupations might hold (Zanetti et al. 1999). Yet, within study 2, participants with dementia clearly articulated their understanding of the risks around getting lost and sought to use their smartphones and other safer walking technology to navigate outdoors; they also put into practice strategies to minimise the risks they were exposed to and supported positive risk-taking. This type of behaviour and this way of using safer walking technology is previously unacknowledged in the research literature, although the researcher was able to reflect that she had seen similar self-management behaviours in clinical practice.

It should be noted that not all participants in study 2 wanted to take responsibility for all aspects of their health and well-being and the benefits they sought varied from person to person. The existing evidence around assistive technologies being used within the implementation of responsibilisation policies is mixed, and practical implementation of these policies has come under considerable criticism (Wilberforce et al. 2011, Vrangbaek et al. 2012). A policy analysis review by Steel (2019), in Australia, showed that assistive technology provision is often interpreted through an economic discourse, even when it was intended to provide greater choice and autonomy. Steel found that the presumptions about capacity and willingness to take responsibility, that came with the policy interpretation, led ultimately to decreased choices for individuals in practice. Dennhardt and Rudman (2012: 127) also argue that the increased emphasis in government policy to ‘self-manage’ risks fails to adequately understand how these policies impact on the everyday lives of real people nor take into account the individualistic nature of people’s experience. Further research is needed to understand how best to design and use safer walking technology to meet the needs of people with dementia who wish to use the technology to autonomously manage their own needs, whilst acknowledging that this is not the ‘right’ solution for all.

7.4.2 Different types of safer walking technology

The findings of this PhD indicate that family carers and people with dementia are likely to choose to adopt very different forms of safer walking technology when they are the one leading the adoption of technology, as they use the technology differently. Participants for both studies were recruited during the same time period and often through the same gatekeepers and recruitment methods, yet the difference in technology choice was consistent across both participant groups. It should also be noted that the family carers and people with dementia interviewed for studies 1 and 2 respectively were not related and there was no connection between any of the two groups or people interviewed. Because There were clear differences in the types of safer walking technology being used between study 1 and study 2 and this may reflect the individual needs of both the person with dementia and their family carers. The family carers actively led selection of technology in study 1, and the people with dementia in study 2 led selection of their technology rather than carers.

Family carers seemed more likely to select and use a ‘purpose-built' tracker, marketed or provided to specifically support people with dementia, whereas people with dementia were more likely to use smartphones or other mainstream GPS technology in common use by the general population and adapt it to their individual needs. The reasons behind this difference in technology used between the two groups were not clear but are likely to be complex. It is possible, that for some, the restrictive prescribing criteria around traditional assistive technologies and safer walking technology could play a role in this. Particularly where technologies are only provided to manage an identified and already established risk. (This was observed in study 1 where several family carers reported being unable to gain access to such technology until their family member had already experienced an incident of getting lost that involved a police search). Further exploration of the potential barriers to the use of safer walking technology is discussed in the next section of this chapter.

The current range of dementia-specific safer walking technology available through social services or private purchase remain grounded in the narrative of managing risk and offering reassurance and safeguarding, (Maze and Hunt 2018) framing the person with dementia as the vulnerable person who requires protecting. The family carers in study 1 all used a device designed expressly to track a person with dementia or locate them when lost. These carers felt a great responsibility towards their family members and sought to ensure greater protection against potentially risky situations such as the person getting lost. Such findings have also been highlighted in other studies explored within the literature review in chapter 2 (Neubauer et al. 2018, Dale 2010). The findings of study 2 appear to indicate that some people living with early-stage dementia want a greater level of independence and empowerment from the safer walking technology and so are seeking to be enabled rather than to be protected. As identified in chapter 1, the diagnosis of dementia now occurs increasingly early in the condition's presentation (Smith et al. 2018) and people with dementia may not associate themselves with the typically understood experiences of people with more moderate or advanced dementia. Within this context, the traditional safer walking technology that allows others to track a person offers very little to people living with the early stages of dementia and so does not appear to meet their needs.

The findings of study 2 showed that people with dementia adopted a form of technology they already had access to that they could use for safer walking purposes; this was usually their smartphone, tablet or other smart devices with GPS capability. Earlier research in this field (Cahill, et al. 2007, Rosenberg, Kottorp and Nygard 2011) also identified the importance of familiarity with technology, emphasising that a minimum of new learning should be required of the person with dementia. It is not clear if the people with dementia in study 2 wished to maintain the use of familiar technologies to avoid the need to learn new skills, as this was not described by participants, and they often had to learn to use the technology very differently than previously to enable it to work in this way. It is not known exactly how many people with dementia are now using different forms of mainstream technology as safer walking technology, but it appears from the difficulty in participant recruitment to this study that adoption rates in general, remain low, in part due to lack of awareness or challenges in accessibility (including financial) and support. Astell (2019) argues that adopting mainstream technologies raises important questions about funding and finance, as many consumer devices (e.g. smartphones) are not classified as assistive technology and therefore cannot be 'prescribed' by clinicians. This makes them unobtainable for those without the financial means to purchase them privately. Yet, with the wide-ranging use of smart phones and inbuilt GPS technologies, it may be that such devices are more likely to already exist within many people's homes as part of their everyday lives. Which indicates the need for wider training in how people with dementia could use these tools that they already have, with new aps on smartphones they are already familiar with.

7.4.3 Bricolage

Another challenge faced by participants within this thesis was the limitations of the safer walking technology they used. For many, the technology did not provide the exact combination of functions that they needed or was limited to use for only one aspect. Participants demonstrated several innovative ways in which they used their safer walking technology to compensate for the difficulties they experienced because of their dementia. This innovative use of multiple technologies is known as 'bricolage' (Greenhalgh et al. 2013) and challenges the failure of technology manufacturers and others to offer technology that can be customised and adapted by users. Originally derived from the French term for 'Do it yourself or DIY' (Oxford French Dictionary 2009), the Oxford dictionary defines bricolage in English as "Something constructed or created from a diverse range of things" (Oxford English Dictionary 2003). Gibson et al. (2018) found that people with dementia or their carers use bricolage to overcome challenges where assistive technologies are inadequate or unavailable to meet their needs. He describes how people manage with bricolage by adapting assistive and everyday technologies in dynamic ways according to their lived experience and their current needs. Such adaptations can be simple or complex, depending upon the situation and needs of the person. Examples given range from sticking tape over a button to reprograming smart devices.

Although examples of bricolage in other forms of assistive technology are common, it has not previously been seen in the research evidence for the use of safer walking technology. Study 2 identifies several bricolage examples of people with dementia using GPS technologies in conjunction with other technology to combine the information, guidance or functionality to meet their individual needs. For example, one participant with dementia (Fiona) combined the use of a digital running watch, her smartphone and home computer, which allowed her to plan, map and review her marathon training, this was a task that she felt she would otherwise have been unable to do. Each device supported a different task, but none could individually provide her with all of the functionality that she required. Although it could be argued that this combination of technologies highlighted the lack of a ‘specific technology’ currently designed for her needs, it is unlikely that there would be a large enough market for the development of an off-the-shelf running or marathon training technology designed specifically for people with dementia. Bricolage allows users and family members to take the initiative in ‘co-producing' the technology solution to suit their unique needs (Proctor et al. 2013). Research by Gibson et al. (2015) also acknowledges bricolage as a common feature in the use of more general assistive technology by people with dementia and their family carers. However, this approach to technology adoption does have potential difficulties. One participant in study 2, (Cynthia), who used her telecare pendant alarm to access the small part of her garden that was in the range of the base box located in her house; this enabled her to feel reassured and increased her confidence in going outside. However, although she would have been able to press the call button to alert the call centre that she required assistance she would not have been able to speak directly to the person at the other end, which could have led to an inadequate or delayed response from the call centre in an emergency.

The universal design (Mace, Hardie, and Place 1990: 157) and usability of modern smart technology have made safer walking technology potentially more accessible to people with dementia. In research around the acceptability of assistive technologies by people with disabilities, Vanderheiden (1998) suggested that both assistive technologies and mainstream products offer advantages and disadvantages in accommodating the needs of people with disabilities. Vanderheiden argued that the best solution may be a combination of the two, using universal design wherever possible and practical, using assistive technologies wherever it provides sufficient additional advantage to the user. The current mobile phone app market may offer this exact combination where the universally accepted hardware of smartphones and tablets could be combined with the more bespoke and niche software apps that can communicate and interact with each other to meet the individual requirements of the user. In a review of research where mobile phone apps are used as a support tool for people with dementia, Klimova, Bouckova and Toman (2018) identified a wide range of phone apps being designed and used by people with dementia, but only a small proportion of these were being used to support engagement in meaningful activity. At present this market has primarily developed apps to support diagnosis, treatment, and monitoring of health data (Astell 2019). There is, therefore, the future potential within the app market to further develop more bespoke solutions to meet the needs of individuals that allow the easy combining of apps and devices.

7.5 Barriers and enablers to successful safer walking technology use

The second research objective within this research sought **to identify what barriers and enablers were experienced when using safer walking technology**

Within this PhD, participants were keen to discuss the challenges they had experienced using safer walking technology. They provided detailed accounts of their experiences and the often complex and individual circumstances in which they used the technology. The findings of this research indicated that it is possible to overcome some of these difficulties to enable more effective and wide-ranging use of safer walking technology. Therefore, this section offers a discussion of the main issues raised by participants across both studies and is divided into three main areas:

- Adopting safer walking technology.
- Using and giving up safer walking technology.
- Stigma and ethical concerns associated with safer walking technology.

7.5.1 Adopting safer walking technology

The findings from study 1 highlight that family carers seeking to privately purchase safer walking technology lacked awareness of reliable sources of information about what technology was available, its function and how to select the most appropriate product for their needs. Lack of advice on how and when to use safer walking technology appeared to feature in almost every participant experience within study 1. In most cases, family carers felt responsible for the selection, organisation, and management of safer walking technology; with a mixed market of private purchase and social services provision this was a complicated role to undertake. In has been estimated that only 44% of people in the UK with dementia receive a formal diagnosis, (Alzheimer's Society 2019) and the majority of those who do have a diagnosis are only seen within primary care services (Department of Health 2009) with their health and welfare monitored by their general practitioner. Therefore, not all people with dementia and their families have direct access to specialist health and social care professionals who might advise on these issues.

In response to this need for information, the UK Alzheimer's Society has published a statement on their website about the use of safer walking technology and has a regularly updated guide to support a selection of the most appropriate assistive technology products in general. Both the safer walking statement and general assistive technology guide are freely available on their website at www.alzheimers.org.uk. Another useful resource freely available to people with dementia and their families is the website AT dementia, www.atdementia.org. This site seeks to provide independent, accessible information on assistive technologies for people with dementia, families, and professionals, (Burrow and Brooks 2012). The consumer advice company Which? also features a general advice page on the use of GPS trackers and although one participant was aware of this, they had been unable to access it online as it was a subscription service and they were reluctant to subscribe. (www.which.co.uk). However, none of the participants in either of the studies in this research had accessed any of these guides or been made aware of them by health and social care practitioners. Most family carers in study 1 reported having no information about the variety of technologies available. If they had reviewed any information before adopting a form of safer walking technology, they had taken advice from family friends, and used manufacturer or retailer websites. Much more prevalent than independent guides online are the sales pages of competing commercial GPS trackers which focus heavily on the 'reduction of risk' and make a range of unsubstantiated claims about the usefulness of the products they sell (Vermeer, Higgs and Charlesworth 2018). One participant, (Ivor), described how he wanted 'the best' tracker and so bought the most expensive one he could find on the market, with the most functions, but later found it too complicated to set up whenever they changed locations and the negative experience of 'failing' to use the technology harmed his confidence in using technology in the future. Another participant, (Diane), found that poorly selected technology led to both the raising and then subsequent dashing of hopes for improved access to outdoor environments for her husband. This experience was both disappointing for her as a carer but inflicted real emotional harm to her husband. This raises real questions around the ethical issues surrounding the poor provision of guidance and advice in this field. If the use of safer walking technology is to be encouraged as an empowering tool to enable greater independence, rather than just as a risk management strategy, then greater support is needed to provide easily accessible, reliable and up to date information to support the decision-making process for those individuals not currently engaged directly with services. Almost all the articles identified in the literature review in chapter 2 considered how health and social care professionals can best support people to make decisions about the use of safer walking technology. Previous research demonstrates the need for a more active role to be played by professionals in the decision-making process about the use of safer walking technology and Landau et al. (2011) called for a clearer 'family decision-making process,' facilitated by professionals. The findings of study 1 show that despite consistent calls from the research literature (Werner and Landau 2011, Miller, Whitlach and Lyons 2014, Bantry White 2018), this is still not happening in practice.

For those accessing technology through adult social services, the quality of information and advice also appeared very variable, with Carl describing being provided with safer walking technology by an early onset dementia team long before his wife needed it, yet Emma found it almost impossible to get the same technology provided in the same county because of what appeared to be short-sighted prescribing criteria in the main social services team. This seemingly unfair system leads to even more potential for harm as family carers interviewed within study 1 felt their relatives were 'set up to fail'. Several of the participants found the person they were caring for was prescribed safer walking technology through social services with little or no consultation of the carer. For these participants, the technology was imposed upon them with little or no collaborative decision making, yet the ultimate success of it's use rested on the carers ability to manage and use the technology to support the person they cared for. Family carers were expected to undertake complex and demanding roles in maintaining and managing the technology with limited support or recognition of this role. Findings from study 1 indicated that the reasons for not routinely involving family carers in decision making are complex and individual to the circumstances of the person. The provision of assistive technology to people with dementia should, according to Sugarhood et al. (2014)

and others (Greenhalgh 2018, Pols and Willern 2010), be considered as a complex intervention, requiring a detailed individual assessment (Woolham 2018). In the findings of the UTOPIA project, Woolham et al. (2018: 48) advised that involving family carers as fully as possible in the decisions about providing assistive technology such as telecare may reduce the risks of the technology being subsequently abandoned. This suggests that greater inclusion of family carers in the decision making around the provision and required support to use safer walking technology would also reduce potential early abandonment of the technology. Research from the wider assistive technology landscape (Verza et al. 2006, Johnston and Evans 2005) reinforces this, indicating that a lack of confidence in the device by family carers or service users is also frequently associated with technology abandonment.

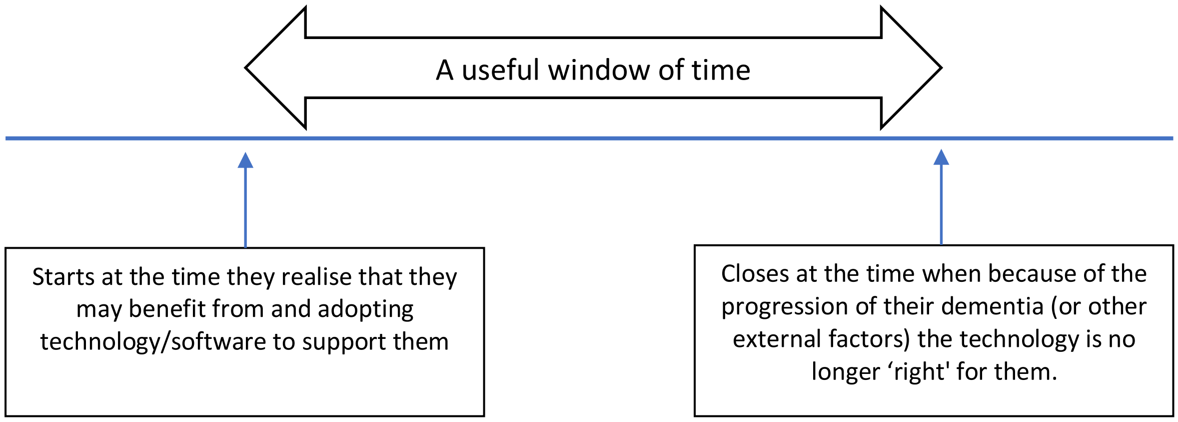
7.5.2 Using and giving up safer walking technology

Once safer walking technology was introduced, family carers in study 1 reported that the responsibility for maintaining the safer walking technology often fell to them. Such maintenance included daily activities such as charging batteries and setting up systems and routines for the person with dementia to follow and also involved more complex roles, such as using computer software or apps to log in and track the person if needed. Several of the participants reported that the safer walking technology was difficult for them to manage and build into their routines. Within the literature review in chapter 2, a number of research studies were identified that sought to understand the factors which increased the acceptance of safer walking technology (Liu et al. 2017) and other forms of assistive technology (Yusif, Soar and Hafeez-Baig 2016, Heuvel, Jowitt and McIntyre 2012) by people with dementia. There is also a small, but growing, call to improve ongoing support to use safer walking technologies (Bantry White and Montgomery 2016, Stupple, Marks-Maran and Morrris-Thompson 2015). The experiences of participants within this thesis indicates that there is a need to provide ongoing support whilst a person is using safer walking technology. Within study 1, family carers discussed the importance of developing routines to enhance the person's ability to learn new skills when adopting new technologies. This is a widely reported feature of assistive technology and is a common practice within occupational therapy and social care settings. The challenges of learning new skills were also acknowledged by some people with dementia interviewed in study 2, who reported finding it harder to adopt new habits and technologies. The current nature of assistive technology as an ever developing and changing tool makes this a particularly challenging issue for people with dementia.

Within study 2, the majority of the people interviewed used their safer walking technology without assistance or support from others. However, for some participants, the role of family carers in setting up and ongoing ‘tech support' was vital to their use. The findings of study 2 demonstrate that even where safer walking technology is being used independently by the person with dementia, they may continue to rely upon family carers to support its use, whether this was to ensure regular charging of the devices, software updates or problem-solve technical issues. This ‘hidden work’ undertaken by carers and associated with the use of assistive technology, is largely unrecognised within the field (Gibson 2019:67) and for many people with dementia may be key to the ability to continue using safer walking technology. Research by Gibson et al. (2015) identified similar difficulties experienced in maintaining assistive technology use by family carers of people with dementia. Gibson et al. (2015) also found that family carers played a key role in facilitating the integration of assistive technology into the usual routines of their relatives by undertaking much of the everyday suport required to ensure their habitual use; this mirrors the reported experiences of the participants in study 1 who found the requirements for them to ‘manage' the technology for the person they cared for either confusing or burdensome. For some, this was because of the lack of support in setting up and learning new skills or because of a lack of continued support as the person with dementia’s needs changed.

Within study 2 several of the participants expressed concern or reported difficulties with software and hardware updates when using smartphones, tablets and other forms of smart technology. For example, David was using an older mobile phone handset (a blackberry phone) which contained an early version of the locating apps. The functionality of this was poor and the street maps and other information no longer updated; he had fallen behind with the current generation of smartphones, and now felt unable to take on new technologies, despite describing himself as an ‘early adopter' of new technology in his earlier working life; this experience impacted David’s image of himself as a competent technology user. Research in the wider assistive technology field (Rosenberg, Kttorp and Nyard 2011) identifies the importance of recognising and maintaining a person’s self-image as significant to successful technology use for people with dementia. David's experience highlights how regularly evolving technologies such as smartphones, have the potential to cause great uncertainty and difficulties for people with dementia, who may need to develop routines and habits around using them. The nature of app-based products means that frequent updates may change the look or process of operating them; this caused difficulties for some participants, who found it harder to learn how to use new techniques or ways of accessing the app. Research into how to make apps more accessible for people with dementia is in its infancy, but issues around the impact of updates and other areas of difficulty in the digital divide are being explored (Joddrell and Astell 2013, Astell 2019). For some of the participants in study 2 this eventually led to them feeling frustrated and reduced their confidence in their abilities to use such technologies; for others, the constant need to update or upload information between devices led to a heavy reliance on family carers to support them to maintain the technology. This can be true of many other forms of assistive technology where the 'usefulness' is limited within a time period, as the technology may not have the potential to be adapted or to change how it is used as the person's individual needs change (Figure 15). Within this PhD, both people with dementia and family carers recognised and discussed the essential 'window of time' during which safer walking technology is likely to be useful to them or their family members. As well as identifying the right time to introduce such technology, participants also talked about their experiences of 'giving up' or naturally abandoning the safer walking technology when it no longer served a useful purpose; this appears logical given the inevitable deterioration in cognition and sensibility arising from dementia and its gradual impact upon the functional abilities of the person using the technology.

Figure 15 Useful window of time



There is no identified literature in the review in chapter 2 to support the transition to 'giving up' safer walking technology or identifying where the 'useful window' ends. This leads to a potential period of transition where the once useful technology meets the changing for the needs of the person. Family carers in study 1 all describe how the person they cared for began to struggle to use the safer walking technology they were using. The impact of this transitional period of difficulty is unknown; and at the time of interview all participants who came forward for study 1 were no longer using the technology to support the person they cared for, all reported experiencing a period of difficulty and natural abandonment. Despite these difficulties, the participants had a unanimously positive view about the use of safer walking technology for people with dementia. There is a paucity of information about support to stop using or give up safer walking technology or assistive technologies in general. Findings from this PhD indicate that when safer walking technology is no longer useful it can hinder a person's engagement in meaningful occupations or cause them considerable distress or harm. This is supported by comparison with evidence from the field of driving cessation research, which indicates that experiencing a significant reduction in the ability to get out and engage with current occupations can have a devastating impact (Strogatz et al. 2019) , especially for older people and those with dementia (Scott et al. 2019). With much of the research literature explored in Chapter 2 focussing on the acceptability of technology in the beginning or debates around the ethical nature of tracking, ethical considerations of the harm poorly suited technology or the effect that the cessation of using the technology can have has been largely overlooked in research and guidance, and therefore potentially in the provision of services and clinical practice.

7.5.3 Stigma and ethical concerns associated with safer walking technology

The literature review in chapter 2 highlighted consistent discussions around the ethical nature of the technology that can track a person and the potentially stigmatising effect of wearing or carrying this technology, with this issue often dominating the literature in this field (Hughes and Campbell 2003, Landau and Werner 2012, Neubaur et al. 2018). The findings of this PhD indicated that the family carers in study 1, appeared to have only limited concerns about stigma and did not express concern about the ethics of tracking. It has previously been recognised that in practice, health and social care professionals are far more likely to raise concerns about these issues than people with dementia or their family carers (Dahl and Holbø

2012). These differences have been attributed to factors such as 'balancing the weight of risks. e.g. that it is less restrictive to be tracked than to be locked in, or that people with dementia and family carers generally take a more pragmatic view of such technology (Bantry White and Montgomery 2012). However, within the participant interviews for study 2, there was some limited evidence to suggest that people with dementia were reluctant to adopt what they saw as potentially stigmatising technology designed specifically for the needs of people with dementia. They, therefore, rejected these kinds of specifically marketed assistive technology in favour of mainstream technology. This may also be partially due to the pragmatism of using something they already have, even if for a different use.

In a literature review which looked specifically at 'ethical issues identified in the literature about older people's use of assistive technologies', Zwijsen, Niemeijer, and Hertogh (2011) found that older people and their caregivers often saw assistive technology as being designed for frail and dependent, rather than healthy and independent people. The wear or use of a device is often viewed as a symbol of frailty and dependence and is therefore stigmatising (Coughlin et al., 2007, Faucounau et al., 2009). Yet, in recent years the increasing popularity and acceptability of every day, wearable technology has changed the public perception of safer walking technology and monitoring. Tracking our bodies, movements, and emotions, wearable devices have been incorporated into homes, workplaces, and are an accepted part of 'everyday life' for many (Elman 2018). Forbes projects that the global wearable technology market will generate 34 billion US dollars by 2020 (Lamkin, 2016). The greater acceptance of wearable technologies presents a potential opportunity for people with dementia, by enabling them to continue to engage in outdoor occupations that hold meaning for them, without the fear of stigmatisation. In addition to the inclusion of wearable technology in everyday life, the use of GPS tracking and locating technology has also become more accepted as a form of getting around in mainstream society. Therefore, stigma and concern about the use of this technology to way-find because of a disability appears to have also reduced.

Meiland et al. (2017) completed a systematic review of literature on ethics and found that within the wider assistive technology literature issues were described in terms of ethical dilemmas and could be categorized into 2 areas of discussion: The first was about obtaining informed consent to use assistive technologies for people with dementia; the second was about privacy and respect for autonomy versus safety and minimising risks. The second of these categories reflects the earlier findings of the literature review in chapter 2, which found that issues of autonomy versus risk featured heavily within the safer walking technology literature, particularly during the earlier period of literature collection (2008-2013). Within the published literature on safer walking technology, high importance appears to have been placed on considering ethical issues of privacy, (Landau and Werner 2012, Wherton et al. 2018) yet this is not mirrored in the views expressed by participants in either study 1 or 2. In study 2, this may also be because the way in which safer walking technology is being used, by participants in this study, to way-find rather than track. The one research study within the literature review in chapter 2 that also focussed on wayfinding (Kwan, Chung and Kerr 2018) had a notable lack of discussion around ethics compared to other research within the review. For the participant experiences examined within studies 1 and 2, there is evidence to suggest that there is also a much more pertinent ethical issue that should be explored. This is the potential harm that incorrect provision or lack of support to use a technology may cause and how to protect against this, as discussed earlier in this chapter (section 7.3.1). The experience of participants within this PhD research indicate that protective factors might include the provision of accurate information, skilled assessment, good matching of need to technology, intensive monitoring for a few weeks after installation or first use and an efficient social response, but there is no research in this area yet to explore these protective factors in detail. There is also little or no published literature on this ethical concern in general and it does not appear in the ethical considerations of any of the small-scale research studies or case studies published in this field and discussed within the literature review chapter.

Ethical issues around privacy have not necessarily been removed by the evolving design and use of the technology, but instead, they are changing. Smartphones and other GPS locating devices have the potential to generate significant volumes of data about those wearing them. Whilst some researchers (Czarnuch and Astell 2019: 180) recognise the potential use of ‘mining this data’ in dementia research, concerns have also been stated about the nature of data use, storage and data security, (Rosenfeld, Torus and Vahia 2017). This highlights questions about who potentially access to the data has being collected by the safer walking technology devices. None of the participants in this study spoke about these concerns and so it is unclear whether they were aware of these risks, or if they were happy to accept these risks as the price to pay for being able to benefit from the 'digital revolution', and if the risk outweighed the benefits obtained within their mainstream lives. However, it should be noted that the potential privacy risks around the 'big data' being collected through devices such as smartphone GPS locators are not unique to the experiences of people with dementia. In the wider social commentary, there have been repeated calls for greater transparency, regulation and public awareness of how this data is being collected and used (Information Commissioners Office 2010), with warnings that the UK, in particular, is 'sleepwalking into a surveillance society' (Graham 2010). Further research in this area is needed to determine the views of both family carers and people with dementia on this issue and to determine if there is an adequate level of awareness around these issues with all stakeholders in this industry, including developers, health and social care providers and professionals.

7.6 Safer walking technology supporting occupational identity and wellbeing

The third research objective within this research sought:

To determine the potential role of safer walking technology in supporting occupational identity and well-being through outdoor occupations for people living with early-stage dementia.

This final section of the discussion explores: how the relationship that some people with dementia have with natural environments, and the meaningful occupations they engage with, to enable them to express their identities; how findings indicate that people with dementia are using safer walking technology to support their health and wellbeing through the maintenance of their occupational identities. The following section is divided into three main areas of discussion:

- The restorative effect of woodland and green spaces.
- Usage of safer walking technology to maintain occupational balance.
- Support of occupational identity and personhood.

7.6.1 The restorative effect of woodland and green spaces

Maintenance of connections to nature and the restorative effects of woodlands and green spaces were the most highly reported benefits of using safer walking technology for people with dementia across both studies of this PhD. As discussed in the introductory chapter, research suggests that connectedness with nature and the outdoors has an important role in maintaining well-being (Barton and Pretty 2010) particularly for people with dementia (Gilliard and Marshall 2012:11). Connectedness to nature has been identified before in the dementia literature but it is important to note here because of the focus of this PhD on the ‘lived experience' (Smith, Flowers and Larkin 2009: 2) of participants and hearing about this issue from their own perspective. People with dementia in study 2 identified their primary motivations for using safer walking technology as being to gain access to outdoor environments and spend time in nature; several of the participants with dementia described their love of nature and the outdoors. As seen in the following quotation from David:

“*It gives me pleasure. I love seeing things grow, I love trees. I love growing things from seed. It’s difficult to say, really. I love birds, I do a lot of bird-watching. I just like being outside”.* (David page 197- 200)

This strong affinity to outdoor spaces and nature is a recognised phenomenon and is known as Biophilia (Wilson 1984: 1), which, as outlined in the introductory chapter, is described as an instinctive tendency to make contact with nature. This aspect of the participant's personality influences the way they choose to spend their free time and aspects of their personality and self-identity. Descriptions of connecting with nature and natural environments are present in all the interviews in study 2 and reflect the common characteristics in this group of volunteer participants. This would appear to indicate that at present, people with dementia seeking to use safer walking technology are more likely to share these same characteristics.

The experience of family carers also highlights how for some people with dementia, urban and ‘man-made' environments are challenging and anxiety-provoking, whereas being outdoors in natural environments were often viewed as a place of safety or a kind of sanctuary. Chalfont (2006) identified the positive impact of nature-based activities, but also emphasised the important role that family play in enabling people with dementia to maintain a connection to nature. The findings within study 1 indicate that family carers saw the safer walking technology as key to enabling them to support this connection to nature; they discussed the potential benefits to the person's health and well-being through both enabling connectedness to nature and maintaining meaningful occupations.

A large number of the family carers identified that the person they cared for regularly sought out woodland areas locally to where they lived. These environments are often more ‘natural’ and less urbanised than other outdoor environments such as a maintained public park. Research by Wyles et al. (2017) indicates that both connectedness to nature and psychological restoration were sensitive to the natural environment visited. One family carer in study 1, Helen, articulated why she felt this was the case for her husband, describing how he found urban and ‘man-made' environments increasingly challenging and anxiety-provoking, whereas conversely, he found being outdoors in natural environments calming as he has always lived an ‘outdoor life'. She stated that she believed her husband found access to natural environments essential to his psychological well-being because “he can relate to it and not make mistakes”. Research by O’Brien and Morris (2014) also suggests that motivations for using woodlands for well-being included opportunities for escape and freedom from everyday life, interest in nature, memories and the importance of childhood experiences (Milligan and Bingley 2007; Ward Thompson, Aspinall and Montarzino 2008).

According to Ryd et al. (2018), our environment offers both opportunities and resources, as well as creating demands and restraints on the individual’s ability to engage and perform desired occupations. People with dementia in study 2 described their experiences of the outdoor environment as important to maintaining good health and contrasted this with periods of being in an indoor environment, which they linked to low mood and ill health. Participants were keen to draw parallels between both getting outdoors and being well as well as those between staying indoors and being unwell. For example, Hugo returned several times to discussing both outdoor and indoor environments and their impact upon him. He described ‘going stale’ and ‘vegetating’ inside. This mirrors the findings of Duggan et al. (2008) who found that people with dementia value the outdoor environment for reasons such as exercise, fresh air, and emotional well-being, and that conversely not going out was associated with feelings of depression. In keeping with the work of Mapes (2016), Barton and Pretty (2010) and Mayer et al. (2009) this PhD also evidences that spending time outdoors was perceived by participants to reduce stress and give a sense of psychological wellbeing when in these natural environments.

A number of the key concepts explored in the introductory chapter featured in the participant interviews of both studies in this PhD. Although the participants did not label them with the same terminology, the participants discussed their positive experiences of a ‘greencare’ approach (Sempik, Hine and Wilcox 2010) and the benefits of ‘green exercise therapy’ (Pretty et al. 2005). All nine of the family carers in study 1 discussed the importance they placed on enabling the person they cared for to maintain regular access to the outdoors; for many, this was framed specifically in discussions about the health and wellbeing benefits of getting out into green outdoor spaces. As discussed earlier in this discussion chapter, many of the people with dementia interviewed in study 2 were motivated to engage in outdoor occupations such as walking and running to maintain their own physical health and well-being; they also described the importance of maintaining a connection with nature, for both spiritual and psychological well-being. For all participants, some form of connection to nature was highlighted as holding importance to them as individuals, but for some, this also held a spiritual nature, where outdoor environments and the occupations engaged in offered opportunity for both restoration and reflection. Sempik, Hine, and Wilcock (2010) argued that spirituality is key to understanding the therapeutic efficacy of greencare and general psychological benefits of connecting with nature. Dakin (2009) maintained that every person has a spiritual dimension to their lives and that this is true not only of those who attach importance to faith and religious practices but also those who profess no particular affiliation to faith or tradition. In a reflective review of research, Hammell (2007) argued that through the understanding of the relationship between meaningful occupation, health, and well-being occupational therapists can promote spiritual well-being in clients through engagement in meaningful occupation.

7.6.2 Safer walking technology to maintain occupational balance

A great variety of outdoor leisure occupations were identified by participants across both studies, including, golf, running, fishing and cycling (Table 21). Walking was identified as the most common occupation undertaken by participants across both studies, with all but one participant regularly using their safer walking technology to engage in walking activities; this supports the findings of the Natural England commissioned Report ‘Is it cold outside? – Consulting people with dementia and their carers about engaging with the natural environment' (Mapes et al. 2016). Mapes et al. (2016) suggested that people with dementia were more likely to be engaged by occupation or activity than by a place or specific natural setting and the most popular outdoor occupation reported was walking, with 38% of their participants identifying this as an activity they enjoyed. This compared to 94% of participants across studies 1 and 2 of this PhD. The findings of both studies also indicate that walking was meaningful to participants as it formed a part of their occupational identity, enabled them to maintain their health and well-being and facilitated connections to nature. These findings are consistent with those of Wensley and Slade (2012), who undertook a qualitative Interpretative Phenomenological Analysis (IPA) study to explore experiences of walking for leisure; they identified that participants found walking to be a meaningful occupation and amongst the key themes they identified, connectedness to nature and personal wellbeing were key to this meaning. Walking is promoted to the general public through a range of schemes in the UK such as the ‘Walking the way to Health Initiative’ (WHI) and Walk4Life campaigns (www.walkingforhealth.otrg.uk 2019) which seek to improve health and wellbeing through walking and access to outdoor environments. National Institute for health and Care Excellence (NICE) recommendations for maintaining mental well-being amongst people aged over 65 includes a specific focus on both occupational therapy interventions and the promotion of ‘walking schemes’ (NICE 2018); this agenda has particularly been targeted at older people and government policy in the UK has included repeated commitments to achieving the goal of healthy ‘active ageing’ (Age UK 2010:4).

Whilst recognising the benefits of continued engagement in outdoor occupations, both family carers and people with dementia, who were participants in this PhD, identified concerns about the potential risks posed by outdoor environments. As previously mentioned within this chapter, fear of getting lost remained a key motivator for people with dementia in study 2 in adopting safer walking technology. These findings support the work of Bartlett and Brannelly (2019) who suggested that people with dementia can experience vulnerability in some outdoor environments. In study 1 family carers also expressed concerns about other potential risks, and many described the ability to maintain a connection with and monitor the safety of the person they cared for as ‘important’ or ‘essential’. Participants across both studies reported using safer walking technology to support continued engagement in outdoor occupations that carried additional risks, such as walking along the canal towpaths, running across large open countryside and fly fishing in open water; even where an acknowledged risk was identified, people with dementia and family carers supported the continued engagement in these outdoor occupations because they held personal meaning.

As identified in the Chapter 1, all people can be viewed as occupational beings, (Yerxa et al. 1989) with a need to engage in meaningful occupation and to exercise choice and control over how they orchestrate their occupational lives (Bateson 1996: 7). Wilcock (2007) argues that occupation and health are inseparable, and that occupational limitation has long been recognised as a measure of disability and as a negative indicator of the quality of life and perceived health (World Health Organisation 1986). Engagement in meaningful leisure occupations is an important component in achieving occupational balance (Backman 2010: 232), and when unable to access outdoor environments to engage in these leisure occupations people with dementia may experience an occupational imbalance (Riley 2012: 175). The participants in both studies 1 and 2 reported using safer walking technology to enable them or their relative to achieve this occupational balance. For example, in study 2 Brian reported using his safer walking technology to both plan for walks and locate himself whilst walking his dog. Dog walking was undertaken twice a day and served as his main leisure occupation, and the only activity he now undertook independently outside of the family home. Ryd et al. (2018) also reported similar findings in their research, which identified that older adults’ experiences of daily life occupations were influenced by the changes in everyday technology; their research highlighted that the introduction of new technologies has changed the way occupations are performed and that the use of such technologies by older adults has the potential to support their maintenance of occupationally balanced lives.

In addition to occupational imbalance, the impact of health conditions that may limit or prevent us from engaging in our chosen meaningful occupations can lead to both occupational disruption and deprivation, (Unruh, Versnel and Kerr 2002). Several of the people with dementia in study 2 described periods of occupational disruption. In these instances, a participant's ill-health had (temporarily) prevented them from engaging in their outdoor occupations. For example, Hugo identified a decline in his physical and mental health during a period where he was unable, due to a knee injury, to undertake his volunteer role walking dogs for a local charity. This was seen in participant experiences from both studies, and the findings recognise the importance of safer walking technology in maintaining meaningful occupations. Without access to safer walking technology, some people with dementia are at risk of further occupational disruption and even occupational deprivation. This has been described by Turner (2002) as the (permanent) inability to engage in meaningful occupation, and this 'devastating and widespread' outcome may result in loss of roles and routines.

7.6.3 Supporting occupational identity and personhood

As discussed in Chapter 1, occupational disruption and deprivation can be harmful, impacting negatively upon a person's health and well-being, and have the potential to also undermine an individual's occupational identity and sense of self (Riley 2012: 174). Occupationally deprived individuals may also experience compromised self-identity and reduced efficacy (Whiteford 2000). For many of the participants, safer walking technology held the key to them maintaining valued, and sometimes lifelong, occupational identities. For example, Annabel's husband was a wildlife expert and spent much of his life in the countryside, for both his work and leisure occupations. The occupations he engaged in outdoors held meaning to him and shaped his identity. For example, bird watching, river fly fishing, and hedgerow foraging. Annabel felt that her husband's choice to spend his time doing these occupations reflected his lifelong desire to be outside and in nature and was key to his identity and occupational well-being. This reflects the description of occupational well-being as a concept identified previously within the introductory chapter as "*an experience in which people derive satisfaction and meaning from the ways in which they have orchestrated their occupational lives*" (Doble and Caron Santha 2007: 14). Doble and Caron Santha (2007) argue that wellbeing is, in part, achieved through the engagement in meaningful occupations we choose to do with our free time. However, for people with dementia, the restriction of engagement in meaningful occupations that form their identity has the potential to also undermine their sense of self-identity or personhood (Kitwood 1997) and overall quality of life. In study 1, Annabel felt it was important to her husband's wellbeing for him to be able to maintain this occupational identity. Annabel was not alone in seeking to maintain the occupational identity of her husband - other family carers within study 1 also reported outdoor occupations as key to the well-being and identity of the people they cared for. For example, Helen's husband, whose career in poultry farming and lifelong commitment to edible gardening meant he was rarely comfortable inside; Emma's father had been an active member of a cycling club for over forty years. These were all occupations that could not easily be replicated within inside environments and rely upon access to the outdoors. Family carers interviewed, in study 1, were very keen to adopt any strategies or technology that could enable their relatives to maintain these occupations despite challenges arising because of their dementia. For Annabel and other participants within the study, the use of safer walking technology was introduced as practical support to enable the persons they cared for to continue meaningful outdoor occupations for longer, maintaining their occupational identity and sense of personal freedoms.

Similar experiences were described by the people with dementia interviewed in study 2, where meaningful occupations were consistently described by participants as part of their identity. For example, Fiona described engaging in her outdoor occupations as "It's part of what makes me, me". For many of the participants in study 2, their connections to nature and outdoor focussed occupational identity stemmed from childhood experiences, with many describing patterns of occupation such as dog walking that had been maintained throughout their entire lives. These findings, of this PhD, are supported within from the wider disability literature. In research that explored the experience of people with acquired brain injuries, Fenech et al. (2012) found that maintenance of lifelong occupations was important for several reasons including: maintaining links with the past; individual and social identity; maintaining a sense of self-efficacy. Many of the people with dementia within this PhD had lifelong relationships with the outdoors and engaged in outdoor occupations daily, which held significant meaning to them as individuals and reinforced their occupational identity and wider sense of self; they sought out both familiar occupations and new ones that enabled them to continue to engage with the outdoors. For example, Fiona had several outdoor occupations that she had engaged in for many years including dog walking, and outdoor hockey. In recent years, since her diagnosis of dementia, she had also taken up new occupations and had started running. Her access to and ability to use safer walking technology enabled her to adopt this new occupation easily, allowing her to evolve her occupational identity to include ‘marathon runner’. Unruh (2004) describes occupational identity as *“a concept which has at its core the individual self with control over its identity.”* Within this thesis the research identifies that, people with dementia described using safer walking technology to maintain control and choice in the occupations they undertook, thus using the technology to shape their own occupational identities.

Occupational identity, and the identification of meaningful occupations, have traditionally been considered in terms of the individual, but more recently there has been a greater acknowledgment of shared occupational identity, recognising the occupation happens in and is often framed by, people in groups or pairs (Pentland 2018: 4). This was seen in study 1 in the experiences of Carl and his wife, who shared a lifelong passion for walking and walking groups; when not working, they spent much of their adult lives planning, leading and attending organised rambling groups, an occupation that they continued to share even into very old age. Again, the introduction of safer walking technology supported Carl's confidence to continue this meaningful occupation and in turn preserved the shared occupational identity so important in their lives. The findings from this PhD demonstrate that for both the family carers and people with dementia interviewed, safer walking technology appeared to enable them to continue to engage in meaningful occupations far longer and more independently than would have otherwise been possible, with a positive impact on their well-being and their relationships.

7.7 Key Messages from this chapter

- The findings of studies 1 and 2 revealed several previously unrecognised issues and increase the overall knowledge and understanding of how safer walking technology is used by people with early stage dementia.

- The design of this research incorporated both a phenomenologically informed research methodology to explore the ‘lived experience’ of people who use safer walking technology and a person-centred approach to recruitment and data collection. This enabled a detailed picture of how individual users experienced safer walking technology and incorporated it into their daily lives.

- People with dementia and family carers of people with dementia both seek out and use safer walking technology, often purchasing it privately if unavailable through local social services. For both groups of people concern about the risk of getting lost remains the key motivator for its use.

- Family carers are more likely to seek out a tracking device designed specifically for use with people who have dementia. However, people with dementia are more likely to use existing technology they already own such as smartphones. Where the exact technology solution is not available, people with dementia are likely to combine safer walking technology with other technologies to meet their specific needs.

- Lack of reliable information and training to use or support others to use the technology were identified as barriers for both family carers and people with dementia. For people with dementia using smartphones, the rapid development of this technology and the requirement to update software and hardware were also identified as significant barriers to their ongoing use.

- There is a need for ongoing support to continue using safer walking technology and re-assess a person's needs as their dementia changes over time. There is also a need to recognise and support people with dementia and family carers when safer walking technology is no longer helpful and provide support with the transition of giving up the use of this technology.

- Participants reported little stigma around the wearing of tracking devices and were unconcerned about issues of privacy. Although the mainstream use of wearable technology has reduced the stigma around its use, ethical debates remain around data storage and access to tracking data, although such issues were not readily recognised by participants in this PhD.

- For some people with dementia, connectedness with nature is important and they seek to spend time in outdoor environments that facilitate this connection, such as woodlands and green outdoor spaces. Participants found these natural environments restorative and they had a positive impact on their health and wellbeing, with some also identifying a spiritual dimension to their experiences outdoors.

- People with dementia in this PhD engaged in a great variety of outdoor occupations, but the most popular form of outdoor activity was walking. Safer walking technology enabled people with dementia to continue to engage in these meaningful outdoor occupations, supporting them to achieve wellbeing through occupationally balanced lives.

- People with dementia in this PhD used safer walking technology to maintain engagement in meaningful occupations that were essential to their sense of self or personhood. This enabled them to continue to shape and control their occupational identities through their outdoor occupations.

The next chapter offers a conclusion to the thesis, discussing the limitations of the research and considers what the findings mean for people with dementia and family cares. It also explores the indications for the future of safer walking technology. It also considers the implications for clinical practice and recommendations for future research in this area.

Chapter 8 Conclusions

8.1 Introduction

This research has used two separate studies to better understand the lived experience of people with dementia and family carers of people with dementia, respectively. As such, the focus has been upon exploring the individual's experience, and how safer walking technology has impacted their lives. Each of the two studies focused upon a small homogenous group, whose experiences could be discussed together in the context of this research. The findings suggest that there is a difference in how safer walking technology is experienced by people living with dementia and family carers.

By exploring the lived experience of people who use safer walking technology, this research has revealed aspects of its use and provision that have previously been unreported or under-reported within practice or the research literature. Although not generalisable, these findings do offer some new insights to better understand how such technology can support meaningful occupation for people with early-stage dementia now and in the future. The key contributions to knowledge in this area are:

1. Safer walking technology is used to maintain occupational identity and well-being for some people with dementia through enabling access to meaningful outdoor occupations.
2. Family carers and people with dementia are likely to adopt very different forms of safer walking technology, as they use technology differently.
3. People with dementia are creating their own technology solutions.
4. There is a need to provide ongoing support to both people with dementia and family carers when the time comes to give up using safer walking technology as this process has the potential to cause psychological harm.

This chapter discusses the limitations of this research and possible future of safer walking technology, it then goes on to discuss implications for occupational therapy practice and what the findings from this research may mean for people with dementia and family carers. The chapter then concludes with several recommendations for future research in this area.

8.2 Limitation of this research

8.2.1 Developing research competencies

All research can be improved upon and undertaking a PhD is a recognised process to enable the development of effective and professional researcher's skills and competencies (Rugg and Petre 2004: 2). Within this PhD, the development of effective research skills has been part of an experiential learning process (Felicia 2011: 1003) for the researcher, with each stage of the process having a recognised period of learning and development (Lindén, Ohlin, and Brodin, 2013). For example, within the methodology chapter in section 3.8.1, there is a detailed discussion about the development of interview skills and the reflective tools the researcher used to identify and develop an effective interview style. If the researcher were to start the study again, with the skills that have been learnt along the way, then the research process may have been more efficient.

8.2.2 Increased rigour within the literature review selection process

The process of literature selection within both stages of the review were systematic and has been described in detail in chapter 2, section 2.2. However, because the researcher undertook this process alone, the selection process is subject to an increased risk of both potential researcher bias and human error. To increase the rigour of this process a second researcher could have been introduced to either provide a second review by reviewing all of the articles, or moderation of a selection of the articles by reviewing an agreed percentage chosen at random. This moderation approach is recommended by Oliver, Dickson and Newman 2012: 78) who argue that literature screening is better undertaken by two people independently to assure the quality of the work.

8.2.3 A more focused semi-structured interview schedule

As discussed in the methodology chapter in sections 3.3.2, the semi-structured interview schedule was developed in partnership with the stakeholder advisory group. This group had representatives from a range of stakeholders with an interest in the use of safer walking technologies. The group discussed the research question and aim, and a list of possible research questions and prompts was developed within the group. There were in-depth discussions about the appropriate language to use within the interviews and the information from this session informed the final schedule used. Smith, Flowers and Larkin (2009: 59) advise that interview schedules within Interpretative Phenomenology should include questions that are open and expansive, so that the participant can be encouraged to talk at length. Within the developed schedule there were seven key topics and a further eighteen possible prompts (Appendix 20). This is arguably too much information and an overly rigid structure for this style of research approach. The researcher was aware of this at the time of development and so the interview schedule was designed to be used as a guide and so not all prompts were used in every interview. Interviews were participant-led, with the order of discussion being variable and the participant often taking the topic in different and unexpected directions. In a review of published IPA research Brocki and Weardon (2006) found that semi-structured interview schedules were common in IPA research, with the interview style being described as non-directive with open-ended questions; this reflects a flexible and adaptive style of research interviewing, which enabled the experiences of the participants to dominate, rather than the agenda of the researcher.

However, the length of the schedule proved a barrier to effective data collection and as part of the reflective process of learning to undertake effective research interviews, the researcher quickly reduced the volume of prompts she used considerably and used the seven key topics as a basis for discussion instead. The research would have benefited from a more focussed semi-structured interview schedule designed with the stakeholder advisory group. Designing the schedule with a group of people led to the inclusion of lots of different topic areas as there were lots of different opinions about what was important to ask. It may have been beneficial to initially offer advice and guidance to this group about what an IPA interview typically looked like and even given out exemplars of semi-structured interview schedules that are commonly used. Ultimately, the responsibility for developing an effective interview schedule falls to the researcher and therefore recognising the need for a focussed and effective schedule is as important as ensuring the correct language and topics are included.

8.2.4 Greater representation and diversity in the participant group

For pragmatic reasons, participants for both studies were recruited across the West Midlands, in the UK. This included recruitment from urban and rural areas over a wide geographical area. The West Midlands also has a diverse population, with cities such as Birmingham and

Coventry being the most ethnically diverse cities outside of London (www.ethnicity-facts-figures.service.gov.uk). However, the participant profile within both studies did not represent the diversity of this population. All 18 participants across the 2 studies identified as white British and their first language was English. Karney, Kreitz, and Sweeney (2004) suggested that a lack of ethnic diversity is common in self-selecting research populations, despite a recognised need to increase representation. The reasons for this may be complex, yet Neumann (2010) argues that the responsibility to include a wide diversity of participants lies with the researchers, to ensure that the findings they present are representative of the populations on which they focus, especially if such findings may be used as evidence to influence policy and service delivery. There were several ways in which the researcher could have attempted to recruit a more diverse population, including direct advertising within recognised diverse community groups and providing research information and advertising in different languages. An example of this can be seen in the research of Austin-Wells, McDougall and Becker (2006) who developed strategies aimed at both recruiting and retaining a diverse ethnic participant group for the SeniorWISE, a research project, which looked at memory function in community-dwelling adults over 65 years of age.

8.3 Indications for the future of safer walking technology

Whilst it is not possible to speculate about how technology in this field may evolve in the future, it could be assumed that further developments are likely in areas of the technology that currently pose barriers to their effective use, such as limited battery life, the need to update software regularly and reliance on a sometimes ‘patchy' 4G mobile phone network. At present, safer walking devices are also only marketed at family carers, to track people or locate people at risk of getting lost. However, the findings from this research indicate that people with dementia can take more responsibility for managing these risks themselves and so there is a gap in this market for technology designed specifically to help them with wayfinding.

Considering recent developments in GPS technology, it is possible to see how the current developments in mobile and smart technology could be applied to the current safer walking technology industry. There is great potential for the development of apps that increase the usability of inbuilt smartphone mapping tools or that simplify and support the use of multiple smartphone functions together. For example, telling the smartphone artificial intelligence (AI) assistant to follow ‘Dog Walk 1', might enable the user to access pre-set up familiar walking routes; these could be set up to take into consideration weather conditions and outside temperature, or to warn of potential hazards. Such a task utilises several of the inbuilt features of a modern smartphone but would require software to coordinate these tasks in an accessible user-friendly way. The potential combinations of features that could be utilised to support outdoor occupations for people with dementia are probably almost endless, but if carefully researched collaboratively with people with dementia, it could be possible to create new practical and useable technology in this field.

Maze and Hunt (2018) suggest that identifying an individual’s strengths and needs may not be enough if the right technological solution for them is not available. Therefore, there ideally needs to be a greater variety of safer walking technologies, and more choices available to both individual consumers and service providers. However, this would require that technologies companies recognise these market opportunities and find them to be viable commercially. For many, the use of a smartphone may be the answer, for others it may be a smartwatch or a location tracker. The present research has suggested that family carers and people with dementia were likely to select very different forms of technology, when they are the one actively driving selection, demonstrating that despite the potential growth and development of smart technologies, there still may be a role for traditional tracking devices in safer walking technology. Although this PhD only focused on the experiences of people with early-stage dementia, it is possible to speculate that at a time when the technology they currently use is no longer helpful, a different form of safer walking technology might be appropriate to support continued engagement in outdoor occupations. In addition to the need for different types of safer walking technology that offer different functional supports, Wherton et al. (2018) also found that the acceptability of safer walking technology was connected to the type of design the tracker was presented in, e.g. keychain, wristwatch, etc. This is supported by the experiences of participants in this PhD, particularly family carers who noted that the design of the tracking device needed to match the expectations of the person they cared for.

8.4 What do the findings mean for people with dementia and family carers?

Safer walking technology has the potential to enable greater access to outdoor environments for people with dementia, whether this takes the form of purpose-built tracking devices used by family carers or people with dementia using the GPS apps on smartphones. The benefits of this increased ability to access outdoor environments offer real opportunities to improve the quality of life for people with dementia. Findings from this PhD thesis indicate that for some people with dementia, getting outdoors and spending time in natural environments is important to their well-being, as recognised in the work of Mapes (2016) and others. This PhD thesis also indicates that retaining access to outdoor environments likewise has an important role to play in maintaining occupational identity, enabling people with dementia to exercise control and choice in meaningful outdoor occupations.

This PhD thesis indicates that there is currently a new form of safer walking technology being adopted, primarily by people with early-stage dementia to independently way find and self-manage risks associated with being in outdoor environments; this takes the form of smartphones and tablet devices using GPS mapping apps and other everyday technologies likely to be already within a person's possession, and which they may already have some skill in using. However, the PhD findings indicate that even with prior knowledge of the technology, a person with dementia may still need to learn to use this technology differently to how they did previously and may need support from family carers to manage ongoing tasks such as charging or updating software. This PhD thesis shows that there is often a 'useful window of time', for the use of safer walking technology and when the technology is no longer useful, people with dementia may need to move on to a different form of safer walking technology to continue accessing outdoor environments independently and may require support to "give up" the technology when it no longer suitable to meet their needs.

Although prescriptions for safer walking technology are limited through social services and vary around the UK, many different types of technology are available for private purchase. The focus of this PhD thesis on how safer walking technology is being used in a real-life context has highlighted the increased use of privately purchased devices and technology, bought without guidance or support from health or social care services. There is little up to date independent guidance around all the different types of safer walking technology, however, the findings of this PhD thesis indicate that family carers and people with dementia are often unaware of how to access this information and are more likely to rely on product information produced by technology manufacturers. In some cases, this led to participants purchasing expensive devices with a range of functions that were too complex, they did not use or were unhelpful. There was also evidence that within the private sector, there was a potential for sales company marketing to 'raise a person's hopes', and then providing unsuitable technology that does not met their needs; this was shown to be harmful to the participants in this research and caution needs to be exercised when safer walking technology is purchased privately without an individualised assessment of need or an ongoing support system.

8.5 Implications for practice

8.5.1 Safer walking technology as an intervention tool to promote outdoor occupation

For occupational therapists, this PhD thesis also identified the central role that assistive technologies such as safer walking technology, can play in maintaining occupational identity through supporting meaningful outdoor occupation. Safer walking technology has the potential to be used as an effective intervention tool to promote and support greater accesses to outdoor occupations for people with dementia. Supporting the use of assistive technologies in this way is, therefore, an effective way of ensuring an occupational focus to the work occupational therapists undertake. For occupational therapists working in either primary care settings or early intervention memory services, there is also a greater opportunity to offer advice and guidance to people with early-stage dementia, who may benefit from support to use their existing technology, such as their smartphone, to way-find and maintain their independent outdoor occupations. Within these settings occupational therapist often work individually with clients to support maintenance of their everyday occupations and adaptation of their routines and day to day habits. As part of this process occupational therapists could establish the current use of such technologies and if there is potential for them to use the technology differently to support their outdoor occupations.

8.5.2 Occupational therapy practice guidance for safer walking technology

Despite the identified benefits, the potential for the use of safer walking technology for people with dementia to become more widespread are unknown. From the findings, it appears that safer walking technology to track a person (used commonly by family carers) is often provided through social services, but with inconsistent and sometimes limiting prescription criteria. There are no current practice guidelines for the use of safer walking technology for people with dementia in the UK; from the research literature, Landau and Werner's (2012) recommendations for practice remain the only published guidance on the use of safer walking technology. These recommendations are useful but need updating to reflect the changing technologies and issues in this area and to incorporate new evidence in the field. Also, the focus of Landau and Werner's recommendations was on ensuring ethical decision making around the use of GPS safer walking technologies to track a person with dementia, especially if they lacked capacity to give their consent to be tracked. Yet, the findings of this PhD thesis indicate that the successful use of safer walking technology is often dependent upon consideration of other factors, such as the support needed to assess user and carer needs, and the ability to promote independent engagement in meaningful occupations. Guidance is needed to provide evidence-based recommendations that can inform occupational therapists working with people with dementia and their carers. This could help define their role and the interventions required to support the use of safer walking technology by people with dementia.

Contemporary guidance must be based upon up to date evidence in this field and examples of 'best practice' in this area. This could include initial assessment considerations, such as: how best to assess the persons suitability to use safer walking technology, what their navigational or locating needs are, and how their current skills and needs could be best matched to the 'right fit', provide support to carers and identify additional training needs. In addition, an effective assessment process, guidelines should promote greater recognition of the ongoing support needs of both people with dementia and their family carers. Identifying how to ensure timely reassessment of the persons' skills and needs, with the development of a clear pathway to understand when a person may need to move onto a different type of safer walking technology or give up using the technology altogether. Existing research in this area could be used to enable the development of general guidance, but there is not yet enough evidence to develop robust clinical guidelines.

Guidance to support the use of safer walking technology could build on ethical considerations from Landau and Werner's (2012) recommendations, but also provide both a staged linear guidance process. Within the wider field of assistive technology, Woolham and Frisby (2002) proposed a 'whole system' approach to the provision of assistive technologies for people with dementia that recognised the need for continued support. This in turn built upon earlier work by Bjorneby, Topo and Holthe (1999) and the ASTRID project by Marshall (2000). Woolham and Frisby's 5-stage linear guidance process included recognition of the need to support both its installation and use, with regular reviews of the person using the technology's needs. (This can be seen in Appendix 29) The findings from the research described in this thesis also highlight the need for individualised and ongoing assessment of needs and abilities, with the focus on providing the 'right fit' solution for the individual and ensuring that support is provided to select, adopt, continue using and eventually stop using safer walking technology. This research identified that in addition to these issues, support needs to be given when a person with dementia stops using safer walking technology, acknowledging that this may be a challenging or distressing experience and that they may need additional support to seek alternative ways to continue maintaining their meaningful outdoor occupations. This new insight does not appear in previous practice guidelines for assistive technology use but is an area that should be addressed within clinical practice. Therefore, the development of occupational therapy guidance for safer walking technology use could include a similar linear process, recognising a grounding in Woolham and Frisby's initial 5 stages, but with an additional 6th stage that focusses upon the process of supporting giving up the technology or substituting one technology for another, recognising the changing needs of the individual.

8.6 Recommendations for future research

The findings from this research identified several new areas of knowledge in this field. These require further research to fully understand their implications for both clinical practice and to best support the needs of people with dementia. From this research four key areas for future research and development are identified:

8.6.1 Understanding the evolving ethical debate in the use of safer walking technology

Within the findings of this PhD thesis, there was also a notable lack of concern about privacy and the ethics of tracking with safer walking technology. However, views about this topic were not directly sought in the interviews and so this is a potential area for future research. The findings from this research did initially indicate that concerns around stigma have reduced because of the increased acceptability of wearable technologies, and the use of safer walking technologies to way-find rather than be tracked. However, some safer walking technologies continue to be used to track people with dementia and issues around data protection, privacy and autonomy remain important topics, within the published literature in this field. Research is needed to understand the potentially changing climate around the use of wearable technologies that track a person, and how the increased acceptability of tracking devices and raised awareness of the use of personal data in the general population may impact upon its use for people with dementia.

With the increased use of smartphones and app technology, there is also a new and emerging ethical consideration around the privacy of the data collected by this software. There are several questions to be asked around where information about a person's movements is stored, who has access to it and how secure that data is. There are several considerations around the use of this data, including data theft, and the use of such information by private health insurance companies. Further research in this area is needed to determine the views of both family carers and people with dementia on this issue. There is a need to improve our understanding of awareness around these issues among stakeholders including developers, manufacturers, health and social care providers and professionals.

8.6.2 The process of giving up technology

The process of giving up safer walking technology was discussed by family carers in study 1. Several participants identified the negative impact on both them and the person they cared for in losing the ability to use safer walking technology. (This did not feature in the interviews in study 2, as none of the participants in study 2 had stopped using their technology at the time of interview.) Further research is needed to understand how this process occurs, how the process of giving up the technology is experienced and if there are common identifiable characteristics. This PhD thesis indicates that it occurs at a time of difficulty when skills and abilities are deteriorating, but it is unclear if the added complication of giving up a previously 'essential' technology adds to the trauma of this period. There was some limited evidence that giving up this technology was associated with both negative experiences and was experienced as a personal loss. If so, this phenomenon needs to be better understood. It may be possible to learn how best to support people through this transition and what safeguards can be put in place to help mitigate the potential negative impact on the person and their family carers - acknowledging their emotional needs as well as the practical risk management.. A better understanding of how to support someone to give up safer walking technology may also provide valuable insight into how people with dementia experience such a process with other forms of assistive technology.

8.6.3 The use of smartphones by people with dementia to way-find

Greater knowledge is needed to understand how smartphones are currently being used by people with early-stage dementia to way-find independently. This PhD thesis identified that this is a common form of safer walking technology, with all the participants in study 2 choosing to use this. However, little is known about its use with just one study in the literature review focused on this type of technology. In their research, Kwan Cheung and Kor (2018) trialled the use of the Siri voice activation software in combination with the map's app on an iPhone smartphone. They tried to find out if people with dementia were able to successfully use this combination of software to navigate in a busy urban environment. The performance of participants was measured against a control group of 'cognitively intact' older adults to determine if their dementia had any impact on their ability to use the smartphone in this way. Whilst this generated useful and relevant data, it did not reflect the way that people with dementia are already using these applications in the real-world.

Research is needed to explore what apps and smartphone tools people with dementia are using and how they are using them, and if there is evidence of further digital bricolage as seen in this PhD thesis. Such an approach could identify both the barriers and facilitators to their use, with the possible potential to develop a dementia-specific app tailored to the need of people with dementia but using the existing inbuilt GPS tools in the smartphone. Further research is needed to understand how best to use and design safer walking technology to meet the needs of people with dementia who wish to use the technology to autonomously manage their own needs, whilst acknowledging that this is not the ‘right’ solution for all. Understanding these aspects of smartphone use by people with dementia could also contribute to a better understanding of how a greater number of people with dementia could be supported to use this technology and the potential role for occupational therapists and other health and social care professionals in providing this support.

8.6.4 Using safer walking technology to promote occupational identity

This PhD thesis has identified the potential for safer walking technology to be used to support occupational identity for people with early-stage dementia. Further research is needed to understand how occupational therapists could use this as a practical intervention tool to support occupational engagement. Research in this area could include a case study approach or small trials, highlighting the beneficial use to individuals who wish to engage in outdoor occupations. Practice-based research of this nature has the potential to generate new insights about how safer walking technology could be used by occupational therapists to support people with dementia. Such research could and inform and enhance the practice of occupational therapists, more widely, promoting and encouraging the use of safer walking technology as a person-centred intervention to promote outdoor occupations.

8.7 Chapter Summary

The findings of this PhD thesis highlight the experiences of people living with dementia and family carers. They emphasise the commonly shared aspects of these individual experiences and so offer some useful insights for other similar users of safer walking technology. There is considerable scope for further development of safer walking technologies, both as purpose-built tracking devices and within the growing apps market. People with dementia are keen to use safer walking technology but may need different types of technology at different times to meet their changing needs.

There are several recognised limitations with this research, which could be improved upon in future work by the researcher. These mainly stem from the development of the researcher’s skills during the undertaking of this research, however, the lack of diversity in the participant group recruited is a clear limitation within this thesis. However, this research identified several different areas for future research within this field. These include how smartphones are being used by people with dementia to way-find, how occupational therapists could use safer walking technology to promote occupational engagement, understanding the evolving ethical issues surrounding this technology and how the process of giving up safer walking technology is experienced.

There are several clinical implications form this research, including useful information to inform occupational therapy practice in this area and a wider understanding of how safer walking technology is being used in the UK today. In addition, there is a need for the development of practice guidelines in this field to enable occupational therapist and other health and social care professionals to support people with dementia and their carers to make use of technology to maintain their engagement with outdoor occupations that sustain an individual’s occupational identify, health and well-being.

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Zwijsen, S. A., Niemeijer, A. R., and Hertogh, C. M. P. M. (2011) 'Ethics of using Assistive Technology in the Care for Community-Dwelling Elderly People: An Overview of the Literature'. *Aging & Mental Health* 15 (4), 419-427

Appendices

Appendix 1 Ethics certificate for preliminary literature searches

Coventry University
Priory Street
Coventry CV1 5FB
Telephone 024 7688 7688

Professor Guy Daly
Executive Dean

30 July 2019

Dear Sir/Madam

Re: Ethical Approval – P16888

I am writing to confirm that Esme Wood has received ethical approval on **21 October 2013** for the research project: *How is technology used to enable people with dementia to access outdoor spaces?*

The research project has addressed the main ethical issues appropriately, and has been approved by a member of the Faculty of Health & Life Sciences, Ethics and Governance Committee at Coventry University.

If you have any further queries please do not hesitate to contact me.

Yours sincerely

This item
has been

Dr Andrew King

Chair of Ethics Committee
Tel: (024) 7765 3805
Email: ethics.hls@coventry.ac.uk

Appendix 2 Ethics certificate for stage 1 2014 literature searches

Coventry University
Priory Street
Coventry CV1 5FB
Telephone 024 7688 7688

Professor Guy Daly
Executive Dean

Coventry University

30 July 2019

Dear Sir/Madam

Re: Ethical Approval – P17866

I am writing to confirm that Esme Wood has received ethical approval on **8 November 2013** for the research project: *Saferwalking Technology for people with Dementia: a review of the literature*

The research project has addressed the main ethical issues appropriately, and has been approved by a member of the Faculty of Health & Life Sciences, Ethics and Governance Committee at Coventry University.

If you have any further queries please do not hesitate to contact me.

Yours sincerely

This item has
been removed

Dr Andrew King

Chair of Ethics Committee
Tel: (024) 7765 3805
Email: ethics.hls@coventry.ac.uk

Appendix 3 Ethics certificate for stage 2 2019 literature searches

Certificate of Ethical Approval

Applicant:

Esme Jones

Project Title:

The use of safer walking technology by people with early stage dementia: review update

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low Risk

Date of approval:

30 April 2019

Project Reference Number:

P90130

Appendix 4 Database search results and reasons for paper rejection

Stage 1 Database Search Results 2008 - 2013

Database	**Papers Identified in the database search**	**Rejected from Review**								**Relevant to Review**
		Focus on Technology Development Process	Use of Technology for Diagnostic/ Medical Purposes	Use of Technology to Enhance Cognitive Skills	Technology for Use by Carers	Technology for Use within Care Homes	Technology for Use within the Home	Duplication within Search	Duplication from the Previous Database	
CINAHL	261	0	60	25	27	33	40	18	0	**58**
MEDLINE	35	0	4	4	4	2	13	2	0	**6**
AMED	15	0	0	0	0	6	1	1	6	**1**
PschINFO	23	4	0	2	0	0	4	0	13	**0**
Academic Search Complete (ASC)	98	4	17	15	6	5	22	7	4	**18**
ASSIA	25	3	1	0	4	3	8	0	2	**4**
SCOPUS	151	8	11	20	11	19	32	0	25	**25**
TOTAL	**608**	**19**	**93**	**66**	**52**	**68**	**120**	**28**	**50**	**112**

Stage 2 Database search results 2014 - 2019

Database	Papers Identified in the database search	Rejected from Review								**Relevant to Review**
		Focus on the technology development process	Use of safer walking technology for Diagnostic/ Medical	Use of Technology to with other client groups	Technology other than safer walking technology	Technology for Use within Care Homes	Technology for Use within the Home	Duplication within Search	Duplication from the Previous Database	
CINAHL	218	21	4	0	7	16	0	3	0	**167**
MEDLINE	839	151	409	3	7	48	29	23	49	**120**
AMED	9	1	0	1	0	3	0	1	0	**3**
PschINFO	506	22	6	2	111	63	12	35	206	**49**
Academic Search Complete (ASC)	555	61	2	2	14	143	160	22	89	**62**
ASSIA	82	46	22	0	0	3	11	0	0	**0**
SCOPUS	103	0	3	3	5	5	1	27	47	**12**
TOTAL	**2312**	**305**	**446**	**11**	**144**	**281**	**213**	**111**	**391**	**410**

Appendix 5 Data extraction form

Paper	Research Design	Purpose	Key Findings	Limitations	Other

Appendix 6 Recommendations for the use of safer walking technology

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

Recommendation 1: It is crucial to maintain balance between the needs of persons with dementia for protection and safety and their need for autonomy and privacy.

Recommendation 2: The decision on using GPS for tracking elderly people with dementia should be made jointly by the person with dementia and family caregivers.

Recommendation 3: People with dementia should be asked for their informed consent regarding the possible use of GPS in tracking their outdoor mobility, and they should not be coerced into being tracked.

Recommendation 4a: Advance directives, a durable power of attorney for health and social care or appointment of a designated proxy appear to be the best solutions for coping with the issues of informed consent when the person with dementia is unable to give informed consent.

Recommendation 4b: The proxy decision on using assistive technologies, such as GPS tracking must be based on the prior attitudes and values of the person with dementia.

Recommendation 5: In deciding whether to use GPS for tracking people with dementia, not only the prior attitudes and values of people with dementia but also the best interests of both the persons with dementia and their family caregivers must be considered.

Recommendation 6: Professional caregivers in both community and care homes /institutions should be more actively involved in making important decisions for their patients’ life, including deciding whether to use GPS.

Recommendation 7: From the beginning, the treatment program for dementia care should include formal structured meetings in which the person with dementia, his/her family and professional caregivers make important end-of-life decisions, such as the use of GPS tracking.

Recommendation 8: The devices used to track people with dementia must be lightweight, small, and comfortable to wear and use.

Appendix 7 Research Timeline

			Maternity leave		Maternity leave		
	2013	2014	2015	2016	2017	2018	2019
M001RDC	X						
Literature Review	X						
M001HLS	X	X					
PRP 1	X						
M001CAW		X					
Design Study Protocol		X					
Ethical Approval		X					
PRP 2		X					
PRP 3				X			
Produce Recruitment video				X			
Stakeholder Advisory Group				X			
Participant Recruitment 1				X			
Data Collection 1				X			
Transcription of Data 1				X			
PRP 4				X			
PRP 5						X	
Participant Recruitment 2						X	
Data Collection 2						X	
Transcription of Data 2						X	
Data Analysis						X	
Write Up Findings						X	
PRP 6						X	
Update Lit Review							X
Write up Thesis							X
Thesis Submission							X
Viva							X

Appendix 8 Participant consent form

Access to green outdoor spaces: what are the experiences of people with dementia who use safer walking technology?

The purpose of this study is to develop an understanding of how safer walking technology might help people with dementia, and the potential impact that accessing green outdoor environments has to their health and well-being

Please initial

1. I confirm that I have read and understood the participant information sheet for the above study and have had the opportunity to ask questions ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason ☐

3. I understand that all the information I provide will be treated in confidence ☐

4. I understand that I also have the right to change my mind about participating in the study for a short period after the study has concluded ☐

5. I agree for things I say to be audio recorded and for anonymised quotes to be used as part of the research project ☐

6. I agree to anonymised quotations of things I may say to be used in my Ph.D. thesis, and in any reports or articles that might be written ☐

7. I agree to take part in this research project ☐

Page 1 of 2 *Please see overleaf for further information*

Name of participant: ....

Signature of participant: ....

Date: ....

Name of Researcher: ....

Signature of researcher: ....

Date: ....

Page 2 of 2

Access to green outdoor spaces: what are the experiences of people with dementia who use safer walking technology?

- **We are inviting you to take part in a research study.**

- **It is important that you understand what the research involves and why it is being done.**

- **Please take the time to read this sheet with the researcher and your carer or family member.**

- **It is up to you whether or not to take part in this research, only you can decide to take part, no one can do this for you.**

- **Ask any questions if there is anything that isn’t clear.**

- **Ask any questions if you need any more information.**

What is safer walking technology?

Safer walking technology is a new and developing area of technology. This technology has been used to track, find, support or safeguard individuals with dementia when accessing outdoor environments.

Examples of Safer Walking Technology currently in use

Whilst safer walking technology comes in a number of different formats and is being developed by a range of companies, the types of technology currently available for use can be broken down into three main types:

Navigational Technology; which informs the user of their whereabouts, such as *handheld satellite navigation*, ideal for rambling in open countryside.

Global Positioning Satellite (GPS) Technology which informs the user where someone else is, such as *GPS trackers,* typically worn as a watch or a keychain, these are useful for identifying the current location, for returning to a specific location such as home or a parked car or finding a person if lost.

Mobile Technology, which has the potential to do both of these tasks and be tailored to meet very specific needs or tasks. These are mainly being developed as *Mobile phone/ tablet apps* - New Apps being developed all the time to suit a range of specific uses where the user has access to 3G or 4G networks.

We want to understand your experiences of walking and accessing green outdoor spaces, particularly if you have used any form of Safer Walking Technology

What is the research about?

The purpose of this study is to develop an understanding of how Safer walking technology might help people with dementia, and the potential impact that accessing green outdoor environments has to their health and well-being. If you consent to participate in the study, a researcher will come and visit you to conduct an interview.

Why have I been chosen?

You have been chosen as you are a person with mild dementia and have expressed an interest in participating in the study.

Do I have to take part?

No, it's up to you to decide if you want to take part.
You will be given this information sheet to read and keep. You will be asked to sign a consent form if you decide to take part. You need to be able to give consent for yourself – it is up to you, and no one else, whether you take part or not.
Even if you do decide to take part, you are can change your mind and withdraw from the study at any time without giving a reason.

What will happen if I decide to take part?

1. A researcher will come and visit you in your home, or another location agreed by you, to talk to you about consenting to the study.

2. If you are able and happy to consent to the study, she will conduct an interview with you about your experiences.

3. Following the completion of the interview, you may be asked to undertake a second interview approximately 6 months – 1 year later.

How long will the interview take?
The interview length can vary from person to person but is expected to take between 40 minutes and 2 hours.

If at any point during the interview you feel you would like to break or end the interview, this will happen immediately and (if necessary) the interview re-started or rescheduled at a time convenient to you.

What happens to the information I give during the interview?
The interviews will be recorded on a digital tape recorder, and an electronic tablet so the researcher can re-read and analyse the interviews.
All data collected will be kept securely and only seen by the research team.
A false name will be used instead of your name, so you won't be identified in any reports that are written about the research.

What are the advantages of taking part?
The benefits of taking part in the study are that you will be helping to develop our understanding of both safer walking technology and the value of accessing green outdoor spaces for people with dementia. This might, in turn, lead to changes in the way support for people with dementia is designed, and/or improvements in the design and accessibility of safer walking technology.

What are the disadvantages of taking part?
As with any new technology you might feel frustrated with using safer walking technology and might not like using it anymore. If this happens, and you don't want to use it this

is fine, and we would still be interested in understanding your experiences.

What if there is a problem?

If you have a concern or a complaint about the study, please talk to:

Principal Investigator – Esmé Wood – 07500933369
Director of Studies – Dr. Gillian Ward – 024 7688 8941
If you are still unhappy and want to complain further, please contact:
Coventry University Ethics Chair Professor Ian Marshall – 024 7688 7688.
The address to write to is Coventry University, Priory Street, Coventry, CV1 5FB.

What will happen to the results of the study?

All personal information about participants, including your name, address and contact details will be kept confidential. This information will not be shared with anyone else at the university or any other organisation without your prior permission.
The research team and a small research advisory group will explore the information from the interviews you take part in.

A summary of the results can be sent to you if you are interested in the outcome of the study.
At a future date, the study may be published, for example, in a journal or at a conference presentation. You will not be identified in any report or any future publications or presentations.

Who is organising and conducting the research?

The study is being organised by Esmé Wood at Coventry University. The study is being undertaken as part of her doctoral studies and is funded by the Faculty of Health and Life Sciences, Coventry University.

Who has reviewed the research?

The study has been reviewed through the Coventry University Ethics process.

It has not been approved under the Mental Capacity Act so only people who can give consent for themselves can take part.

How to contact us

If you would like further information about the study, please contact Esmé Wood

Address: Esmé Wood - Principle Investigator
Lecturer in Occupational Therapy
Charles Ward Building
Coventry University
Priory Street
Coventry
CV1 5FB

Tel: 07500933369

Email: esme.wood@coventry.ac.uk

Appendix 10 Advert 1 Leaflet / Poster

Dementia Study 2016

Coventry University are currently seeking volunteers to help with a research study which looks at the importance of getting outdoors for people with dementia. We want to understand your experiences of nature and accessing green outdoor spaces, particularly if you have used any form of Technology to help you with this. We are also hoping to speak to carers and family members of people with dementia who have used any form of technology to support them get outdoors.

Could you or someone you know help?

What will happen if I decide to take part?

1.A researcher will come and visit you in your home, or another location agreed by you, to talk to you about consenting to the study.

2.If you are able and happy to consent to the study she will conduct an interview with you about your experiences.

3.Following completion of the interview, you may be asked to undertake a second interview approximately 6 months – 1 year later.

Scan the QR code or use the web address to view a short video about the study online

https://youtu.be/5WES2FhJi90

If you would like further information about the study, please contact

Esmé Wood

Charles Ward Building
Coventry University
Coventry
CV1 5FB

Tel: 07500933369
Email: esme.wood@coventry.ac.uk

Appendix 11 Ethical Certificate for main research studies

Certificate of Ethical Approval

Student:

Esme Jones

Project Title:

Access to green outdoor spaces: what are the experiences of people with dementia who use safer walking technology?

This is to certify that the above named student has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

24 September 2014

Project Reference Number:

P26732

Appendix 12 Ethical Certificate to include JDR database recruitment

Coventry University

Certificate of Ethical Approval

Applicant:

Esme Wood

Project Title:

Using Safer walking technology to access outdoor natural environments; an exploration of its use by people with early stage dementia.

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

21 July 2016

Project Reference Number:

P45311

Appendix 13 Advert 2 Recruitment video link
https://youtu.be/5WES2FhJi90

Appendix 14 Smaller gatekeeper organisations

Organisation	Location	Contacted	Gatekeeper	Participant Enquiries	Participants Recruited
ACE Club	North Wales	01/05/2016	Yes	0	0
Camden Minds	London	01/05/2016	No		
Clear Voices	Bedford	01/05/2016	Yes	0	0
De-Active	West Sussex	01/05/2016	No		
Dementia Action Forum	Derbyshire	01/05/2016	Yes	2	0
Dementia Voices	Worcestershire	01/05/2016	No		
Dementia Voices	Stockton	01/05/2016	No		
Dementia Voices	Lancashire	01/05/2016	No		
EDUCATE	Stockport	01/05/2016	Yes	0	0
Forget me Not	Swindon	01/05/2016	No		
Friends together	Redditch	01/05/2016	Yes	6	0
Friends together	Bromsgrove	01/05/2016	No		
Healthy Living Club	SE London	01/05/2016	Yes	0	0
Hope and Doodle Advocacy Group	Lewisham	01/05/2016	No		
Hope Group	Brighton	01/05/2016	No		
Open Doors Project	Salford	01/05/2016	No		
Ramblers Association	City of Birmingham	01/05/2016	Yes	0	0
Ramblers Association	Coventry	01/05/2016	No		
Ramblers Association	Rugby	01/05/2016	No		
Ramblers Association	Leek	01/05/2016	No		
Ramblers Association	Shropshire	01/05/2016	No		
Ramblers Association	Lichfield	01/05/2016	No		
Ramblers Association	East Cheshire	01/05/2016	No		
Ramblers Association	Congleton	01/05/2016	Yes	3	0
Ramblers Association	Warrington	01/05/2016	No		
Ramblers Association	Vale Royal + Knutsford	01/05/2016	No		
Ramblers Association	Maesteg	01/05/2016	Yes	0	0
Ramblers Association	Vale of Glamorgan	01/05/2016	Yes	0	0
The Beth Johnson Foundation Group	Stoke on Trent	01/05/2016	No		
The Kymin Group	Cardiff	01/05/2016	No		
The Laverstock Memory Support Group	Salisbury	01/05/2016	Yes	0	0
Weekend Day Centre	Stockport	01/05/2016	No		
West of Berkshire Empowerment Group	Berkshire	01/05/2016	Yes	0	0
York Minds and Voices	York	01/05/2016	No		
Young Dementia UK	Oxfordshire	01/05/2016	Yes	0	0

Appendix 15 Research Facebook page link

https://m.facebook.com/dementiastudy2016/

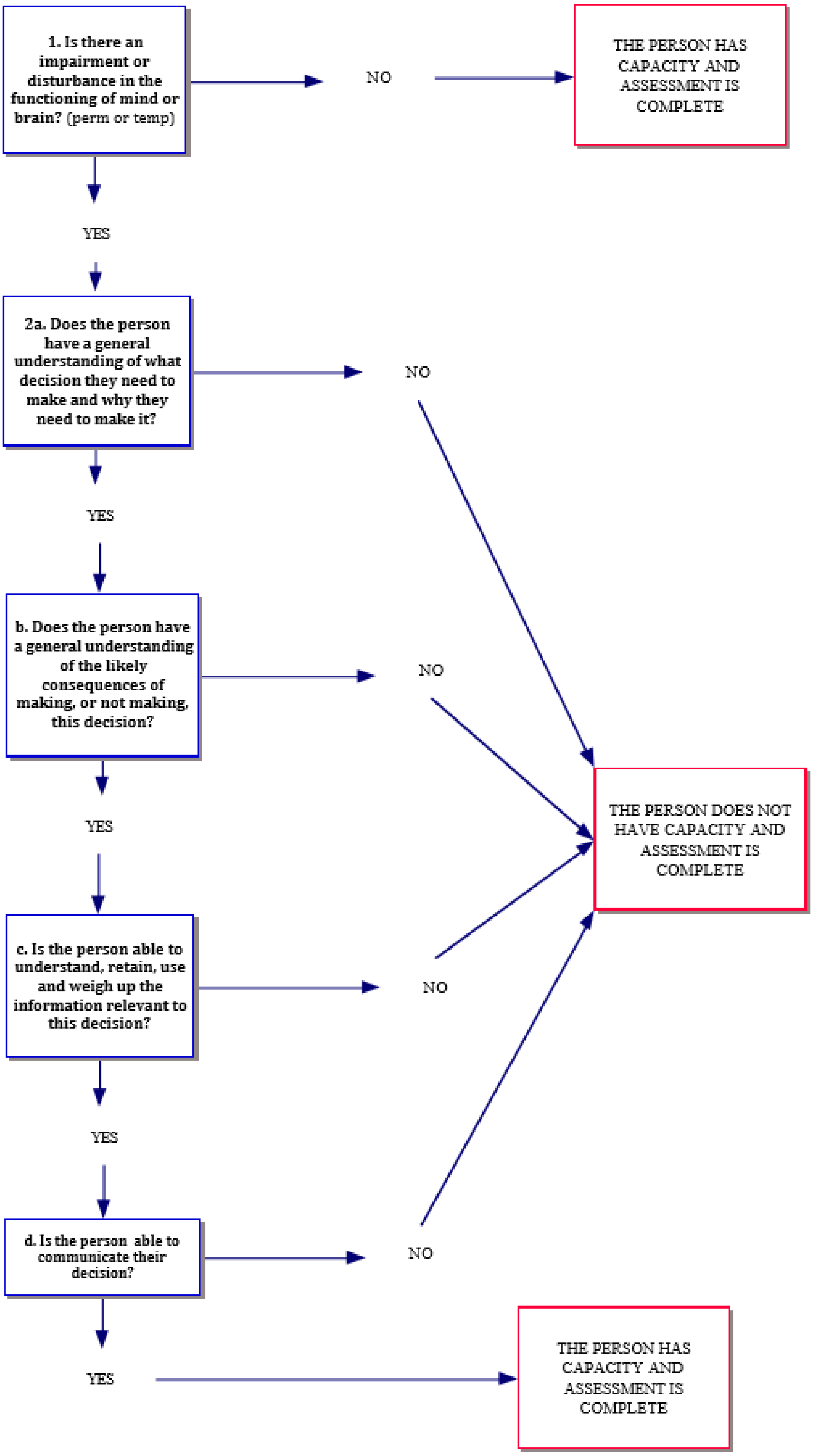
Appendix 16 Use of paid adverts within social media

Month	March	April	May
Facebook			
FB posts	10	11	10
Advertising Spend	0	£40	£40
Total post reach	1760	5977	7321
New page followers	39	49	54
Monthly page reach	961	3702	4740
Shares	73	83	90
Twitter			
Study Tweets	3	4	5
Re-tweets	5	5	3
Recruitment Outcomes			
Enquiries for information	16	42	38
Participants recruited	3	0	0

Appendix 17 NIHR Join Dementia Research recruitment

Research Study	Potential participants matched and contacted	Participants who responded	Participants who were recruited
Study 1: family carers of people with dementia	202	158	4
Study 2: people with dementia	174	48	7

Appendix 19 Capacity to consent assessment



Appendix 20 Semi-structured interview script and notes

Interview Script

1. **Historic relationship with the outdoors**

Have you always enjoyed getting out into the outdoors? Tell me a bit about this?
When did you first start walking/ fishing/ etc (insert activity as described by the participant)?
How often did you/ do you currently go out and engage in this activity?
Why is this important to you personally?

2. **Impact of Dementia**

How did developing dementia affect your life initially?
-Friends/ family reactions
-Personal identity
-Practical tasks
-Other interests and activities

How has this impacted your ability to access outdoor spaces?

3. **Attitude towards technology as a supportive tool for people with dementia**

Have you always used technology, such as gadgets and or computers?

Generally, do you find them helpful in your life?

4. **How do you feel about the use of technology being used to support people with dementia?**

5. **Use of Safer walking Technology**

Interviewer note – Before stating this section please refer the participant to the information sheet that was provided, in particular, the description and images of safer walking technology.

What type of technology have you used/ are you currently using?

What made you think to use it?

How did you expect it to would help you?

You have some experience of using a form of safer walking technology. Can you tell me a little about this…?

-Did it improve your ability to go out?
-Did you need any help from others to use the technology?
-Did it increase your feeling of security when out?
-How did this make you feel?

[Impact on overall health and well-being, identity, or others]

Do you still use this technology? If not, why not?

6. Looking forward to the future

Tell me about the future, how do you see the future of your (insert activity as described by the participant)?

-Impact of dementia
-Opportunity to engage in activity
-Support you might need
-Importance of this to you

What would it mean to you if you had to stop engaging in (insert activity as described by the participant) completely?

How might Technology be of assistance to you in the future?

Would you continue to use the technology you have already experienced?

7. Closing questions

How did you find the experience of doing this interview? Was it useful to you?

What things were really important to you?

Is there anything else you feel I have missed, or you would like to talk about?

Appendix 21 Full Individual participant analysis

Emma - Interview Summary

Technology used	Outdoor activity engaged with
Buddi tracker	Cycling Walking for pleasure

Emma's father developed vascular dementia suddenly following a vascular event that happened whilst he was driving. Luckily no one was hurt, but it caused him to cease driving. He and/ his wife found the diagnosis of Dementia challenging, as he remained 'high functioning', able to continue with many of his daily activities as before but had a considerably impaired short-term memory. Unfortunately, they lost a great number of their friends at his time and Emma feels that this was in part because for the stigma associated with dementia, and also because people were worried, they would be asked to help out with lifts, etc. Emma's mother became increasingly isolated and was unaware of the help and support available to them through local organisations or statutory services. It appears that they were not signposted by the GP or others at the hospital to these services. Emma became the main carer for her father after her mother's death and by chance came across the Alzheimer's Society in her local supermarket. Since then she has started to attend the memory café's and accessed a range of support for her father, including financial benefits and advice from an Admiral Nurse.

At this time Emma was starting to have some concerns about her father, who lived independently and still went out daily on his own. He enjoyed cycling and went out on leisure cycles as well as using it as his main form of transportation. Despite dementia, Emma describes her father as a 'homing pigeon' who always found his way home by following the river that ran through their town. However, she knew that his dementia would eventually deteriorate further and didn't want to have to restrict his life. One evening he didn't return home and the family and police all went out looking or him, he turned up safe and well having been out to an evening talk in the local town. However, with the support of the admiral nurse this prompted Emma to apply for a buddi system to prevent future re-occurrences, *however because her father had not actually been 'lost' he did not meet the criteria for provision and Emma feels they missed the vital window of time where he would have learned to use the buddi and develop the habit of wearing it. Around 18 months later he became lost in the local area twice and was provided with a buddi system as well as carer support. However, it was hard to get her father to develop the habits of wearing and charging the system. This was also not helped by a poor understanding of this need to develop habits by the carer, who discouraged her father from wearing the system when out with him. Consequently, the buddi system was used sporadically, and he was not wearing it when he several falls from his bicycle, including when he fell and broke his hip.*

Emma's father never fully recovered from this fall and experienced a long period off illness in the hospital before moving into a care home. He is now too frail to live alone and unable to ride his bike. Emma's very happy with the small care home where he lives but wishes he could get access to the outdoors more, especially in the winter months. She feels that even the little time he spends in the home garden is of great value to him and tries to take him out whenever she can. Reporting that recently they went out for a family meal and he asked to say outside for some time to watch the trees as the season was changing.

Emma - Intermediate Themes

- Fathers driving cessation
- Parents social isolation
- Fathers decreased ability with technology
- An issue with equipment provision criteria
- Family worry for father when out
- Fathers Critical vascular event
- Deterioration in overall health
- Father is a keen cyclist
- Father has repeat cycling accidents
- Awareness increases fathers anxiety
- Father gave up cycling
- Increased support meant tracker was used less
- Parents not aware of financial support available
- Getting outside important to fathers wellbeing

- Parents unaware of local support groups
- Cycling maintained fathers health
- Carer education an issue
- Father not worried by monitoring
- Not part of his own assessment
- Father gets practical support from family to remain independent
- Father can’t get outside anymore
- If they had had the tracker earlier….Father no using technology in emergencies
- Tracker benefits daughter more than father
- Relationship of giving and take
- Father a homing pigeon
- Father compliant for daughter’s benefit
- Father felt he was a burden
- Tracker provided too late
- Father needs outside
- Father loved getting outside
- Father wants to spend time outside
- Tracker provided too late to develop a habit
- The age difference between daughter/father unusual
- Battery life is an issue for tracker
- Awareness increases suicide risk
- Impact of not getting outside
- Father had to give up cycling
- Time of tracker provision important

Emma - Theme Development

From the emergent themes 15 common/over-arching themes and 5 individual participant themes were developed:

Emma - Thematic Table

	Individual Participant Themes		**Intermediate Themes**	**Line no**
1	"Dad always came with us": Family relationships are based upon giving and take	1	Concern for father’s welfare when out	941-944 949-950 960-961 966-969
		2	Family support each other	552-553 573-574 574-584 591-594
		3	Father wants to reduce the impact on others	529-536 546-550
		4	Tracker primarily supports family carers wellbeing	1101-1105 1198-1205
2	“Better not get back on my bike”: A shrinking world	5	Parents social isolation	472-473 483-485 491-492

				498-504
		6	Fathers decreasing ability to manage technology	928-933 1296-1300 1352-1356
		7	Cycling accidents and cessation	268-272 280-281 1226-1233
		8	Impact of not getting outdoors	1441-1448
		9	Unable to live at home anymore	704-706 1547-1549
3	"Do you have to lie to get this stuff?": Let down by services	10	GP not signposting to basic support	156-164 170-178
		11	Not assessed in his own right	886-892
		12	Equipment provision criteria	198-801 855-857
		13	Lack of carer understanding	827-832 1083-1085 1422-1425
4	"Timing is important" : The importance of developing habits	14	A homing pigeon, habits developed over time	588-591 648-649 683-684 906-908 1002-1006 1708-1711
		15	Tracker provided too late	789-792 814-818 1030-1031 1385-1397 1769-1771 1840
5	"He's always been a keen cyclist" : Fathers well-being	16	Loves getting out	699-708 716-726 1484-1494 1516
		17	Keen cyclist	251-253 262-266 370-377
		18	Insight can have a negative impact	413-415 610-613 1136-1144

Emma - Key data extracts

""Dad always came with us": Family relationships are based upon give and take

Concern for father's welfare when out

She rang me from there, he wasn't at home. So, you then trying to suppress this panic and she said, 'I'll say here a bit and I said, 'ok, then', and then I was like half 7, quarter to eight, still nothing. (941-944)

Nothing was adding up and I didn't really want to panic but obviously eight o'clock you know it is starting to turn… (949-950)

You don't know and didn't really want to start ringing around the hospitals first but we hadn't heard anything (960-961)

So we did end up ringing the police and the woman from here was actually down at dad's, she got sent on route and then we had a phone call back from the police to say your dads just been brought in (966-969)

Family support each other

At the end of the day they were very much there for me when my marriage broke down so (552-553)

Yeah. When mum was alive, obviously he had mum prompt him. When she was in hospital we, it was like his tablets (573-574)

When she was in hospital we, it was like his tablets he had to have aspirin every day…And either mum would remind him beforehand…so when she was in hospital and she was in for virtually a month she had pneumonia herself and that we, the girls could, well the older one XXX the older one, she constructed a chart for him……and we got him to tick it that he had it… (574-584)

Then after mum died we then like appointments. We did get a diary for him. First time he had a diary in years (591-594)

Father wants to reduce the impact on others

I think since mum died he's felt more a burden because obviously I mean there's 34 years isn't there between dad and I which a lot of people that are involved in this…they're on the same playing field, their husbands and wives…there's not many that are that much age wise (529-536)

He's felt guilty that he's stopped me from doing stuff and it's the case of well, no we've been on holiday since mum died, dad always came with us. We've had a fabulous time…and he's just fitted in with us… (546-550)

Tracker primarily supports family carers wellbeing

He'd have gone out regardless, I don't think it altered what he did…it just made me feel safe, is not quite the right word but more relaxed that I knew where he was…should that arise again that he wasn't (1101-1105)

I think so because he was absolutely mortified that we panicked and the police …were there cos it's the older generation isn't it, sorry to put you out and when we said that we you know, we've got this the admiral nurse managed to get it through and that and this is so that we don't have to worry about where you are we don't have to get the police involved, then I'll put it on. (1201-1205)

""Better not get back on my bike": A shrinking world

Parents social isolation

Friends yeah, one lot of friends just dumped him because obviously dad gave up driving (472-473)

So, but a lot of his friends 'oh, oh we might be called upon to, to be a taxi service' cos mum couldn't drive at the time (483-485)

Everybody just dumped him and nobody would come near…Even his main his cycling buddi…(491-492)

He still went out with the cycling club…but his main cycling buddi who obviously still were both retired that it was a nice day and dad would ring XXX up and XXX would ring dad and…just go out but no, they just ditch them. (498-504)

Fathers decreasing ability to manage technology

He got used to using his mobile but then he didn't, he'd forgot that it needed charging……Because he put obviously we have cordless phones so he'd put that back on, he used to get the two confused basically (928-933)

One time XXX had called in to see him and she said, 'you ought to come home', and he'd cut his head, there was blood and he'd obviously had a fit and blood all over the carpet, never even thought to press the button which would have summoned help (1296-1300)
And going back to the mobile I think that was part of it because he's old nokia packed up so we ended up having to buy him a newer version…Still a nokia, still the same layout but it wasn't the same (1352-1356)

Cycling accidents and cessation

So he went out on his bike, he went over the river, down the St Johns side back over the river and was coming home and like majority of accidents within, what is it, 5 mins at home caught the edge of a pot hole, down he went, fractured neck and femur (268-272)
You know even know he knows he's done it – oh better not go back on my bike (280-281)
Cos he came off his bike May of last year but he'd also came off it probably twelve months prior to that and going across XXX you've got a path and though retched blocked paving and the grass and he'd moved over to let a family…And the wheel just slipped off these and down he went, didn't break anything just bruised (1226-1233)

Impact of not getting outdoors

It's just gonna go downhill in it really…and probably quicker than had he have been able to remain in his own home. We sort of said that we're gonna have to, especially noticing the big difference in him since the weather has gone colder, he probably be alright if he took up smoking because he'd put his coat on and go outside but he hasn't smoked in years. (1441-1448)

Unable to live at home anymore

They've got a garden outside with the weather we just sat outside and I've noticed now it's gotten colder he is starting to get a little bit, shall we say, institutionalised…because he can't get out (704-706)
It's awkward because he's in the home environment so he wouldn't be going out on his own because obviously the doors are locked (1547-1549)

"Do you have to lie to get this stuff?": Let down by services

GP not signposting to basic support

I think that the GPs need to know what is out there because nobody had even said that the Alzheimer's society existed…Mum would have like….going to the cafés which is where we first met you…but we didn't know about those (156-164)
That was when I found out about a lot of stuff …one being dad should of got a deduction on the council tax obviously after mum died we did the deduction for single person but he didn't need to pay council tax. GP had never even told …mum at the time (170-178)

Not assessed in his own right

We just assumed that everybody gets one, I think it might have been the admiral nurse actually that …recommended, and thinking about it, that we asked her and she did the referral…As part of my carer's assessment (886-892)

Equipment provision criteria

But the council wouldn't give dad a buddi until he got lost…well, by the time they got lost, it's too late (798-801)
I asked at the doctors and then obviously we got referral through to social services, social services said, 'has he got lost', well, do you have to lie to get this stuff? (855-857)

Lack of carer understanding

The original carer had to give up due to ill health so we then had another one, he was very good, but he wouldn't enforce dad putting the buddi on …well, he's out with me but that's not the point. (827-832)
And we'd know that had the carer not said, 'it's alright, he's with me', dad would have got into the routine of putting it on (1083-1085)
They ended up having to call the police because they had lost him …Even that didn't make them put it on (1422-1425)

"Timing is important" : The importance of developing habits

A homing pigeon, habits developed over time

And with dad, with the repetition he then get, gets into doing it. It becomes second nature …To him (588-591)
There was never any worry until three years ago that he wouldn't (not even then) that he wouldn't find his way home. (648-649)
But he got this route that he used to call it the two bridges (683-684)
I thought, 'Oh where's he going I mean we've never stopped him going out for a walk as I say he's a home-in pigeon, he's always found his way back home….(906-908)
Well, all he needs is the river…And he'd find his way home (1002-1006)
If they are at the stage where they are wandering but I suppose with dad, as I say he's just a home-in pigeon and he knew how far he could go and come back…(1708-1711)

Tracker provided too late

It's got to be given at the right time…And that is the crocks of it, with dad I think it was given too late because… (789-792)
He's developed that habit …dad never had the chance to develop that habit…Because he was too late. (814-818)
That if he'd, the same thing had happened, I could have logged on and found where he was and it would have shown me (1030-1031)
Yeah, yeah, so we didn't bother and because the carer hadn't reinforced, I mean dad was going to a day centre two days a week and he was with the carer three so it was like Monday, Wednesday, Fridays he was with the carer and then Tuesdays and no…Tuesday and Wednesdays he was at the day centre Mondays and Fridays he was with the carer and then at the time I'd drop Thursday as well. (1385-1397)

And I think that's the crooks of, of all of it and people need to reinforce it even don't to like carers, had they reinforced as soon before they went out through the door, put it on (1769-1771)
Timing is important (1840)

"He's always been a keen cyclist" : Fathers well-being

Loves getting out

He'd just loved getting out and we've noticed now obviously he's been in the home since February they've got, it's only a small home, there's only 15 people in it…and they've got a garden outside with the weather we just sat outside and I've noticed now it's gotten colder he is starting to get a little bit, shall we say, institutionalised …because he can't get out (699-708)
And last week on his birthday we had a taxi over to the local Toby carvery and all the trees opposite are changing and he said, 'I don't want to go in yet'…he wanted to just stand, he said I wanna have a look at the outside and I thought…Yeah, so noticed a different change…because he can't get out…. (716-726)
I mean the home they do, do a lot, they have entertainment, they have a physio going in that does chair exercises and that sort of stuff so they do, do a lot he still needs to get out, he needs some outside..yeah. I say that rang big bells last week, dad didn't want to go in yet, 'I just want to look at the trees'…there's trees in the garden… and I thought, 'ooh Yes' (1484-1494)
Getting out would definitely improve his wellbeing (1516)

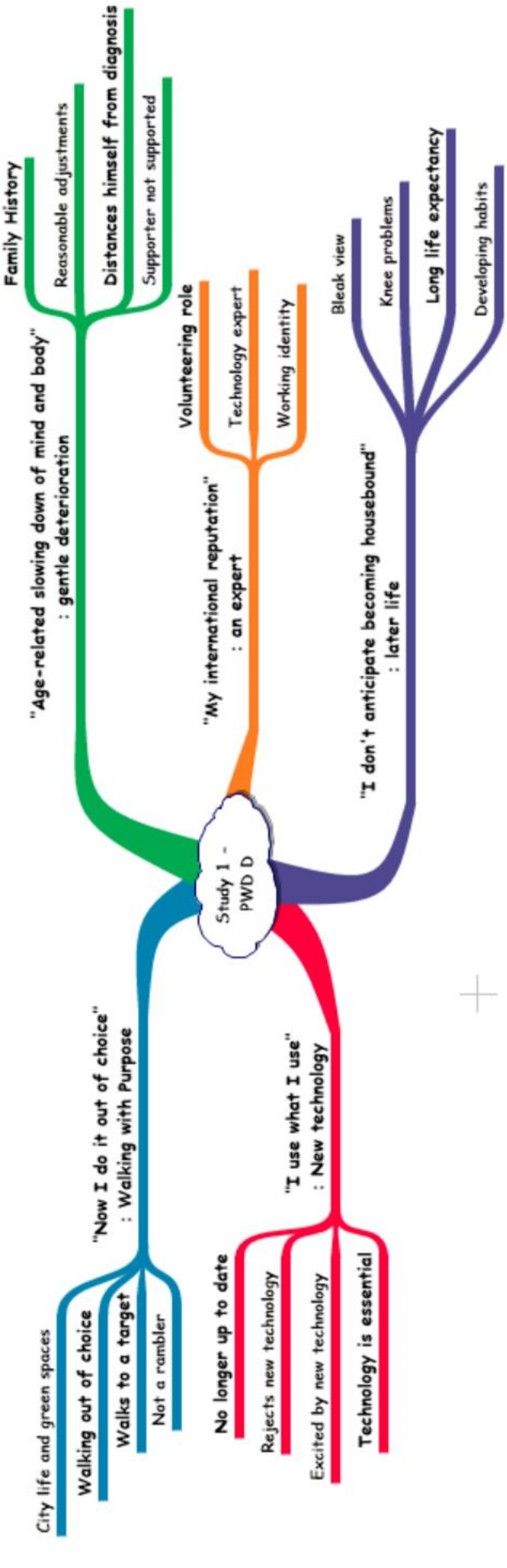
Keen cyclist

He's always been very fit and active and he was 84 last week he was, he's been a keen cyclist all his life…(251-253)
Yeah, so he's always been a keen cyclist which has probably kept him very, very fit…until May of last year when it was a beautiful day and he thought 'oh, I know what I'll do, I'll go out' (262-266)
Obviously they tell him stuff and mum said, 'it might be better to tell my daughter because you know XXX not going to remember'…'what do you mean? Oh well he has got vascular dementia, no no way!' They couldn't believe it…and that is obviously down to the cycling (370-377)

Insight can have a negative impact

Dad knows he's got a problem…and he dwells on that and the anxiety (413-415)
He'd look at the diary and he'd look at the clock and he'd look at the dairy and he'd go and sit back down again. 'Oh you're going', so then this would, it used to take us about 10 mins to actually get out. (610-613)
Or what had happened to him. I mean gosh that's basically we've had some guy haven't we that chucked himself in the river with dementia and that because this is where I say dad is just too aware and he's got a problem…And you do hope that, that never happened…but how desperate could he have got, he'd just gone to find out about dementia (1136-1144)

Appendix 22 Individual participant thematic map


Study 1 - PWD D
"Age-related slowing down of mind and body" : gentle deterioration
Family History
Reasonable adjustments
Distances himself from diagnosis
Supporter not supported
"My international reputation" : an expert
Volunteering role
Technology expert
Working identity
"I don't anticipate becoming housebound" : later life
Bleak view
Knee problems
Long life expectancy
Developing habits
"Now I do it out of choice" : Walking with Purpose
City life and green spaces
Walking out of choice
Walks to a target
Not a rambler
"I use what I use" : New technology
No longer up to date
Rejects new technology
Excited by new technology
Technology is essential

Appendix 23 Reflection table - Borton's Developmental Framework

What?	**So What?**	**Now What?**
Researcher closing down conversations to follow interview schedule	Prevents participants from explaining their experiences in full.	Researcher to be more self-aware and to pause after each subject to give the participant time to add further to their discussion if needed
Researcher interrupting participant to agree with them or ask for more detail.	Stops the flow of ideas and redirects conversation to new question.	To write ideas or further questions down on post it notes, to be looked at together afterwards
Conversational style of interview to develop rapport	Reduces opportunity for participants to provide detailed answers and encourages short responses.	Researcher to spend more time listening to participants and try to give non-verbal ques such as nods rather than spoken ones.
Leading statements following open questions	Encourages participants to follow the researchers trail of thinking, rather than their own. Creating a potential bias	To stick to the simple questions, leaving the participant free to interpret them as they want.
Summarising of interviews key points led by researcher	Researcher controls the narrative and summary, not necessarily representing the experiences of the participant fully.	For researcher and participant to write key ideas down on post it notes as the discussion progresses. To review these together at the end of the interview

Appendix 24 Study 1 Individual participant analysis

Annabel – Individual interview analysis

Annabel - Interview Summary

Technology used:	Outdoor activity engaged with:
Buddi System	Walking on holiday Local walking

Annabel lives with her 80-year-old father who has dementia, she moved in with him three years ago and during that time his dementia has progressed considerably. Her mother died several years ago and although her father's dementia has been evident for many years, he has never acknowledged it himself and appears to have limited insight into the difficulties he faces. He has always enjoyed walking and went on lots of outdoor holidays with his wife, living abroad for part of the year and getting up and out of the house early when at home.

Annabel provides all care for him now, but there was a time when he lived independently, and social services put formal carers in to support him at home. Unfortunately, there was a breakdown of communication between Annabel and the social workers and she felt the introduction of formal care was handled poorly, giving her little choice as his main carer. She does not know what led to the introduction of carers or what assessments were undertaken with her father. It was at this time that social services provided her father with a 'buddi' system, which enables a carer to track the person wearing it. However, it was not initially clear who was supposed to monitor the system and Annabel appears to resent the initial burden of setting up an online account and managing the system. Annabel also describes having very low expectations for the effectiveness of the system, usefulness of tracking and her father's likely compliance with wearing the devise. However, despite this these difficulties and concerns she talks very positively about using the system and the ability she must track and monitor her father's whereabouts when he goes out walking. In particular she is keen to discuss the emotional reassurance it gives her to know where he is and that he can be found if needed. Annabel describes herself as being IT literate and uses a range of smart devises in her own life, embracing the opportunities technology offers in her everyday life. Annabel see's the buddi system as an extension of that 'everyday technology' that is part of daily life for most people. Demonstrating a somewhat paternalistic attitude she jokes that all pensioners should wear a buddi system.

Annabel's father can no longer use technology easily and has forgotten how to use some technology he used to be good with. However, she reports that in his past he was always keen on new gadgets and liked to have the latest kit. The buddi system was introduced to Annabel's father once his dementia was already quite progressed and although he has seemed happy to wear the system she does not believe he understands what it is for or how to operate the emergency help button featured within the wearable part of the technology.

In recent months Annabel feels the 'Buddi 'system has become less relevant and they have stopped using it. This is because her father no longer goes out alone and has lost interest in going outdoors for walks. They have also had to cancel a planned holiday as the recent deteriorations in his dementia have become increasingly difficult for her to manage. Annabel indicates that although the buddi system was very helpful for them at one time, it has reached the end of its usefulness.

Despite her own positive attitude to technology and the successful use of the buddi system, Annabel is not in favour of the introduction of technology for people living with dementia. She dismissively asks, "what is the point?" indicating that in the end all technology will become less useful as the persons dementia progresses. She also expresses some fears about the use of technology in place of human contact.

Annabel - Intermediate Themes

- Breakdown of communication between family and social services
- Daughter/ father relationship changes
- Buddi system benefits Annabel as a carer
- In denial of father's needs
- Other family members aware of changes but not father
- Can't see a use for technology in her father's future

- Low expectations of father’s compliance with buddi system
- Father no longer enjoys being outside
- Lack of interest in father’s motivations/ meaning making
- Finds reassurance in use of the buddi system
- System provided to father without communication to family
- Dismissive of the use of technology/ gadgets for people living with dementia
- Concerned about the use of technology to replace humans in dementia care
- Burden on her as a caregiver
- Finds caring difficult
- Not willing to see fathers needs
- Father needed support to change technology
- Father loved gadgets
- Doesn’t feel technology is good for people living with dementia
- Cancelled holidays as unable to manage
- Paternalistic attitude towards father
- Compares father to a baby
- Considers herself IT literate
- Father loves getting away on holidays
- Social walking on holidays
- Annabel feels he can’t be alone anymore
- Driving cessation following small accident
- Upset / angry by services provided to father
- Experience of diagnosis and memory clinics was good
- Buddi system no longer useful as dementia progresses
- Burden of caregiving
- Praise for the buddi system
- Paternalistic attitude from services to family
- Want to support father
- Father lacks insight into his condition
- Father loves the outdoors
- Father enjoys a range of hobbies, very skilled craftsman
- Father finds walking relaxing
- Annabel feels the buddi system has no impact upon her father
- Decrease in father’s skills to use technology
- Used buddi system to balance/ plan the demands of her own life and caring.
- Symptoms of dementia evident long before diagnosis

Annabel - Theme Development

From the intermediate themes 5 individual participant themes were developed:

1. **"I find he doesn't seem to like being in the house at all": Father always liked to be busy**

2. **"It's like having a baby": A changing relationship**

3. **"What on earths that around your neck": A difficult introduction to the buddi system**

4. **"I knew I could find him if I needed to": Helpful to Annabel but not necessarily her father**

5. **"Tomorrow they'll forget it" : Negative attitude towards technology for people living with dementia**

Within these themes a further 18 themes were identified, with each individual participant theme having between 3-5 themes each.

Annabel - Thematic Table

	Individual participant Themes		**Intermediate Themes**	**Line no**
1	"I find he doesn't seem to like being in the house at all ": Father always liked to be busy	1	Father enjoyed the latest gadgets	231-239
		2	Enjoys the relaxing in the outdoors	39-40 91-94 102-105
		3	Looked forward to holidays	82-88 115-116 490
		4	Skilled craftsman	61-69
2	" It's like having a baby": A changing relationship	5	Paternalistic attitude but wants to support her father	14-20 191-196 199-200 388-389
		6	No longer enjoying the outdoors	520-524
		7	Not always empathetic to fathers needs	145-149 202-205
		8	Finds it difficult to manage caregiving	652-656
		9	Dementia progressed further	457-463 489-492 500-503 512-515
3	"What on earths that around your neck": A difficult introduction to the buddi system	10	Breakdown of communication	301-303 309-317
		11	Annabel upset by services provided	297-299 327-332
		12	Not consulted about the buddi system	282-286 339
4		13	Praise for the buddi system	385

	“I knew I could find him if I needed to”: Helpful to Annabel but not necessarily her father			387-389
		14	System supports her as a carer	393-394 398-399 417-425
		15	Father unaware of the buddi system	397-398 412 442-443
5	“Tomorrow they’ll forget it”: Negative attitude towards technology for people living with dementia	16	Low expectations of buddi system	433-437
		17	Concern about the loss of human contact	636-641
		18	Doesn’t feel technology is a good thing for people living with dementia	250-253 578-583 624

Annabel - Key data extracts

1. “ I find he doesn’t seem to like being in the house at all“: Father always liked to be busy

Father enjoyed the latest gadgets

Year’s ago they had double decked tape recorders, remember when we use to tape a tape and we had all that, he had the gadgets and he’d sit here doing all this but that was television stuff it’s not computer stuff…It was, exactly, exactly. Oh he was well happy. …..Oh god yeah, he knew exactly what he was doing with that. (231-239)

Enjoys the relaxing in the outdoors

I find he doesn’t seem to like being in the house at all. (39-40)

Well the weather for start, it was obviously…even though the Portuguese might be wearing coat and jackets they could still walk around in shorts and short sleeves if they wanted to. (91-94)

They used to take my dad’s sister, she liked to do a lot of walking so they probably did walk a lot when she was around. Just went there to relax really and you know. (102-105)

Looked forward to holidays

They did holiday only to Weston Super Mare in the summer once a year but they used to go Portugal six weeks every year at the end of the year, it’s cheaper to go over there than run the house over here, so they used to shut down the house for six weeks and go off to

Portugal and they did that every year and they loved it, they did it for years and years. (892-88)

Oh he loved it, he loved getting away.. He's been an active person all his life and he get's bored very quickly. (114-115)

We did actually book a holiday to Cornwall (<u>490)</u>

<u>Skilled craftsman</u>
We've got a massive shed at the top of the garden and he used to do every tool under the sun up there he could do anything. I mean you know they say jack of all trades, master of everything well he is, he even put his hand to decorating, model making, anything, the only things he doesn't touch is gas and electric, anything else he used to be able to do it. (<u>61-69)</u>

2. " It's like having a baby ": A changing relationship

<u>Paternalistic attitude but wants to support her father</u>
Well a little about me as in like I'm single, I've never been married, I moved in with dad 3 years ago come this December because something happened and, you know, well I was getting made redundant anyway so it was a no brainer just basically move in with dad and go on from there and my relationship is obviously I'm his daughter, so this is my father <u>(14-20)</u>

She said 'is there any other things' and I said well I know he's knocked the headlights, and she said 'well it might be time to take him off the road' and she said 'if you don't do it, I will'. So that day I came home and took him off the road. (<u>191-196)</u>

I said 'well if you wanna go anywhere I'm here anyway, well I'm around I can come and take you'. (199 - 200)
All pensioners should be wearing them now (388-389)

<u>No longer enjoying the outdoors</u>
But we go somewhere and he goes "oh we going home now?" and I'm like "we've just

got here". Yeah it is and you get home and he goes "are we going out today then" and I'm like "well we have". (520-524)

Not always empathetic to fathers needs

I don't think he would have even…he wouldn't have known because there was nothing wrong with him, he just carried on…yeah…..I don't think it affected him at all. (145-149)

I'm tired and I'm like I've had enough now I just wanna put my head back, there's only so much you can do and only so many places you can go and how many times can you go shopping per week (652-656)

I mean occasionally we'll be doing something and he'll go 'I miss my car because I used to drive' you know things like that but it was an easy transition (202-205)

I'm tired and I'm like I've had enough now I just wanna put my head back, there's only so much you can do and only so many places you can go and how many times can you go shopping per week, you know, I'm finding it hard (652-657)

Dementia progressed further

Progression of dementia, things occurring that there's no way I'm going to leave him on his own now. If he does somewhere he's either with one of us, me or XXX, do you know what I mean? He's never really on his own. If I have left him on his own he's already in bed and I've told him I'm going and I'll be half an hour, I'll be back as soon as possible. (457 – 463)

That's where the incontinence really kicks in 5 to 6 and, you know, we did actually book a holiday to Cornwall at the end of August to September last week there in a holiday cottage but we had a few issues prior…. I can't afford to clean somebody else's carpets, so I cancelled the holiday. (489-492)

I thought renting a cottage can you imagine if he wees somewhere if I'm asleep, I can't afford to clean somebody else's carpets, so I cancelled the holiday. (500-503)

I take provisions with me in case anything happens, if we have accidents, I've always got water with me, wet wipes, you know, it's like having a baby, you take the baby out…(512-515)

3. "What on earths that around your neck ": A difficult introduction to the buddi system

<u>Breakdown of communication</u>

I come up the one day and there was a lady sat and I said "and who are you" she said "I'm one of dad's carers" I said "since when?" and they'd be coming… (301-303)

Well I was not impressed because I came up the one day to visit him and he said "oh my god I've had loads of people in this house today", I'm like "who would you have in the house" he's like "I don't know but he's asking me lots of questions" and it's only after I started pried and prodding I found out it was…well the 'side by side team' because their envelope…their file sorry was there and I rang them and said what's this all about, so obviously. (309-317)

<u>Annabel upset by services provided</u>

And I sound very negative because I am angry that they actually put care into this house without my knowledge. (297-299)

I was the one who had to claim the attendance allowance and all things like that and I had to sort out all the bills when they started coming through. If they'd have put me or had me in the picture from day one I may have changed my life around to sort it out better. (327-332)

<u>Not consulted about the buddi system</u>

I didn't ask for it, they gave it to him. I came up one day and said "what on earths that round your neck" [interviewer laughs] didn't even know. (282- 286)

They brought it in. (339)

And I sound very negative because I am angry that they actually put care into this house without my knowledge. (297-299)

4. “I knew I could find him if I needed to”: Helpful to Annabel but not necessarily her father

Praise for the buddi system

It my…it’s an amazing piece of kit.(385)

It’s phenomenal, something as small as that with the range it’s got, all pensioners should be wearing them now (387-389)

System supports her as a carer

Piece of mind and I knew I could find him if I needed to. (393-394)

The fact he was wearing that made me feel better to him going out even more (398-399)

Only once when a friend of mine called about going somewhere and I said “dad’s not back yet, I’m expecting him any minute” I said “hang on, I’ll just go online and see where he is” but he was actually in town so I couldn’t go out that day with my mate so…but at least I knew I could tell my mate “you’ll have to go off and do it yourself mate cos I can’t come, my dad’s still in town”. So for that reason but I’ve never, I’ve never actually used it in an emergency ever. (417-425)

Father unaware of the buddi system

Well he was going out all the time anyway, with or without it but the fact he was wearing that made me feel better to him going out even more. (397-398)

No I don’t think he really knew what it was. (412)

He just knew he had to wear it and that’s it, he didn’t know what it was for. (442-443)

5. “Tomorrow they’ll forget it”: Negative attitude towards technology for people living with dementia

Low expectations of buddi system

For start I thought I wouldn't wanna carry that round my neck all day long but it didn't bother him, he took to it straight away, I thought he'd be taking it off and when I come in it'll be on the Table or something but no he was very good with it. (433-437)

Concern about the loss of human contact

I personally don't know, unless there's a physical being like me with that person, I can't see what you can put in place to make it easier, I just can't see it. (638-641)

I know this sounds very negative but I can't see a point to it because you're teaching how to turn a telly on and then tomorrow they'll forget it. (250-253)

Doesn't feel technology is a good thing for people living with dementia

I know this sounds very negative but I can't see a point to it because you're teaching how to turn a telly on and then tomorrow they'll forget it (250-253)

I can't answer that at all. I think once they get passed the stage I can't see [pause] no I'm sorry but I can't see a gadget…[talks to dad]…no I can honestly say oh if you had a smarter phone than this and had a little button then [shouts] I just can't see what gadget, how it would help. (578-583)

I can't answer your question on gadgets for future. (624)

Barbara – Individual interview analysis

Barbara - Interview Summary

Technology used	Outdoor activity engaged with
Buddi tracker system	Gardening
	Dog walking
	Walking for pleasure
	Social walking

Barbara worked as an EEG technician at the local hospital and often undertook diagnostic scanning for people who were diagnosed with dementia. She feels that this role and experience enabled her to see the signs and symptoms of her husband's dementia long before others and that she knew about his condition long before he did.

Barbara's husband was a sociable man, who enjoyed walking their dog in the local area for many years. Even after the dog passed away he would go out and walk around the local housing estate talking to the many neighbours with whom he had a friendship. They enjoyed dog walking together and often walked for pleasure along the nearby river or across local fields. Barbara's husband was always keen to walk at a fast and purposeful pace and eventually she found it difficult to keep up with him and so stopped walking with him. He continued to walk in the local area every day until he moved to a care home in the last few months, shortly before his death.

Barbara reported that early signs of his dementia included an inability to manage basic technology he was previously skilled at, such as TV remotes and small household gadgets. Although her husband dismissed these difficulties, their 3 sons noticed some changes in him when they visited, but this was not often as they lived some distance away. Eventually a critical incident where he became lost prompted Barbara to encourage her husband to seek a diagnosis. Over the following years there were a number of incidents where her husband would go out for a walk and not return, prompting a search for him in the local area. As his dementia deteriorated Barbara tried a range of measures to reduce the incidents *and risks associated with them, including him carrying an identity card with her phone number, keeping the household doors locked when he was at home and using a 'buddi' tracking system.*

The buddi system was provided through the local social services following a missing person search when Barbara's husband had walked away for several hours and was found near a local motorway bridge. At this point in time he could no longer operate the 2-way radio system and was not aware of the purpose of the buddi itself as a tracker. The system worked well as a reassurance and enabled Barbara to leave him in the care of others for brief periods of time, knowing that should he 'abscond' from their care, he could always be located. However, the buddi system is quite large and required the user to wear it around their neck. Barbara found that although her husband was compliant with wearing it outside, he would not wear it inside and so if he 'slipped out' of the house he was often not wearing it. Inside their home he would often take the buddi off and 'hide' it around the house. There were several more instances of him walking off over the following years including him being missing for several hours in very cold and wet weather in February, during this incident a police helicopter was used in the search to find him.

Barbara found these experiences very challenging and the responsibility of caring for him alone was increasingly difficult as he did not recognise her. Often telling Barbara that he needed to leave so that he could return to his wife and children. At the very end of his life Barbara conceded that her husbands need's would be best met in a secure nursing home and he moved there shortly before his death. She continued to use the Buddi system with him right up until this move and feels that it was useful and valuable to her for a long period of time.

Barbara - Intermediate Themes

- Family knew about dementia before husband did
- Early signs and symptoms
- Wife knew he had dementia before he did
- Barbara embraces technology where it's helpful
- Initially dismissed/ denied problems
- Critical incident of getting lost led to diagnosis

- Outside activities together with her husband
- Husband was not aware of dementia
- Dog walking
- Husband out walking
- Husband getting lost
- Husband out walking
- Husband enjoyed talking to people
- Useful window of time
- Husband reduced technology skills
- Worry when husband went missing
- Husband getting lost
- At risk
- Reassurance
- Not recognising home
- Buddi system provided by social services
- Husband not accepting buddi
- Not recognising wife
- Barbara believes a watch would increase compliance

Barbara - Theme Development
From the Intermediate themes 4 individual participant themes were developed:

1. **““He was oblivious to it”: Barbara’s husband lacked insight into his condition**

2. **“He was obviously in a different world to me”: The life they lived together not recognised anymore**

3. **“If he could get out of the house he was off”: Husband frequently tries to get ‘home’ and gets lost in the local area**

4. **“At least we’ll know where he is”: The buddi ‘tracker’ offers reassurance for Barbara**

Within these themes a further 13 themes were identified, with each individual participant theme having between 3-4 themes each.

Barbara - Thematic Table

	Individual participant Themes		Intermediate Themes	Line no
1	"He was oblivious to it": Barbara's husband lacked insight into his condition	1	Family knew about dementia before he did	31-33 43-49 65-67
		2	Initially dismissed / denied problems	72-73 82-84
		3	Wouldn't accept the buddi system	289-290 310-311
2	"He was obviously in a different world to me": The life they lived together not recognised anymore	4	Outdoor activities together	106-107 120-122 129
		5	Dog walking led to daily walks on his own	146 -153 157-159
		6	Not recognising wife	452-454 496-500
		7	Not recognising home	432 489-493
3	"If he could get out of the house he was off": Husband frequently tries to get 'home' and gets lost in the local area	8	Frequently getting lost	35-40 460-461 469-470
		9	Worry when he went missing	349-352 358-359 367-370
		10	At risk	361-362 393-396 462-467
4	"At least we'll know where he is": The buddi 'tracker' offers reassurance for Barbara	11	Differing levels of ability with technology	196-202 220-224
		12	Reassurance	286-287 405-409 414-421
		13	Useful window for buddi system	238-240 273-276 391-392

Barbara - Key data extracts

1. ""He was oblivious to it": Barbara's husband lacked insight into his condition

Family knew about dementia before he did

He was first diagnosed in 2008 and that was when we knew he'd got dementia. I knew he'd got dementia a long time before that. (31-33)

Say I work for the NHS. I've EEG technician so I EEG patient with dementia so we knew about it. My husband didn't …but I did. (43-49)

We got 3 boys and they all live away- so they did see probably a difference when they came to see their dad like when they came here. (65-67)

Initially dismissed / denied problems
So, I think he was oblivious to it to be honest. (72-73)

It was just little things and in the early days of it even when I was still 'umming and arring' about has he go dementia or not I'd put it down to the stupidity of men. (82-84)

Wouldn't accept the buddi system
Took it off the minute he walked in, he took it off. (289-290)

But all this new way it was and then he'd bring it and then he'd hide it (310-311)

2. "He was obviously in a different world to me": The life they lived together not recognised anymore

Outdoor activities together
Like when we were both retired we always went out every day to garden (106-107)

We did like walking and walking particularly hill. We got the river, the river literally about 300 possibly about 400 metres away from here. (120-122)

We did dog walking so we did enjoy that. (129)

Dog walking led to daily walks on his own
He'd go out every day……he's fast walking, I said on your bike lad, I'm not coming …and he'd know everybody on a big estate that's just across on the other side of the main road and little old ladies, he seemed to know everybody. (146-153)

Yes but even after the dog passed away [laughs], he was 13, bless him, so I mean, yeah he knew everybody in the road and I'd say, 'who your talking about', I don't know that person but he did (157-159)

Not recognising wife

He did tell me he was very sorry but he got to go home cos his wife and kids were waiting for him (452-454)

He was found by the cathedral which was about 400 metres from where he lived as a boy…that's where he was, that's was where he was living. He seemed to be always heading there. (496-500)

Not recognising home

They told me he wanted to go home (432)

So it was always, he needed to go back to his wife and his children…so he was obviously in a completely different world to me. (496-500)

3. "If he could get out of the house he was off": Husband frequently tries to get 'home' and gets lost in the local area

Frequently getting lost

What really made me definitely go and take him to see the doctor was he forgot the way to our local garden centre which we'd been going to probably for 50 years. (35-40)

He said, 'I'm ever so sorry. I've just got to go home' and he just walked out. (460-461)

Fortunately he was still able to ask someone, he was lost and told them he was a lost (469-470)

Worry when he went missing

Yes, it was just something, you know, it was terribly worrying to find he's been gone for 2 hours…where the heck is he? (349-352)

Yes and you've got that dilemma, do I go out and look for him, do I get in the car and go off or do I stay here. (358-359)

For him to be a little bit less mobile would have been a blessing…because I couldn't keep up with him if he went off. (367-370)

At risk

Well, like eventually I got the police involved obviously and then the police helicopter at one point so. (361-362)

I mean in February, he'd taken off, he got out and taken off. It was cold, wet and horrible and I think he was out for about 5 hours and that was when we had the police here. (393-396)

It was prior to that and he ended up…have you come across the new bridge down the motorway? Well, when you go actually across the river if you turn about 4 miles up the road, that's where he walked to. He walked from here, which is fair old walk. (462-467)

4. "At least we'll know where he is": The buddi 'tracker' offers reassurance for Barbara

Differing levels of ability with technology

But when the VCR's sort of came in to being and he could manage those but gradually he lost the knack of….when we had the sky, we had sky quite early on in the sky [laughs] and he could never manage the sky control, you know, little things like whether that was the start of it or whether he decided oh to hell with this, she can do it like (196-202)

I have recently got a SMART phone which is… and I now google things …basically to answer the question on a crossword. (220-224)

Reassurance

It did in me because I thought well if he gets lost at least we'll know where he is. (286-287)

I knew he couldn't get out unless someone left the door open accidentally or whatever, so, so he did have the buddi on then so I knew if he got out where he was at the day centre. If he got out of there at least I'd know where he'd started from. (405-409)

I had respite for a couple of hours a week when carers came in to play puzzles or talk to him or just sit and watch the telly with him and I'd made sure he'd got the buddi on then…and I told the carers he's…make sure he keeps his track on because if he goes off these girls are not going to be able to find him are they? (414- 421)

<u>Useful window for buddi system</u>

I think someone suggested it actually whether it was a social worker or something or whether it was at the Alzheimer's society (238-240)

It was probably in the very early days of the buddi system, you know to be honest, it was, I think it was someone, I think the council were running it. (273-276)
I used it right up to the time he went into a nursing home (391-392)

Carl – Individual interview analysis

Carl - Interview Summary

Technology used	Outdoor activity engaged with
Buddy tracker system	Social walking groups
	Walking for health

Carl and his wife have 3 children and have always been keen on ensuring they and the children spend lots of time outdoors being active. They have been lifelong members of the Ramblers Association and helped establish local 'family ramblers' groups within the association when their children were young. As the years progressed they also established 'Wild Forest' Rambling groups which included a focus on foraging for fruits and other wild ingredients to support their home-made wine making. These shared activities were an important part of their marriage and life together and Carl is keen that they continue walking several times a week despite their various health complaints and age, both being in their 80's.

Carls wife was diagnosed with Dementia 6-7 years ago but has seen a sharp decline in her abilities in the last 12 months. They downsized 2 years ago and have settled into their new bungalow well. They moved closer to their daughters and get a considerable amount of support from their family. They have also had regular support from statutory services, including day care, carer respite breaks and regular assessments of need. Carl reports that it was through these assessments that an Occupational Therapist first became involved in his wife's care. At that time his wife went out in the local area unaccompanied and there was very little concern about her becoming lost. However, it had been recognised that she was easily confused and had started to struggle if faced with any changes to the local environment. The Occupational Therapist recommended they start using the Buddy system. This was provided to them to use and training on how best to use it given. However, Carl felt that the system was difficult to use and after a period of time stated that he would prefer to give it back to services, so that someone else who needed it could use it.

In recent months Carl has found it increasingly difficult to are for his wife because her dementia has deteriorated rapidly. She has on a number of occasions left their home through an unlocked door and been found walking around the streets unaware of here she is. Whilst staying at her daughter's house this has also happened several times at night and the family are unsurprisingly concerned about the risks this poses to her. Carl feels that his wife would now benefit from using a tracker system such as the buddy, but has been told that the system is no longer being issued to new users.

Carl - Intermediate Themes

- Downsized house to adjust to changing needs
- Moved to be closer to daughters
- Wife walking off and getting lost
- Recent deterioration in dementia
- Married a long time
- Buddy tracker would be helpful now
- Support from daughters
- Critical incident at Christmas led to diagnosis
- Worried about the expense of tracker to services
- Forest Ramblers
- Engaged with local community
- Wife couldn't operate the 2-way radio
- Decreased health limits engagement in walking
- Family rambling
- Buddy tracker didn't meet expectations
- Re-hab walking group
- Gave up home computing
- Wife not accepting of buddy tracker
- Planning for the future
- Provided prior to urgent need

- Not engaging with technology now
- Lots of problems with buddy tracker
- Not having emergencies so gave buddy tracker back
- Wife couldn't operate the 2-way radio
- Provided by social services
- Assessment of need led to the provision of the tracker
- Not keen on current technology

Carl - Theme Development

From the Intermediate themes 4 individual participant themes were developed:

1. **"We do a lot of walking together, always have" : Walking is a consistent feature in their shared identity**

2. **""There's been quite a change": Adjusting and changing their lives**

3. **"If you can get used to this, you know for the future": providing the tracker at the right time**

4. **"It's not as easy to learn now": Finds technology increasingly difficult**

Within these themes a further 13 themes were identified, with each individual participant theme having between 3-4 themes each.

Carl - Thematic Table

	Individual participant Themes		Intermediate Themes	Line no
1	“We do a lot of walking together, always have” : Walking is a consistent feature in their shared identity	1	Walking as a family	380-389 401-406 371-374
		2	Leading a walking group	410-412 406-407
		3	Walking for rehabilitation	512-514 519-520 531-534 536-540
2	“There’s been quite a change”: Adjusting and changing their lives	4	Increased support from family	148-151 315-316 318-321 1047-1048
		5	Moved house/ downsized	146-151 274-276
		6	Impact of age and deteriorating health	299-302 423-425 455-456
		7	Wife’s deteriorating dementia	291-292 829-830 1003-1007 1009-1012 1031-1034 1042-1045
3	“If you can get used to this, you know for the future”: providing the tracker at the right time	8	Provided based on an assessment of need	752-759
		9	Planning for the future	779-780 794-795 807-808
		10	Not available when needed	814-818 827
4	“It’s not as easy to learn now”: Finds technology increasingly difficult	11	Reduced skills with existing technology	607-617
		12	Not engaging with new technology	635-637 961-962
		13	Difficulties with the buddy tracker	805-808 814 940-944 1209-1210

Carl - Key data extracts

1. “ “We do a lot of walking together, always have” : Walking is a consistent feature in their shared identity

Walking as a family

The ramblers association in that period were keen on getting family rambling …and we were very much involved with family rambling because we had the children. We had children so we were probably every, every Sunday or every other Sunday that there would be a family ramble…very much part of family life (380-389)

The family rambling must have ran for something like about 10 years and other families joined but it gradually petered out…they gradually petered out and but the adults side that continued. (401-406)

Foraging, that was good because and during the, when we moved to XXXXXXX, 1990, we joined, were forest ramblers and we were very much involved with wild forest, wild forest ramblers (371-374)

Leading a walking group

I led lots of walks so I would lead the walks. I led the walks and yeah, so I've been chairman and secretary and treasurer, walks organiser, walks co-ordinator. (410-412)

I led lots of walk up until about 7 years ago, I did 50 walks, 50 Sunday walks in one year. (406-407)

Walking for rehabilitation

Based upon the hospital they had a group called stride and strong and when it started up, it started up from the hospital with senior nurse starting up the walking group and it became a rehab. (512-514)

And, of course my wife came along and joined that walking group and up until 3, no 4 years ago now she was doing 3 miles every Saturday. (519-520)

Stride and stroll group started Thursday morning where they do, less than 3 miles where in fact they do, they do a few hundred yards and they might, I think the longest walk might be a mile. I take my wife on that. (531-534)

I take XXX on a Sunday, now that we moved to XXXX, the local forest, there's walking group, similar walking group on a Sunday and Tuesday…and so my wife's down to doing the warm up walk. (536-540)

2. ""There's been quite a change": Adjusting and changing their lives

Increased support from family

When we moved 2 years ago he accepted that we needed to downsize. I couldn't cope with a house and everything. (148-151)

Well the 2 daughters, XXX and XXX have both helped enormously. (315-316)

I think that's natural, daughters, and XXX in particular because she's so close then we go to our daughters and take it in turns every Sunday and occasionally in the week (318-321)

That was, that was, yes, I mean because it was, my wife stopped with our daughter so I had a break (1047-1048)

Moved house/ downsized

When we moved 2 years ago he accepted that we needed to downsize. I couldn't cope with a house and everything. (146-148)

It's not the move cos we moved 2 years ago and my wife coped quite well with the move (274-275)

Impact of age and deteriorating health

Obviously XXX a few years older than myself so she's 85, so XXXX doesn't have very many relatives around now. Your brother XXX died 2 years ago and, and that was a great loss (299-302)

That finished XXX's long distance walking about 8 years ago so that finished long walking (423-425)

We stopped in October and the second week in November I had a heart attack. (455-456)

<u>Wife's deteriorating dementia</u>

This year there's been quite a change, quite a change. (291-292)

Because now, my wife won't stop somewhere in the car, in the house, wherever you are, she won't stop anywhere (829-830)

Up until this year, I go and park in a disabled place, we was walking in XXXXX and I could go to the building society and I would do by internet banking at the building society cos I don't trust the robot, you see, but then when was that, oh a few months ago, I came back, I probably been half an hour, slightly more and there was a car with the keys in, empty. (1003-1011)

Fine, but then when was that, oh a few months ago, I came back, I probably been half an hour, slightly more and there was a car with the keys in, empty. Unfortunately weaver's car park is quite large. (1009-1012)

I go down to town, get a loaf, park the car, post a letter and cos I wanted to make sure it would go. There's no going back up the road, my wife was walking down. (1031-1034)

Beginning of August, our wife stopped at our daughters overnight, she got out at 3 o'clock in the morning because they're on a hill, walked down the hill. (1042-1045)

3. "If you can get used to this, you know for the future": providing the tracker at the right time

We got involved then we were involved with early service probably for over 12 months and so I think it was, it was the nurse whose name I can't remember who probably introduced us because that's why an OT was involved (752-759)

Oh yes, to track my wife because at that time the worry was she going off and getting lost you see. (779-780)

Yes, the sort of suggestion was if you can get used to this, you know for the future…(794-795)

My wife couldn't act, activate it and we didn't progress far enough I suppose because she didn't sort of didn't activate it and the OT went with her but it didn't seem to work terribly well, you know…(807-808)

We felt or I felt that you know it's an expensive piece of kit, we're not making use of this …and it needs to go on to somebody else. (814 – 818)

It would have been more helpful now…(827)

4. *"It's not as easy to learn now": Finds technology increasingly difficult*

Yeah and when we moved so I didn't become sufficiently proficient. I was doing internet banking etc. then but when we came to move the computer that I had, funnily enough was our sons cos when he, when he on one occasions when he did leave us it was his computer but he left it and by the time we moved it was all, it was then about 10 years old. So, I kept the hard disc for the photographs hopefully and threw the rest away. I then borrowed and I still borrowed our daughter's old computer, laptop. So, when we moved then the printer got thrown away (607-617)

Positive, it's positive; the dilemma is the amount of time and obviously age. It's not as easy to learn now and I certainly can't keep up with the children (635-637)

Yeah, there's lots of things you can do with smartphones but I don't have those (961-962)

My wife couldn’t act, activate it and we didn’t progress far enough I suppose because she didn’t sort of didn’t activate it and the OT went with XXX but it didn’t seem to work terribly well, you know…(805-808)

Because it didn’t work very well (814)

There was 2 things really, there was, my wife had difficulty coming to terms with it, it didn’t seemed to have worked terribly well from my end. I tried to find a, find it on the computer so the technology wasn’t working very well anyway (940-944)

It didn’t seem to work so the technology was not at the stage whereby it was easy for me to interact with and it has presumably moved on a pace from just a few years ago. (1209-1211)

Diane– Individual interview analysis

Diane - Interview Summary

Technology used	Outdoor activity engaged with
Binatone 2 way radio	Nature Walks
	Cycling along canals
	Fly Fishing river
	Keeping and flying birds of prey
	Running a wildlife rescue centre
	Bird watching
	Foraging

Diane married her husband later in life and they both ran successful businesses in the local area to where they lived. They saw grandchildren from his side of the family frequently and had a good network of friends. Diane's husband was an 'Outdoors man' running a local wildlife recue centre, going into schools with animals and writing books. He engaged in many outdoor occupations including fly fishing, keeping and flying birds of prey and bird watching. As a couple they shared many occupations too, often cycling along local canal networks, foraging from local plant life and taking nature walks. Diane feels she had a happy marriage and appears to have loved her husband very much.

Unfortunately, he developed an aggressive form of Lewy – body dementia which deteriorated rapidly over and he died 3 years later. During this time Diane cared for him, despite the many challenges posed by his deteriorating abilities, altered perception of reality and the stigma she experienced from others. They lost contact with many friends and all of his family, as they either didn't want to see him deteriorate (preferring to remember him as he was) or were afraid of the illness in some way. This left Diane with very little support and she appears to feel considerable guilt for having to stop her husband from engaging in occupations due to either his deteriorating health or safety concerns. She blames herself for not managing better and ultimately for feeling forced to move him into nursing care for the last few weeks of his life.

During the period of his illness Diane found some support through local chariTable organisations and groups, such as the Alzheimer's Society. It was at a memory café run by the society that she first encountered a man offering to provide technology to help people living with dementia. He came to their home and without assessment of her husbands needs or abilities, he provided them with a 2 way radio system to enable Diane to keep in touch with her husband when he went out to the shops to buy a newspaper. However, the technology was poorly designed, overly complicated and not suiTable for her husband's current abilities. It therefore did not enable the independence promised and gave both Diane and her husband false expectations. After trialling the technology for some time, they returned it. The experience was negative for both Diane and her husband, but despite this she still felt that there was a potential role for technology in this area, if better designed and provided to the family at the right time for them person.

Diane - Intermediate Themes

- Breakdown
- Ran a wildlife rescue centre
- Nature based hobbies and interests
- Always been an outdoor man
- Kind and caring man
- Focus on his feelings rather than her own
- Personal sacrifice
- Caring for someone with dementia is hard
- Loss of shared future
- Feelings of guilt
- Burden of responsibility
- No assessment of husband's abilities or needs
- Technology was very complicated
- Design was poor
- Interference with police frequency

- Gave false hope
- Damaging to husband
- Loss of friends
- Loss of family
- Loss of outdoor occupations
- No access to outdoors

Diane - Theme Development

From the Intermediate themes 4 individual participant themes were developed:

1. "The Birdman": Husbands professional and personal identity linked to nature and the outdoors

2. "It might as well have been a banana in his hand": Inappropriate technology provided for husband

3. "People are afraid of it" : Husbands illness stigmatised them both

4. "The saddest time of our lives" :The challenges of being a carer

Within these themes a further 16 themes were identified, with each individual participant theme having between 3-5 themes each.

Diane - Thematic Table

	Individual participant Themes		**Intermediate Themes**	**Line no**
1	"The Birdman": Husbands professional and personal identity linked to nature and the outdoors	1	Opened and ran a wildlife rescue centre	48-52 54-56 85-87
		2	Nature based hobbies and interests	59-63 88-91
		3	Always been an outdoor man	80-82
		4	A kind and caring man	87-88 122-128 449-451
2	"It might as well have been a banana in his hand": Inappropriate technology provided for husband	5	Gives false hope	327-328 364-366
		6	Too complicated	284-289 323-324 366-371
		7	No assessment of need or ability	308-313 359
		8	Poor design	316-321
3	"People are afraid of it" : Husbands illness stigmatised them both	9	Loss of friends	153-164 559-562
		10	Loss of outdoor occupations	97-106 134-143
		11	Loss of family	146-157 168-185 198-208 167-169
4	"The saddest time of our lives" :The challenges of being a carer	12	Loss of shared / planned future	228-231
		13	Caring for someone with dementia is very hard	379-365 400-406 529-534 536-544
		14	Focus on his feelings rather than her own	231 227-228
		15	Felt guilt for husbands losses	385-389 391-396 423-430 453-454
		16	Personal sacrifice	12-13

Diane - Key data extracts

1. "The Birdman": Husbands professional and personal identity linked to nature and the outdoors

Opened and ran a wildlife rescue centre

He opened up a wildlife centre at XXXXXXX…which he built himself and then he used to be called the birdman of XXXXXX [interviewer laughs] and he used to fly birds of prey which he kept in his garden (48-52)

He used to go around schools showing all the children these spiders and birds and snakes and that was his job. So he was very much an outdoor man (54-56)

He just enjoyed the outdoor life, the birds and the freedom and the, you know, being able to be his own boss in his own business (85-87)

Nature based hobbies and interests

He knew nearly every bird and every tree, he used to grow herbs and things and we would go out on our bicycles and collect different things like stinging nettles and he's come back and make stinging nettle soup. (59-63)

And he loved fishing on the Wye…… it was his favourite river. (88-91)

Always been an outdoor man

He always wanted to go on the bikes in the canals and you know walks, nature walks, but he told me it had stemmed from childhood, right from the word go. (80-82)

A kind and caring man

To be outside and tend all the animals and help all the animals and birds, he just loved it, it was him (87-88)

And then a very strange malody, he couldn't tread on your shadow, so we always had to walk the other way. It was a very hard thing and very mysterious to me, he said "I can't walk on that, I hurt it", I said "but it's you" no. (122-128)

He was a very sad man up towards the end when he knew I was, he knew that I couldn't cope and he didn't' like it (449-451)

2. “It might as well have been a banana in his hand”: Inappropriate technology provided for husband

Gives false hope

So I was really disappointed because I thought it would give him the freedom. (327-328)

He tried and tried and in the end he just cried. He said I can’t go out now. He just cried cos it was too complicated. (364-366)

Too complicated

This in particular one the binatone mobile radio was of no help whatsoever and had I had purchased it I would have very angry because it was so complicated and a gentleman like XXX with dementia he had no idea when he was out how to work this thing, it might as well have been a banana in his hand. (284-289)

When he came back to talk to me about this he said there’s 38 channels and I said that’s just no good. (323 – 324)

It was, it was too many buttons, you still got your push to talk button, up and down buttons to change the channels, speakers, you’ve got all your core buttons, you’re transmit buttons and microphone, it was all just too much for him. (366-371)

No assessment of need or ability

Well it was a gentleman that came to the dementia café and the carers meeting who got all these items from the technology department. (308-313)

He got very frightened. (359)

Poor design

But when he was out and I’d call him and I’d say XXX, you know, where are you, I’d get the police come up on mine saying base to Bravo one over, there’s a burglary going on and I’d come on and I’d say excuse me and they’ve say well you’re on our wavelength. So that was *dodgy. (316-321)*

3. "People are afraid of it" : Husbands illness stigmatised them both

Loss of friends

And then my friends said it was catching, so we lost all our friends, they thought it was a catching disease. (153-164)

I just wish that people were a little bit more compassionate with the dementia people because they're not mad, they're just people who've got an illness who were once like themselves and it's sad. (559-562)

Loss of outdoor occupations

Well with the fishing he couldn't remember how to tie the knots, that was the start and the fine knots you have to tie and he couldn't do that so he got very exasperated and I couldn't do it so he couldn't do that anymore and with the cycling he began to lose his balance, so then of course that was out of the question because we liked the canals and a couple of times he nearly fell in the canal…and he also hit his head on the bridges which are low and knocked himself out a couple of times. (97-106)

Very and then you've got that he couldn't do stairs, he would go up one and then back down two, so we never really got anywhere. You know and that was awful, especially in this flat and I was going to have a stair lift put in but sadly he died…..But yes the outdoors became indoors. (134-143)

Loss of family

My husband's family, his brothers and sisters completely cut off all contact….which was devastating, his children were never very, you know, interested since I took place of their mother, but they became very absent and they really were no help at all. (146-157)

I've had no contact with his family at all, they completely written me off. And they were no help at all with the funeral, had to do it all myself, I didn't even have a card, nothing. So, I *find with dementia people are afraid of it and the family didn't…I don't think his brother and sisters how I felt was that they didn't want to see their brother not recognise them anymore. They would rather of remembered him as he was rather than to see this dreadful decline of a man that was so clever into nothing. So I was left on my own and when I had Cancer I begged them to look after him for a week, any of them and they all had an excuse. (168-185)*

That's right and my husband used to see things, so he used to say perhaps to the grandchildren, little girls, there's a tiger coming or there's an elephant in the room and they couldn't understand it, you know, why granddad had gone like this and I think it frightened them and their mother said it's not safe for them to come anymore. I said he's not violent, he's just got dementia. So, their mother wouldn't let them come anymore and we used to bring them up really, looked after them a lot so he was very sad about that. (198-208)

Since he died I've had no contact with his family at all, they completely written me off. (167-169)

4. "The saddest time of our lives" :The challenges of being a carer

Loss of shared / planned future

He said he'd always look after and he just felt a failure in society because he wanted a good retirement and a happy retirement with me and he knew that wasn't to be. (228- 231)

Caring for someone with dementia is very hard

I mean I used to take him as much as I could and in the end ended up with a wheelchair but with the wheelchair he used to drag his feet along the floor. He wouldn't put his feet on the stirrups, on the rest……he'd put them on the floor, constantly so of course I'd always got the brake on so that was no good (379-385)

It was a complete failure of the mind really in the eyes, writing, the double incontinent, lots of trouble with diarrhoea and constipation so try and help with constipation and that gave him the diarrhoea and dressing him and I had to do the whole thing in the end till he started to fall, that's what happened. (400-406)

Yes I couldn't leave him here on his own because I had passport in the freezer, it took me weeks to find it, a frantic search, socks in the microwave, he'd turn the boiler up full, everything full on, it was a danger and I couldn't leave him anymore. (529-534)

If I took him out shopping he'd go and take somebody else's trolley. It was funny really because you know the other lady would be shouting, 'you've got my trolley' and he'd say, 'no, it's my trolley'. And then she'd say well he's off his trolley, you know, it all went so funny in the end but it wasn't funny. (536-544)

Focus on his feelings rather than her own

So he did feel a lot of things. (231)

Yes, yes, didn't like it at all, it was very, very sad and I think he just felt a failure to me who he said he'd always look after. (227-228)

Felt guilt for husbands losses

He just used to say to me, 'can we go out and you know pick some hop shoots, I want to make some more wine' and I used to say, 'XXX, I'm sorry love I can't do that anymore' and he used to just look so sad. (385-389)

I mean I couldn't do it and I couldn't walk with him cos I say he started to falter and bend and we had to stop the walking group with him because he'd just was bent almost double. (391-396)

Well I'll never get it right….I know he gave up in the last month when I put him in the home and I feel, I shall always feel guilty cos I always promised him I wouldn't but you can't look after a man who keeps falling and I couldn't lift him. (423-430)

He didn't want me to suffer so he gave up, never ate for months or drank, nothing. (453-454)

Personal sacrifice

And then of course the time came that I could only be a full time carer to him so I had to give up everything. (12-13)

Emma – Individual interview analysis

Emma - Interview Summary

Technology used	Outdoor activity engaged with
Buddi tracker	Cycling Walking for pleasure

Emma's father developed vascular dementia suddenly following a vascular event that happened whilst he was driving. Luckily no one was hurt, but it caused him to cease driving. He and/ his wife found the diagnosis of Dementia challenging, as he remained 'high functioning', able to continue with many of his daily activities as before but had a considerably impaired short-term memory. Unfortunately, they lost a great number of their friends at his time and Emma feels that this was in part because for the stigma associated with dementia, and also because people were worried they would be asked to help out with lifts etc. Emma's mother became increasingly isolated and was unaware of the help and support available to them through local organisations or statutory services. It appears that they were not signposted by the GP or others at the hospital to these services. Emma became the main carer for her father after her mother's death and by chance came across the Alzheimer's Society in her local supermarket. Since then she has started to attend the memory café's and accessed a range of support for her father, including financial benefits and advice from an Admiral Nurse.

At this time Emma was starting to have some concerns about her fathers, who lived independently and still went out daily on his own. He enjoyed cycling and went out on leisure cycles as well as using it as his main form of transportation. Despite the dementia, Emma describes her father as a 'homing pigeon' who always found his way home by following the river that ran through their town. However, she knew that his dementia would eventually deteriorate further and didn't wat to have to restrict his life. One evening he didn't return home and the family and police all went out looking or him, he turned up safe and well having *been out to an evening talk in the local town. However, with the support of the admiral nurse this prompted Emma to apply for a buddi system to prevent future re-occurrences, however because her father had not actually been 'lost' he did not meet the criteria for provision and Emma feels they missed the vital window of time where he would have learnt to use the buddi and develop the habit of wearing it. Around 18 months later he became lost in the local area twice and was provided with a buddi system as well as carer support. However, it was hard to get her father to develop the habits of wearing and charging the system. This was also not helped by a poor understanding of this need to develop habits by the carer, who discouraged her father from wearing the system when out with him. Consequently, the buddi system was used sporadically, and he was not wearing it when he several falls from his bicycle, including when he fell and broke his hip.*

Emma's father never fully recovered from this fall and experienced a long period off illness in hospital before moving into a care home. He is now too frail to live alone and unable to ride his bike. Emma's very happy with the small care home where he lives but wishes he could get access to the outdoors more, especially in the winter months. She feels that even the little time he spends in the home garden is of great value to him and tries to take him out whenever she can. Reporting that recently they went out for a family meal and he asked to say outside for some time to watch the trees as the season was changing.

Emma - Intermediate Themes

- Fathers driving cessation
- Parents social isolation
- Fathers decreased ability with technology
- Issue with equipment provision criteria
- Family worry for father when out
- Fathers Critical vascular event
- Deterioration in overall health
- Father is a keen cyclist

- Father has repeat cycling accidents
- Awareness increases fathers anxiety
- Father gave up cycling
- Increased support meant tracker was used less
- Parents not aware of financial support available
- Getting outside important to fathers wellbeing
- Parents unaware of local support groups
- Cycling maintained fathers health
- Carer education an issue
- Father not worried by monitoring
- Not part of his own assessment
- Father gets practical support from family to remain independent
- Father can’t get outside anymore
- If they had had the tracker earlier….Father no using technology in emergencies
- Tracker benefits daughter more than father
- Relationship of give and take
- Father a homing pigeon
- Father compliant for daughter’s benefit
- Father felt he was a burden
- Tracker provided too late
- Father needs outside
- Father loved getting outside
- Father wants to spend time outside
- Tracker provided too late to develop habit
- Age difference between daughter / father unusual
- Battery life is an issue for tracker
- Awareness increases suicide risk
- Impact of not getting outside
- Father had to give up cycling
- Time of tracker provision important

Emma - Theme Development

From the Intermediate themes 5 individual participant themes were developed:

1. **"Dad always came with us": Family relationships are based upon give and take**

2. **"Better not get back on my bike": A shrinking world**

3. **"Do you have to lie to get this stuff?": Let down by services**

4. **"Timing is important" : The importance of developing habits**

5. **"He's always been a keen cyclist" : Fathers well-being**

Within these themes a further 15 themes were identified, with each individual participant theme having between 2-4 themes each.

Emma - Thematic Table

	Individual participant Themes		**Intermediate Themes**	**Line no**
1	"Dad always came with us": Family relationships are based upon give and take	1	Concern for father's welfare when out	941-944 949-950 960-961 966-969
		2	Family support each other	552-553 573-574 574-584 591-594
		3	Father wants to reduce the impact on others	529-536 546-550
		4	Tracker primarily supports carers wellbeing	1101-1105 1198-1205
2	"Better not get back on my bike": A shrinking world	5	Parents social isolation	472-473 483-485 491-492 498-504
		6	Fathers decreasing ability to manage technology	928-933 1296-1300 1352-1356
		7	Cycling accidents and cessation	268-272 280-281 1226-1233
		8	Impact of not getting outdoors	1441-1448
		9	Unable to live at home anymore	704-706 1547-1549

3	“Do you have to lie to get this stuff?”: Let down by services	10	GP not signposting to basic support	156-164 170-178
		11	Not assessed in his own right	886-892
		12	Equipment provision criteria	198-801 855-857
		13	Lack of carer understanding	827-832 1083-1085 1422-1425
4	“Timing is important” : The importance of developing habits	14	A homing pigeon, habits developed over time	588-591 648-649 683-684 906-908 1002-1006 1708-1711
		15	Tracker provided too late	789-792 814-818 1030-1031 1385-1397 1769-1771 1840
5	“He’s always been a keen cyclist” : Fathers well-being	16	Loves getting out	699-708 716-726 1484-1494 1516
		17	Keen cyclist	251-253 262-266 370-377
		18	Insight can have a negative impact	413-415 610-613 1136-1144

Emma - Key data extracts

1. ““Dad always came with us”: Family relationships are based upon give and take

Concern for father’s welfare when out

She rang me from there, he wasn’t at home. So, you then trying to suppress this panic and she said, ‘I’ll say here a bit and I said, ‘ok, then’, and then I was like half 7, quarter to eight, still nothing. (941-944)

Nothing was adding up and I didn’t really want to panic but obviously eight o’clock you know it is starting to turn… (949-950)

You don’t know and didn’t really want to start ringing around the hospitals first but we hadn’t heard anything (960-961)

So we did end up ringing the police and the woman from here was actually down at dad's, she got sent on route and then we had a phone call back from the police to say your dads just been brought in (966-969)

Family support each other

At the end of the day they were very much there for me when my marriage broke down so (552-553)

Yeah. When mum was alive, obviously he had mum prompt him. When she was in hospital we, it was like his Tablets (573-574)

When she was in hospital we, it was like his Tablets he had to have aspirin every day…And either mum would remind him beforehand…so when she was in hospital and she was in for virtually a month she had pneumonia herself and that we, the girls could, well the older one XXX the older one, she constructed a chart for him……and we got him to tick it that he had it… (574-584)

Then after mum died we then like appointments. We did get a diary for him. First time he had a diary in years (591-594)

Father wants to reduce the impact on others

I think since mum died he's felt more a burden because obviously I mean there's 34 years isn't there between dad and I which a lot of people that are involved in this…they're on the same playing field, their husbands and wives…there's not many that are that much age wise (529-536)

He's felt guilty that he's stopped me from doing stuff and it's the case of well, no we've been on holiday since mum died, dad always came with us. We've had a fabulous time…and he's just fitted in with us… (546-550)

Tracker primarily supports carers wellbeing

He'd have gone out regardless, I don't think it altered what he did…it just made me feel safe, is not quite the right word but more relaxed that I knew where he was…should that arise again that he wasn't (1101-1105)

I think so because he was absolutely mortified that we panicked and the police …were there cos it's the older generation isn't it, sorry to put you out and when we said that we you know, we've got this the admiral nurse managed to get it through and that and this is so that we don't have to worry about where you are we don't have to get the police involved, then I'll put it on. (1201-1205)

2. ""Better not get back on my bike": A shrinking world

Parents social isolation

Friends yeah, one lot of friends just dumped him because obviously dad gave up driving (472-473)

So, but a lot of his friends 'oh, oh we might be called upon to, to be a taxi service' cos mum couldn't drive at the time (483-485)

Everybody just dumped him and nobody would come near…Even his main his cycling buddi…(491-492)

He still went out with the cycling club…but his main cycling buddi who obviously still were both retired that it was a nice day and dad would ring XXX up and XXX would ring dad and…just go out but no, they just ditch them. (498-504)

Fathers decreasing ability to manage technology

He got used to using his mobile but then he didn't, he'd forgot that it needed charging……Because he put obviously we have cordless phones so he'd put that back on, he used to get the two confused basically (928-933)

One time XXX had called in to see him and she said, 'you ought to come home', and he'd cut his head, there was blood and he'd obviously had a fit and blood all over the carpet, never even thought to press the button which would have summoned help (1296-1300)

And going back to the mobile I think that was part of it because he's old nokia packed up so we ended up having to buy him a newer version…Still a nokia, still the same layout but it wasn't the same (1352-1356)

Cycling accidents and cessation

So he went out on his bike, he went over the river, down the St Johns side back over the river and was coming home and like majority of accidents within, what is it, 5 mins at home caught the edge of a pot hole, down he went, fractured neck and femur (268-272)

You know even know he knows he's done it – oh better not go back on my bike (280-281)

Cos he came off his bike May of last year but he'd also came off it probably twelve months prior to that and going across XXX you've got a path and though retched blocked paving and the grass and he'd moved over to let a family…And the wheel just slipped off these and down he went, didn't break anything just bruised (1226-1233)

Impact of not getting outdoors

It's just gonna go downhill in it really…and probably quicker than had he have been able to remain in his own home. We sort of said that we're gonna have to, especially noticing the big difference in him since the weather has gone colder, he probably be alright if he took up smoking because he'd put his coat on and go outside but he hasn't smoked in years. (1441-1448)

Unable to live at home anymore

They've got a garden outside with the weather we just sat outside and I've noticed now it's gotten colder he is starting to get a little bit, shall we say, institutionalised…because he can't get out (704-706)

It's awkward because he's in the home environment so he wouldn't be going out on his own because obviously the doors are locked (1547-1549)

3. "Do you have to lie to get this stuff?": Let down by services

GP not signposting to basic support

I think that the GPs need to know what is out there because nobody had even said that the Alzheimer's society existed…Mum would have like….going to the cafés which is where we first met you…but we didn't know about those (156-164)

That was when I found out about a lot of stuff …one being dad should of got a deduction on the council tax obviously after mum died we did the deduction for single person but he didn't need to pay council tax. GP had never even told …mum at the time (170-178)

Not assessed in his own right

We just assumed that everybody gets one, I think it might have been the admiral nurse actually that …recommended, and thinking about it, that we asked her and she did the referral…As part of my carer's assessment (886-892)

Equipment provision criteria

But the council wouldn't give dad a buddi until he got lost…well, by the time they got lost, it's too late (798-801)

I asked at the doctors and then obviously we got referral through to social services, social services said, 'has he got lost', well, do you have to lie to get this stuff? (855-857)

Lack of carer understanding

The original carer had to give up due to ill health so we then had another one, he was very good, but he wouldn't enforce dad putting the buddi on …well, he's out with me but that's not the point. (827-832)

And we'd know that had the carer not said, 'it's alright, he's with me', dad would have got into the routine of putting it on (1083-1085)

They ended up having to call the police because they had lost him …Even that didn't make them put it on (1422-1425)

4. "Timing is important" : The importance of developing habits

<u>A homing pigeon, habits developed over time</u>

And with dad, with the repetition he then get, gets into doing it. It becomes second nature …To him (588-591)

There was never any worry until three years ago that he wouldn't (not even then) that he wouldn't find his way home. (648-649)

But he got this route that he used to call it the two bridges (683-684)

I thought, 'Oh where's he going I mean we've never stopped him going out for a walk as I say he's a home-in pigeon, he's always found his way back home….(906-908)

Well, all he needs is the river…And he'd find his way home (1002-1006)

If they are at the stage where they are wandering but I suppose with dad, as I say he's just a home-in pigeon and he knew how far he could go and come back…(1708-1711)

<u>Tracker provided too late</u>

It's got to be given at the right time…And that is the crocks of it, with dad I think it was given too late because… (789-792)

He's developed that habit …dad never had the chance to develop that habit…Because he was too late. (814-818)

That if he'd, the same thing had happened, I could have logged on and found where he was and it would have shown me (1030-1031)

Yeah, yeah, so we didn't bother and because the carer hadn't reinforced, I mean dad was going to a day centre two days a week and he was with the carer three so it was like Monday, Wednesday, Fridays he was with the carer and then Tuesdays and no…Tuesday and Wednesdays he was at the day centre Mondays and Fridays he was with the carer and then at the time I'd drop Thursday as well. (1385-1397)

And I think that's the crooks of, of all of it and people need to reinforce it even don't to like carers, had they reinforced as soon before they went out through the door, put it on (1769-1771)

Timing is important (1840)

5. "He's always been a keen cyclist" : Fathers well-being

<u>Loves getting out</u>

He'd just loved getting out and we've noticed now obviously he's been in the home since February they've got, it's only a small home, there's only 15 people in it…and they've got a garden outside with the weather we just sat outside and I've noticed now it's gotten colder he is starting to get a little bit, shall we say, institutionalised …because he can't get out (699-708)

And last week on his birthday we had a taxi over to the local Toby carvery and all the trees opposite are changing and he said, 'I don't want to go in yet'…he wanted to just stand, he said I wanna have a look at the outside and I thought…Yeah, so noticed a different change…because he can't get out…. (716-726)

I mean the home they do, do a lot, they have entertainment, they have a physio going in that does chair exercises and that sort of stuff so they do, do a lot he still needs to get out, he needs some outside..yeah. I say that rang big bells last week, dad didn't want to go in yet, 'I just want to look at the trees'…there's trees in the garden… and I thought, 'ooh Yes' (1484-1494)

Getting out would definitely improve his wellbeing (1516)

Keen cyclist

He's always been very fit and active and he was 84 last week he was, he's been a keen cyclist all his life…(251-253)

Yeah, so he's always been a keen cyclist which has probably kept him very, very fit…until May of last year when it was a beautiful day and he thought 'oh, I know what I'll do, I'll go out' (262-266)

Obviously they tell him stuff and mum said, 'it might be better to tell my daughter because you know XXX not going to remember'…'what do you mean? Oh well he has got vascular dementia, no no way!' They couldn't believe it…and that is obviously down to the cycling (370-377)

Insight can have a negative impact

Dad knows he's got a problem…and he dwells on that and the anxiety (413-415)

He'd look at the diary and he'd look at the clock and he'd look at the dairy and he'd go and sit back down again. 'Oh you're going', so then this would, it used to take us about 10 mins to actually get out. (610-613)

Or what had happened to him. I mean gosh that's basically we've had some guy haven't we that chucked himself in the river with dementia and that because this is where I say dad is just too aware and he's got a problem…And you do hope that, that never happened…but how desperate could he have got, he'd just gone to find out about dementia (1136-1144)

Francis – Individual interview analysis

Francis - Interview Summary

Technology used	Outdoor activity engaged with
Small tracker	Social walking
	Dog Walking

Francis and his wife have recently retired, they have a close family network around them, including 3 adult children: one of whom still lives them in their family home with their pet dog. Francis's wife has recently received a diagnosis of dementia and the family are adjusting to this slowly. In addition to supporting his wife through this difficult time, Francis and his brother are the main carers for his own elderly parents who are in their 90's and live nearby. The couple enjoy dog walking, visiting gardens and outdoor holidays together and Francis's wife is keen on walking in their local area, going out everyday on the local bridleways, if only to visit the local shop.

Francis feels his wife's memory difficulties and other significant changes started to occur sometime ago but was unable to persuade his wife to seek help until recently. Over the years, Francis has supported her as she struggled to manage complicated tasks, such as cooking Christmas dinner or adapt to new things, such as changing the family car. He now feels that the diagnosis is helpful as it gives them some more certainty and enables his wife to be more aware of their difficulties. It is not clear how she feels about this, but he reports she frequently experiences frustration and anger.

Unfortunately, their family dog is owned by a guide dog charity and used as a 'stud', and when Francis informed the charity about his wife's diagnosis they stated that she was no longer allowed to walk the dog as there was a 'risk posed to the valuable animal.' Francis was clearly outraged by this discrimination and frustrated by the impact upon his wife's well-being and confidence in going out.

It was because of a critical incident where his wife became lost in a familiar place that he finally persuaded her to seek help. The diagnosis process was quick, and they were provided with a range of brochures and leaflets, but no personal advice or support to adapt to the changes ahead. Francis was keen to find a solution to *the 'getting lost' problem and reduce his wife's frustration at always losing her handbag in the house. From one of the brochures he bought a small tracker that attaches inside his wife's handbag and hoped that this would help. There have been a range of difficulties in using the tracker and he now feels that it is useless. But despite this negative experience he is keen to use a GPS type tracking device in the future.*

<u>Francis - Intermediate Themes</u>

- Wife's frustration and anger
- Francis feels technology is becoming more complicated
- Only goes dog walking with Francis now
- Diagnosis effected his wife's confidence
- Limited use to tracker as too complicated
- Wife had difficulty in adapting to change of car
- Francis is dismissive of tracker
- Dog walking is important to wife's wellbeing
- Son living with them offers practical support
- Negative experiences impact upon wife's confidence
- Tracker purchased from brochure with no advice
- Not clear when tracker should be used
- Keen to adopt new technology to help
- Wife gave up driving 5 years ago
- Experienced discrimination and stigma
- Feels thy are coasting along
- Decrease in ability with technology
- He has always had to take on technology
- Unaware of technology solutions and GPS tracking available
- Very recent diagnosis
- Close family network
- Diagnosis increased wife's awareness of difficulties
- Tracker initially increased wife's confidence

- Early onset dementia
- Denied dog walking by charity
- Family aware of difficulties for some time
- Tracker has limited range
- Despite negative experience still thinks a type of tracker could help
- Outdoor occupations part of shared family history
- Tracker is of poor quality
- Planned for tracker to be used independently
- Tracker to help locate handbag
- Tracker to help locate wife
- Tracker to reduce wife's frustration
- Wife in denial / lacked insight
- Previously wife was an advocate for adopting new technology and computing
- Critical incident of getting lost triggered diagnosis
- Wife still walks on bridle path everyday

Francis - Theme Development

From the Intermediate themes 6 individual participant themes were developed:

1. **"Now she knows for sure that there is something": a recent diagnosis of dementia**
2. **""He would take the pressure off by organising or cooking a meal": Early (young) onset with a close family network**
3. **"You can't go taking him for a walk by yourself then": Stigma impacts upon outdoor occupations**
4. **"We were given some brochures and some literature": A lack of professional support or guidance**
5. **"We have no faith in it": Not the right technology solution for them**
6. **"They are there to be mastered": Differing views on technology**

Within these themes a further 19 themes were identified, with each individual participant theme having between 3-4 themes each.

Francis - Thematic Table

	Individual participant Themes		**Intermediate Themes**	**Line no**
1	“Now she knows for sure that there is something”: a recent diagnosis of dementia	1	Recent diagnosis after period of denial	50-51 61-65
		2	Critical Incident getting lost	39-47
		3	Diagnosis increased awareness but decreased confidence	209-212 240-247 231-232
2	“He would take the pressure off by organising or cooking a meal”: Early (young) onset with a close family network	4	Others aware of difficulties for a while	52-55 181-184 232-234 236-238
		5	Adult children support	79-80 81-83
		6	Outdoors part of family shared history	132-133 148-149
		7	Caring for older family members	89-92
3	“You can’t go taking him for a walk by yourself then : Stigma impacts upon outdoor occupations	8	Dog walking part of wife’s life	114-118 102-106
		9	Discriminated against by dog charity	107-113
		10	Still walks as much as possible, everyday	190-191 172-173 175-177
4	“We were given some brochures and some literature”: A lack of professional support or guidance	11	Lack of professional guidance with problem solving or identifying needs	92-93 218-220 357-360 448
		12	Decrease in wife’s skills/ confidence not being supported	184-185 254-256 212-214
		13	Unaware of current technology available	325-329 435-436
5	“We have no faith in it”: Not the right technology solution for them	14	Many different expectations for tracker	360-361 368-369 375-378 425-427
		15	Quality of technology was limited	378-379 410-411 453-455
		16	Mixed experiences so stopped use	416-417 362-363
6	“They are there to be mastered”: Differing views on technology	17	Wife embraced new technology but now struggles more	313-316 254-256 262-263 296-297
		18	Francis reluctantly adopted technology	304-305 309-310
		19	Still feel GPS technology could be helpful	433-434 489-493 514-517

Francis - Key data extracts

1. “Now she knows for sure that there is something”: a recent diagnosis of dementia

Recent diagnosis after period of denial

But to be honest, we had some symptoms before that and she hadn't been persuaded to visit a doctor (50-51)

And that came through after scans and whatever last October. So we're at a very early stage in the evaluation of this and indeed the exploration of this. So I'm sure Simon Cowell will tell you you're on a journey (61-65)

Critical Incident getting lost

She had an incident about last July, where she was walking across the road to the shops, which is 300 metres maximum, and she got halfway across the car park and pretty much all the distance between here and the shops is covered by the car park, around which is a doctor's surgery and a number of other things. And she was halfway across the car park and couldn't remember where she was going, why she was going and effectively who she was. (39-47)

Diagnosis increased awareness but decreased confidence

I think she --- now she knows for sure there is something --- there is a condition, I'm sure she shares my belief that actually provides you more certainty, but she's still aware that she can't do things. (209-212)

So there is a confidence issue there and sometimes when she goes --- you won't necessarily know what I'm talking about, but if you go into one of the suburbs, into XXXXX where she worked, which isn't that far away from here, you have to be careful about which bus you get on, on the way and coming back, otherwise you'll end up in the wrong place. And she's done that a couple of times. So that must impact on her confidence as well. (240-247)

Certainly before she had the diagnosis she was probably more prepared to go to other places on public transport. (231-232)

2. *““He would take the pressure off by organising or cooking a meal”: Early (young) onset with a close family network*

Others aware of difficulties for a while

So little symptoms like going away to see friends and not remembering where she was. So going to Brighton thinking she was in East Anglia or it may have been the other way round. (52-55)

Choice is a difficult thing. So if she decides to go shopping, saying I want to buy some soup, you go into Tesco's and she'll still be there in ten minutes time trying to work out what soup she wants. (181-184)

She'd lost the confidence to drive anywhere about four or five years ago. (232-234)

We had quite a traumatic introduction to a more complicated car which I wanted her to drive and she couldn't cope with that at all. (236-238)

Adult children support

Well, my youngest son lives here most of the time and he's around. (79-80)

when our daughter, granddaughter and other son turn up, he would take the pressure off by organising or cooking a meal, or whatever. (81-83)

Outdoors part of family shared history

Obviously visiting --- yes, walking, visiting National Trust properties or whatever. (132-133)

Walking, sight-seeing and things, visiting historical places, well holidaying, yes, we've done all of that. (148-149)

Caring for older family members

But we've got --- obviously my mother and father are still alive, sorry, they're in their 90s, so they obviously aren't providing much help, but my brother who lives with them, he's also potentially available to help as well. (89-92)

3. "You can't go taking him for a walk by yourself then": Stigma impacts upon outdoor occupations

Dog walking part of wife's life

The irony is that taking the dog for a walk is a good way of actually getting out of the house for her and he's perfectly well behaved in that scenario. Because he's tuned into the fact that sometimes she does something that's slightly unexpected. (114-118)

Now the dog is interesting because he belongs to Guide Dogs and he's a stud. So that means he has to be exercised --- it doesn't follow that he has to be exercised, but he has to be exercised and XXXX and I were joint contract holders. (103-106)

Discriminated against by dog charity

But I had to tell the Guide Dog organisation of XXXXX's condition and they said, "Oh dear, well you can't go taking him for a walk by yourself then, because the dog's at risk, basically." He's a valuable dog, dog's at risk, therefore, you're going to have to find somebody else, i.e. my son, really to act as a joint contract holder. (107-113)

Still walks as much as possible, everyday

Occasionally she comes walking with me and the dog. Yes, we do that and we haven't ruled that out. There's plenty of places round here to do that. (190-191)

She wants to go shopping every day. The shops are in walking distance…….. you don't have to walk down roads to get there, it's across the bridle path, it's about 20 minutes' walk to get there. (172-175)

Across the --- you don't have to walk down roads to get there, it's across the bridle path, it's about 20 minutes' walk to get there. (175-177)

4. “We were given some brochures and some literature”: A lack of professional support or guidance

Lack of professional guidance with problem solving or identifying needs

But at the moment we're coasting along (92-93)

She doesn't seem to have fully come to terms with the fact that if you write things down or always put things in the same place that might be a solution. (218-220)

It was just --- on the initial diagnosis of dementia, I thought it would be useful --- we obviously were given some brochures and some literature, and I thought it would be useful to try something like that so that (357-360)

We've managed without it so far, to be honest. (448)

Decrease in wife’s skills/ confidence not being supported

Whereas going across to the Co-op is a simple task. And I don't want to stop her doing that. (184-185)

Her confidence with, for instance, doing things on a computer or accessing things online, so for her bank account and other things has deteriorated markedly. (254-256)

But doing something --- some of that makes her very cross, makes her very angry, really. So looking for handbags and whatever is a problem. (212-214)

Unaware of current technology available

So the idea of having a specific application to solve a problem with technology is a good one. But it can't be one that gets in the way. So if you're using technology to, for instance, track where you are, or tell you where you're going to be, that would be great. (325-329)

I've seen dogs wearing GPS trackers, that's quite interesting. But there are practical limitations to that anyway. (435-436)

5. “We have no faith in it”: Not the right technology solution for them

Many different expectations for tracker

When she was losing her handbag, which was quite often, daily, you could find it. (360-361)

I just wanted it to help to stop us being frustrated or annoyed, really. I'm not so naive as to expect it would stop her losing her handbag in the first place, but I'd just like it to actually be useful enough (368-370)

I: And were you hoping to use it to be able to locate your wife when she's out and about?
R: Well, partly yes. (375-378)

So providing she knows her handbag's always on channel one, for example, it's nice and simple and she can use that on that basis. (425-427)

Quality of technology was limited

We haven't used it --- the range of the thing isn't that great. (378-379)

The thing only has a practical range of a few metres, so it's not going to find her if she's got on the wrong bus, for example. (410-411)

The units out there in the hall, but we haven't had to use it --- or regard it as being so poor that we have no faith in it, if I'm honest. (453-455)

Mixed experiences so stopped use

I think it improved her confidence initially, but the last time we tried to use it, it wouldn't work, so we've written it off. (416-417)

But it appears to have stopped working very quickly, because we haven't actually used in in the last few months. (362-363)

6. “They are there to be mastered”: Differing views on technology

Wife embraced new technology but now struggles more

So when she was working, she was working as library assistant and one of her roles there was to encourage people, who weren't confident about using technology, about how to do searches and whatever. And she became very proficient. (313-316)

Her confidence with, for instance, doing things on a computer or accessing things online, so for her bank account and other things has deteriorated markedly (254-256)

She's always regarded things that they're there to be mastered previously, whereas I don't think she would now. (262-263)

Yes, so the increasing complexity of things like that, is very difficult for her to understand. (269-297)

Francis reluctantly adopted technology

Well yes, because I worked in an office environment and technology was foisted upon you. (304-305)

Therefore I had, regardless of whether I wanted to or not, I had to embrace the technology. (309-310)

Still feel GPS technology could be helpful

For it to work properly, she'd have to wear a GPS tracker (433-434)

Because I was thinking of this the other day, using a Smartwatch, you could probably --- a Smartwatch could probably provide some of the answers to actually --- it's something that doesn't look particularly intrusive, but you could find out where the Smartwatch was and therefore where she was. (489-493)

So a Smartwatch with some sort of --- a Smartwatch would enable her to work out where she was and can be attached to the phone, so the phone can give her some GPS guidance. (514-517)

Greg – Individual interview analysis

Greg - Interview Summary

Technology used	Outdoor activity engaged with
Personal tracker with 2-way radio	Dog walking
	Fishing – possibly in past

Greg and his wife live in her parent's home and as Greg doesn't currently work, he is the main carer for his mother and father-in-law who both live with long term health conditions. His father-in-law has dementia and within this interview Greg talks about his experiences of supporting his father-in-law and using a personal tracking system.

Greg's father-in-law is a quiet man who likes to get outdoors, he walks the dog several times a day and has always enjoyed outdoor pass times such as fishing. He looks forward to going out and the whole family are keen that he continues to do this for as long as is possible.

Greg reported that he and his family were often worried about his father-in-law in the past when he did not return from his dog walks at the time expected. This had become an increasing problem over the past 12 months as his dementia deteriorated and he became more easily distracted when out. Prior to getting a tracking system there were also several occasions where he got lost or was found in unusual locations, including one incident where his father-in-law had a fall.

When discussing his father-in-law's outdoor activities Greg refers to him as walking with the dog, however whenever discussing an incident where things went wrong he calls this wandering. It is the wandering behaviour that he is keen to monitor, whilst allowing his father-in-law to continue walking as much as possible.

Greg decided to introduce a personal tracker for his and the family's peace of mind. He clearly spent time researching the range of devices available through private purchase and was keen to get one with both a location and 2-way radio function. It is important to Greg to be able to talk to his father-in-law and reason with him, not just find him. The relationship between son and father-in-law was obviously respectful and Greg was apologetic about having to warn his father-in-

law not to 'wander' too far, clearly reluctant to become too paternalistic. Yet it is clear he feels responsible for maintaining his father-in-law's safety and believes the tracker system is a good compromise to achieve this.

The tracker has worked well for them since introduction and they plan to continue using it in the future. He reports that the tracker gives them as a family reassurance, as well as a practical tool. Greg also feels that the tracker gives his father reassurance and increases his safety. However, Greg foresees a time when the tracker may no longer be useful, either due to technological advancement or deterioration in his father-in-law's dementia.

Greg - Intermediate Themes

- Breakdown in communication with services;
- Paternalistic at times
- Stuck in the house
- Carer worry - incidents of concern for father in laws welfare
- Looking forward to getting outside
- Greg is very competent with technology
- Uses tracker for monitoring
- Use the tracker for safer walking
- Uses the tracker as a 2-way communicator
- Greg bought tracker
- Deterioration in father in laws dementia over past 12 months
- Embarrassed about having to tell father in law not to go out too far
- Enjoys dog walking
- Father in law a changed man
- Father in law enjoyed many occupations outside in the past
- Important to father in law to go outside
- Father in law socialises whilst out with dog
- Increased carer responsibility
- Researched all available options
- Reduced worry of family

- Walks the dog / wanders when lost
- Positive impact on father in law
- Limited window of use
- Increases safety

Greg - Theme Development

From the Intermediate themes 4 individual participant themes were developed:

1. **“We need to do something”: A time of change**
2. **“Even though it wasn’t cheap”: Important to get the right technology**
3. **“He likes going out and visiting places”: Important to Father-in-law to get outside**
4. **“Peace of mind”: how it helps them as a family**

Within these themes a further 14 themes were identified, with each individual participant theme having between 3-4 themes each.

Greg - Thematic Table

	Individual participant Themes		**Intermediate Themes**	**Line no**
1	“We need to do something”: A time of change	1	Father-in-law’s dementia changing rapidly	49-53 57 257-258
		2	Increased responsibilities as a carer	158-162
		3	More paternalistic relationship	66-67 75-79
2	“Even though it wasn’t cheap”: Important to get the right technology	4	Did lots of research into options	178-183 186-188
		5	Greg is competent and literate with technology	94
		6	Uses tracker for a range of functions	140-142 146-162 183-186
		7	Limited window of use	332-334
3	“He likes going out and visiting places”: Important to Father-in-law to get outside	8	Tracker has had a positive impact	230-231 306-309
		9	Dog walking	64-65 154-156
		10	Historic relationship with the outdoors	31 33-34 246-247
		11	Not stuck in the house	40-42
4	“Peace of mind”: how it helps them as a family	12	Increases safety	309-311
		13	Reduces paternalistic approach	165-169 239-242

		14	Positive view of technology for people living with dementia	119-120
		15	Benefits to whole family	200-206 237 239

Greg - Key data extracts

1. “We need to do something”: A time of change

Father-in-law’s dementia changing rapidly

And me and my wife were talking about this yesterday and it has affected him quite a lot over the last year or up until now he’s a total changed man compared to what I have known him from before. (49-53)

He has just totally changed over the last year. (57)

When we came back off holiday we went to the shops and dad was down by the shops, now he has never done that. (257 – 258)

Increased responsibilities as a carer

And one time somebody had to bring him back because he fell over, so that was another reason as well. And I think it was like that was the time when we said well we need to do something so that we an find him and see where he is. (158-162)

More paternalistic relationship

I brought this tracker so that I could keep an eye on him. (66-67)

Because I’m being honest and truthful and I will say this in front of him, stay where we know where we know where he’ll be. (75-78)

2. “Even though it wasn’t cheap”: Important to get the right technology

Did lots of research into options

Well because I read it on the reviews and I actually went to the web page and actually went through it, I actually read through the whole lot before I actually purchased it. I looked at the others that were a bit cheaper and they didn’t do half of what this one does. (178 – 183)

So beforehand was studying it and looking which one was the best out of all of them, even though it wasn’t cheap. (186-189)

Greg is competent and literate with technology

He's not like me – up to date with technology. (94-95)

Uses tracker for a range of functions

So the phone number is on my phone. If I can't find him on the GPS, I can phone him and make sure he's alright. (140-142)

Because I have to put a certain message in my phone to locate it, the I go on Google maps and then I can find him on Google maps. (146-162)

I was looking for something where I could communicate with dad just in case. (183-186)

Limited window of use

Because technology changes and then sooner or later we'd have to change it to suit dad and that. (332-334)

3. "He likes going out and visiting places": Important to Father-in-law to get outside

Tracker has had a positive impact

And I was just trying it and I tried it on Google maps and it actually worked and it pinpointed actually where he was. (230-231)

Do I feel that it has impacted on XXXXXX's feelings of security and safety at all? Well I would think so, well I hope so. Because it's there for a purpose, you know what I mean? It's there for his safety as well peace of mind for us. So I hope so"(306-309)

Dog walking

He still goes out, he still does….we don't stop him from going out. (64-65)

When he was walking the dog he was taking a long time compared to what he would normally. (154-156)

Historic relationship with the outdoors

He has come fishing, he walked the dog most days. (31)

He's done fishing. He likes going out and visiting places. (33-34)

Sometimes he used to go out, meet somebody and be talking forever. (246-247)

Not stuck in the house

Instead of being stuck in the house all the while, it's something for him to look forward to to go out and do things. (40-42)

4. "Peace of mind": how it helps them as a family

Increases safety

I: Do you feel that it has impacted on your father in law's feelings of security and safety at all?

P: Well I would think so, I hope so. (309-311)

Reduces paternalistic approach

It was an agreement with everyone, dad included. (168-169)

Just peace of mind that's it, that's all we wanted. (239)

Positive view of technology for people living with dementia

"Sometimes it can be good. Technology regarding Alzheimer's and dementia can be a good thing." (119-120)

Benefits to whole family

Instead of worrying it has brought us more…..we know where he is and then we're not worrying as much, when he dint have it, it was like , well hang on a minute, where Is he? (200-203)

Helen – Individual interview analysis

Helen - Interview Summary

Technology used	Outdoor activity engaged with
Doro tracker phone	Dog Walking
	Bird Watching
	Social Walking
	Golf

Helen and her husband have been married for over 50 years. Her husband undertook postgraduate study at a young age and conducted research into poultry keeping as an academic for many years. She describes him as a clever man who was proud of his research and previously enjoyed completing crosswords as much as sport activities. They have always lived an outdoor life, keeping livestock, growing their own fruit and veg and enjoying outdoor activities together, including hiking and bird watching.

Helen has had 2 careers, the first in agriculture and the second as a special needs teacher. She feels the skills learnt in the later role have enabled her to support her husband since his diagnosis of Alzheimer's disease 4 years ago. Helen has seen a consistent deterioration in his memory, sequencing skills and other cognitive functions such as problem solving. This has led to increased frustration for both Helen and her husband at times and forced him to stop engaging some of his favourite activities, such as playing golf. Helen feels this a particularly loss as her husband misses the company of other men.

Helen feels glad that her husband has some insight into his condition as it means they can plan together. However, sometimes these plans are later misunderstood and she talks in particular about his frustration at having stopped driving and given his car away, accusing her of 'stitching him up'. Despite this, they have very little daily tensions and she feels her husband has a pragmatic and accepting approach to his dementia. Planning and thinking through each difficulty as best as he can. This often makes him slow to complete tasks and focussed upon the sequencing of a practical task, but also patient and willing to take his time. Helen *adapts and adjusts his routines and occupations at home to make things easier for him, whilst preserving his autonomy and control wherever possible. She feels it is her responsibility to learn to adjust each time his dementia deteriorates and is quite hard on herself when she cannot easily. Helen describers her adoption and use of the phone tracker system in the context of this 'support' to enable his freedoms. The phone is simple with just 4 buttons and enables 2 way calling to 4 pre-programmed numbers as well as a tracking facility.*

They have been using the phone tracker for a couple of years and first identified it as a possible tool to help from an equipment/ AT brochure provided at an Alzheimer's Society group meeting. Helen's husband's ability to use the tracker independently was good at first. Helen thinks that knowing he has the tracker on him to seek help offers her husband reassurance and supports him to feel more confident when out, although she is unclear as to whether he can still use this function adequately. However, Helen still uses the phone function to call him when he's out and tracks his afternoon dog walks on her ipad using the phone tracker's app software.

Helen reports that knowing she can always find him gives her peace of mind and allows her to rest in the afternoons whilst he is out. She is not as fit and physically strong as her husband and states that she would not always manage to keep up with his walks, but would feel obliged to go if he didn't have the phone tracker. She no longer feels he would be able to adapt to new technology, but is pleased they introduced the phone tracker early on and hopes that its simple design will make is useable for some time to come.

Helen - Intermediate Themes

- Graded changes in activity
- Tracker enables carer to rest
- Allowing for change
- Carer is confident with computers and technology
- Privacy
- Tracker found in a catalogue

- Technology needs to be introduced at the right time
- Enables Carer to stay at home
- Carer adjusts language
- Carers own health
- Daily outdoor activity
- Stops playing golf
- Sequencing difficulties
- Importance of familiarity
- Maintains a social façade
- Enjoys being outside
- Waling and birdwatching
- Misses the companionship of men
- Older carer
- Daily dog walking
- Gives him reassurance
- Decrease in ability to use technology
- Meaningful outdoor environments
- Outdoor sports
- Rural upbringing
- Stops driving
- Smartphones for next generation
- Gives him feedback
- Critical incident of getting lost led to diagnosis
- Awareness of limitations
- Minimise effect of dementia
- Blame and frustration
- Good awareness of condition
- Doesn’t like ‘failing’ test

Helen - Theme Development

From the Intermediate themes 5 individual participant themes were developed:

1. **"Because he can relate to it and not make mistakes": Feels at home in the outdoors and with nature**
2. **"I know I know you, but I've got dementia and I can't remember your name": insightful into the impact of his dementia**
3. **"If anything happens to me, I'm not sure, that's much more difficult.": The challenges of being an older carer**
4. **"Trying to introduce something new, in my experience, is very hard": Introducing technology at the right time**
5. **"There are some things which go astray, but they are not worth making a fuss about": Adapting to changes whilst promoting independence**

Within these themes a further 16 themes were identified, with each individual participant theme having between 2-4 themes each.

<u>Helen - Thematic Table</u>

	Super- ordinate Themes		**Intermediate Themes**	**Line no**
1	"Because he can relate to it and not make mistakes": Feels at home in the outdoors	1	Getting outdoors everyday	40-41 134-136
		2	Outdoor identity	22-26 32-37
		3	The therapeutic outdoors	42-46 50-54
		4	Freedom	269-273
2	"I know I know you, but I've got dementia and I can't remember your name": insightful into the impact of his dementia	5	Awareness of his limitations	299 318-319 400-403 460-462 498-500
		6	Seeks to minimise the impact	73 77-79 82-83 105-108 473-475 515-519
		7	Frustration	117-123 124-127 151-154 154-156
		8	Consent to tracking	231-235 428-432
3		9	Impact of carers health	330-333 346-350

	“If anything happens to me, I’m not sure, that’s much more difficult.”: The challenges of being an older carer			352-354
		10	Tracker enables her to rest	284-286 291-293
4	“Trying to introduce something new, in my experience, is very hard”: Introducing technology at the right time	11	Critical incidents	59-67
		12	Familiarity is important	210-213 260-264 306-310
		13	Decreasing ability to operate technology	191-196
5	“There are some things which go astray, but they are not worth making a fuss about”: Adapting to changes whilst promoting independence	14	Sequencing difficulties	145-151 368-374
		15	Adjusting language to aid comprehension	378-380 381-390 392-395
		16	Grading activities	339-340 364-366 477-480

Helen - Key data extracts

1. “Because he can relate to it and not make mistakes”: Feels at home in the outdoors and with nature

Getting outdoors everyday

He still goes out and feeds the birds nearly every day, unless it’s pouring with rain, and he walks the dog every afternoon (40-41)

But he’s very protective of her and very proud to show her off and goes for 45 minute walks with her around the lakes here most afternoons. (134-136)

Outdoor identity

He was brought up on a farm in xxxx and had his own poultry as a child and he went to xxxx College where he ended up with an MSc in poultry. We’ve lived at xxxxxx for six years, but then we lived near here with a third of an acre, where he’s always almost produced own veg and fruit. (22-26)

Walking, bird watching and golfing. But he’s also played soccer and cricket. That’s what he’s done mostly in his retirement, but in his youth it was soccer and cricket. (32-37)

The therapeutic outdoors

But the main thing that he still enjoys now is seeing the trees, he doesn't always remember what season it is, but he always comments on the state of the trees and flowers. So he still likes to be taken out into the countryside. (42-46)

Because he can still relate to it and not make mistakes and not feel, I think, inadequate. I think he feels more comforTable, more relaxed. I think in crowded situations, especially if he can't remember or it's changed a lot since the last time we were there, I think there's a panic that sets in - or at least anxiety. (50-54)

Freedom

It works in that it lets him – he doesn't like being mollycoddled. He doesn't like me pushing him all the time, he wants to have his freedom, and this gives him his freedom to go off on his own. I don't always know where he's been. There's a lot of people in the area, other dog walkers know the dog and they always chat to him (269-273)

2. "I know I know you, but I've got dementia and I can't remember your name": insightful into the impact of his dementia

Awareness of his limitations

He is aware that he could contact me with it, if he wanted to. (299)

He does, yes, he does willingly carry it, because he believes he could use it should he need to. (318-319)

And he just turned round and he said, "I know Granddad's no good at remembering, but he can't help it. Nana shouldn't get cross with him, should she?" (400-403)

When he meets people, he will say, "I know I know you, but I've got dementia and I can't remember your name." And he's now confident enough to say that. (460-462)

He has got a watch which is radio controlled that tells him the date, month and the year, which he uses. Fortunately he used it when he was being assessed for Alzheimer's disease as well (498-500)

Seeks to minimise the impact

He is very good at covering his back (73)

He was very chatty and very friendly and, "Do come again." And they went out of the door and he said, "I still can't remember who he is." (77-79)

If he forgets something, he's still quite quick to work an excuse for it. (82-83)

And he wrote down on a piece of paper for me, I've got it upstairs, actually, "To dementia, I will endeavour to remain positive, to minimise your effect on my behaviour." (105-108)

Well, something's happened. He had been going regularly and instead of saying what's happened, he's saying, "I don't want the paper, there's only rubbish in the paper." (473-475)

But no, the idea of failing, because he still sees his assessments to see where he's at as an exam and he's never failed exams. Yes. So he's revising and checking the date and what they're going to ask. (515-519)

<u>Frustration</u>

The worst thing, and the things that really, really upset him was stopping him from driving, because he would say that, "I don't have to remember where to go, you can tell me." But he also forgets where the knobs are and the gears are and the things – it became dangerous and I wasn't prepared to be the passenger that told him which way to go, because the reactions weren't quick enough for today's traffic. (117-123)

That happened in December, but he'd started waking up at about three or four in the morning by Easter and he woke up at five one morning and he says, "You have really stitched me up, you've given my car away. (124-127)

I did go with him a few times, I don't play golf but I did walk round with him, but it got to the stage where he couldn't remember which club did what. (151-154)

He's missing independence of having a car and he misses the companionship of other men playing golf. (154-156)

<u>Consent to tracking</u>

It does send me back the GPS location and I can put that into my iPad and I can see where in this area he is. And he doesn't seem to mind. There are people that say that you're taking away their personal freedom or something by tracking them. (231-235)

I think confidence wise, probably to him, because there are a lot of things now that he still thinks he can do, but in practice can't. But the fact that he thinks that he can ring me possibly helps him, but whether he could actually do it or not, I'm not sure. (428-435)

3. *"If anything happens to me, I'm not sure, that's much more difficult.": The challenges of being an older carer*

<u>Impact of carers health</u>

As long as I stay fit myself, I can still take him out to lunch, different places that he enjoys seeing the views from and drive around and visit people. What happens if anything happens to me, I'm not sure, that's much more difficult.(330-333)

Xxxxx is still physically very fit, he's probably fitter than I am physically. One of the things that we've just done as part of the Alzheimer's advice is the fact that hearing may be an issue, so I took him for a hearing test and to pacify him, I arranged to have the hearing test myself as well. His hearing's alright and mine's not. (346-350)

So I'm having a hearing aid fitted tomorrow. I think I must have been lip reading and body language, because I haven't really missed very much of it, but anyway. (352-354)

Tracker enables her to rest

Oh, it just means I can sit down and go to sleep when he's out or yes, I would worry more if I hadn't got some means of knowing where he was. (284-286)

No, it wouldn't change his ability to get outdoors, it would change my willingness to let him clear off on his own. I think I'd feel more obliged to walk with him (291-293)

4. *"Trying to introduce something new, in my experience, is very hard": Introducing technology at the right time*

Critical incidents

I think it was 2008 when he went to meet ex-colleagues in a pub xxxxx that he'd known for

40 years and couldn't find his way home. I don't know how he came home, I know that he

went via xxxxx, which is way out. But he'd driven that route every day for 40 years to work

and he came out of the pub that night and he didn't tell me that night, he told me the following day. He said, "I don't know whether I should tell you this or not, but I just could

not remember how to get home." And that obviously frightened him and worried him. (59-

67)

Familiarity is important

I think that if they were familiar with them as the disease developed, I think they could be useful. But I think once the disease does develop, trying to introduce something new, with my experience, is very, very hard. (210-213)

For people who've had smartphones before they've developed the disease, they probably really can track those anyway, can't they, without. So I think the next generation of patients with dementia won't need this sort of thing because they'll use the phones they've always had. (260-264)

I'd once forgotten to charge it and I gave him my mobile phone instead and for some reason I did need to speak to him, I can't remember what it was. Only I rang two or three times and he didn't answer it, and that's because he didn't recognise the ring tone. (306-310)

Decreasing ability to operate technology

It's nearly 20 years now and he was just starting to have to try and use emails at work and since he's retired, because I do it, he's left it to me. So he doesn't use computers. He doesn't use mobile phones very much, although he's got one. And he's now struggling with the remotes for the television and for which button to press to get the record player to play and things. (191-196)

5. "There are some things which go astray, but they are not worth making a fuss about": Adapting to changes whilst promoting independence

Sequencing difficulties

He can't play golf anymore because he's always been very particular about things. He can't do anything in a hurry, because he has to work out the sequences of things and it doesn't come quickly anymore. So he did go with admiral nurse support from a carer who came to take him to golf. But by the time he'd changed his boots and changed his socks and decided which club to play, they'd only done three or four holes before it was time to come home again. (145-151)

We'll keep it up as much as we can. It takes him quite a while if it's wet. It takes him about half an hour to get ready to go out because he's got to find his over trousers and change his socks and get a different pair of shoes and try and find the gloves and try and find the hat. So it's quite a process, but he's got all day to do it, so. (368-374)

Adjusting language to aid comprehension

His ability to follow instructions and his comprehension of instructions has gone downhill quite a lot in the last three or four months. (378- 380)

He was with me down in xxxxxxx buying bird seed the other day, so he likes to be helpful, so he wants to push the trolley. So he's got the trolley rammed up against the till and I've got put my credit card in to pay for what we've just got. And I said, "I need to get the credit card in there, Xxxxx." And he didn't move. And I said, "Xxxxx, can you move this trolley back, please?" "Ah, I understand that." So I've got to learn as well. (381-390)

And it's the same with making requests, something to do with the dog, like putting the collar on or something. I have to be much more careful how I say things and he hates it if I raise my voice at all. (392-395)

Grading activities

We used to do ten mile walks, we now do more of a two mile walk. (339-340)

Yes, he can get the bird seed mixed up, but I have to just try and make sure it's in the right place and not – there are some things that go astray, but they're not worth making a fuss about. (364-366)

Because he was doing the small crossword, with a bit of help. That's the other technology that I do use, is I find the answers on my iPad and I tell him the impossible – I tell him the ones that I think he won't get so he can complete the rest. (477-480)

Ivor – Individual interview analysis

Ivor - Interview Summary

Technology used	Outdoor activity engaged with
Personal tracker	Gardening
	Golf
	Walking

Ivor and his wife married later in life. They met at a local golf club and spent much of their time enjoying this shared activity. Although Ivor recognises that his wife had difficulties with her memory many years prior to her diagnosis, he did not know how to help her or how to spot the early signs of her dementia for what type were. Even after the problems became very obvious his wife was reluctant to seek professional support and so it was a considerable time before they got a formal diagnosis, treatment or help to manage the condition. Ivor's wife now has an advanced dementia, but he has supported her for many years through the various stages of the dementia and talked openly within the interview about the various challenges they faced as a couple and how they have met these.

Sadly, because of geographical distance and the strain of the second marriage, Ivor's wife does not see her family often. She no longer recognises them and Ivor does not receive any support help with her care from them. AS a couple they continue to socialise with friends, particularly at the golf club and Ivor's daughter and family are also close by. There retired life together has always been centred on outdoor activities such as walking, gardening and playing golf. Over time, Ivor has found that his wife can no longer engage in all of these activities or has lost interest and motivation. He feels this is down to the combined impact of her deteriorating dementia and poor physical health as they age.

Despite this he has maintained a routine of going away to large hotels with outdoor gardens/ grounds, where they can walk and experience the outdoors in a safe and controlled environment. They still holiday aboard often and visit the golf club several times a week. Ivor feels it is important to his wife's wellbeing and health that she continue to have access to the outdoors and encourages her to join in him and participate in these activities, even if she can only enjoy them in a reduced capacity eg. Having a knock about on the practice green rather than a full game of golf. He is also very aware that she does not remember these activities later in the day, but does not feel this matters as he is concerned about her welfare ‘in the moment’ and seeks to ensure a quality to her day to day life that includes regular access to the outdoors.

Because Ivor was concerned about the risks of his wife walking off and becoming lost or distressed, particularly when they are away) he bought a tracking device for her to carry. Ivor’s wife is unaware of how this device works and could no longer give consent to its use, but is accepting of wearing it. He uses this to ensure that he could locate her using the app on his mobile phone. He also feels that this gives him the freedom to leave her with others eg hairdresser, without making them ultimately responsible for caring for her. He reassures people that if she wants to get up and leave they should let her as he can always find her with the tracker. He describes this ability to locate her as giving him reassurance and peace of mind.

The use of a tracker was first suggested to Ivor by a policeman who became involved when his wife went missing from their home several years ago. Ivor rejected the tracker suggested through services as he felt it was of poor quality. Instead the tracker they use was purchased privately by Ivor after searching online for a suiTable product. It is quite complicated with a range of functions from geo-fencing abilities, tracking, an SOS call button and a 2 way radio function. However, they do not use all of these functions and he has had to call the product developer several times to get assistance in reprogramming or resetting the location when going on holiday.

Ivor - Intermediate Themes

- Early signs of dementia
- Adapting activity
- Adapting environment
- Health benefits of getting outdoors
- Restricted by carer role
- Complicated tracker chosen
- Responsibilities as a carer
- Living in the moment
- Dismissive of original kit recommended
- Feels guilt/ Responsibility for wife’s deterioration

- Living in the moment
- Gives confidence and reassurance
- Tracker too complicated
- Carer interest in technology
- Needs help to learn to use a tracker
- Grading activity
- Decreased motivation
- Tracker support them to do things
- Decreased independence
- Uses the tracking function easily
- Not using all the functions of the tracker
- Shared past times
- Social isolation

Ivor - Theme Development

From the Intermediate themes 4 individual participant themes were developed:

6. **"You never know what the times are until it's too late": Regrets and losses**

7. **""She still has the odd whack on the practice field" : Adapting to changing lives**

8. **"It gives me a degree of confidence" : Benefits of using the tracker**

9. **"It shouldn't be too complicated": choosing a tracker with functions he didn't need or use**

Within these themes a further 15 themes were identified, with each individual participant theme having between 3-4 themes each.

Ivor - Thematic Table

	Individual participant Themes		**Intermediate Themes**	**Line no**
1	"You never know what the signs are until it's too late": Regrets and losses	1	Early signs of difficulty	70-74 189-192
		2	Wife's decreased motivation and independence	36-39 61-62 113-115 146-147
		3	Ivor's guilt and feelings of responsibility	76-80 82-88 166-170 192-199 470-473
		4	Social isolation	94-96 99-102
2	"She still has the odd whack on the practice field" : Adapting to changing lives	5	Shared past-times	21 29-32
		6	Living for the moment	151-155 385-387
		7	Adapting the environment	43-45 46-47
		8	Grading the activity	117-123 126-127
3	"It gives me a degree of confidence" : Benefits of using the tracker	9	Health benefits	58-61 349-352 379-381
		10	Supports Ivor to support his wife	208-213 265-268 352-358
		11	Confidence and reassurance	327-329 332-334 344-348 373-374
4		12	Ivor is keen to adopt technology	162-163 180-182

	"It shouldn't be too complicated": choosing a tracker with functions he didn't need or use			223-227
		13	Ivor wants to use 'the best'	233-236 238-241 284-287
		14	Getting help to use the tracker	291 304-306 307-310 311-312 318-320
		15	Many functions of the tracker not used	254-258

Ivor - Key data extracts

1. "You never know what the times are until it's too late": Regrets and losses

Early signs of difficulty

It was mainly a memory problem and probably around about 2011, maybe 2012, she started to forget the names of the girls, or the ladies, that she played golf with, and she was exhibiting sort of a little bit of a memory problem with other things. (70-74)

No she was computer literate and she did my … when I had my own business she did my accounts up until the point where she was finding it difficult to concentrate and that was probably eight or nine years ago. (189-192)

Wife's decreased motivation and independence

If she can help it she doesn't go out in the fresh air at all in the winter because it's too cold, so I have to drag her out for a walk. In the summer she's happy to walk when I take her, but I think if I left her to her own devices she wouldn't. (36-39)

If she was left to her own devices she wouldn't bother. (61-62)

I think it's the dementia has taken away her ability to choose to do something that she enjoys because she doesn't want to do anything. (113-115)

It's impacted on her ability to do things on her own outdoors; (146-147)

Ivor's guilt and feelings of responsibility

One of the girls said to me "you know that she's got a memory problem don't you?", I said, "yes I've been trying to get her to the doctor but she won't go", and that was the difficulty, and I think it was between 2011 it took me like two goes to get her to the doctor (76-80)

By the time we got her … the time we got to she was persuaded to go and she said "I'm happy to do it" because she knew she had a problem, she was probably a couple of years down the line. Which to me was sad, you know, and then they took a year to diagnose it; ten months. So by that time, you know, the graph had started to drop down. (82-88)

There are certain things that I'd love to be able to do and I just … now I'm at the stage where I would like to learn, I'm tied down by not being able to go to classes and things because Xxxxx is needing my attention. (166-170)

So maybe at that … she was exhibiting minor problems then but I thought it was just she couldn't be bothered, and in fact I wish I had known the signs that she was showing then and what the signs implied, and therefore I would have probably been able to react a little better and a little quicker, but you don't … when you've never encompassed it before and never encountered it. (192-199)

One of the problems with people living with dementia is they start to do tidying up, which a euphemism for untidying, and so having eyes in the back of your head (470-473)

Social isolation

She's lost the ability to recognise anybody in her family, mainly because they don't visit her very often. (94-97)

Her family very rarely visit unfortunately, because they live a long way away, that's one of the reasons, and therefore, you know, they're strangers to her effectively (99-102)

2. ""She still has the odd whack on the practice field" : Adapting to changing lives

Shared past-times

We do outdoor things, we play golf, (21)

It was when we … yeah, after we met I said, you know, if you're going to come with me you're going to have to play golf. She played golf anyway so it was a reasonably good fit. (29-32)

Living for the moment

We go round stately homes as I said, and we go for walks in the gardens, and she'll enjoy it at the time, but of course she won't remember, you know; two hours later she won't remember where we've been, (151 – 155)

I'm trying to give her as much … what's the word … as much activity and as much interest in life as we can afford, and that things are which she'll enjoy (385-387)

Adapting the environment

We walk up through the village. We go to various hotels; we spend a lot ... we've done most of the Warners Hotels and they've got walks around the hotel so we'll do that. (43-45)

We'll go for walks when we go out to a stately home, we'll walk around the gardens (46-47)

Grading the activity

And up until about four or five years ago we were playing golf, but she lost the ability to hit the ball reasonably well and she was forgetting which club to take and all that sort of thing, so we stopped playing proper competition golf about four or five years ago. But we still have a … she still has the odd whack on the practice field. (117-123)

In the summer she'll come over and I'll say "come on, let's hit a few balls then", but then she'll get tired and say she doesn't want to do it and I don't push her. (126-128)

3. "It gives me a degree of confidence" : Benefits of using the tracker

Health benefits

But I go because I feel it's good for her, it's good for me, getting out into … and she does appreciate it when she's out there. She likes the trees, she likes the flowers, and I'll point things out to her and she enjoys it, (58-61)

And I go and do a bit of hunting, shooting, fishing; they've got rifles and archery and stuff like that, so that gives me a bit of a break (349-351)

It's enabled me to do more, to do the things that we would have done with more confidence that I'm not going to lose her. (379-387)

Supports Ivor to support his wife

Well I think if the right technology was available, and what I've got, that tracker device is going some way to helping me keep an eye on Xxxxx, but I don't want her now to be able to wander off and call in to play that thing, because that thing is telling me that I haven't kept an eye on her. So it's basically a very long … it's an insurance policy effectively. (208-213)

I can track her on my mobile phone. There's an app which I'm given which I can then see where she is. There's a map and I can see where she's wandering and I can follow her quite easily. (265-268)

If somebody does lose her, I don't give them the responsibility, I just say "this is Xxxxx, she's got this problem, I'm just going to do some shooting, you cut her hair but I don't expect you to watch over her; if you sit her down there and she starts wandering off, don't worry about it because I've got a device to find her", but they can't get outside; it's very difficult to get outside. (352-358)

Confidence and reassurance

We went to the xxxx before Christmas, and I had Xxxxx to wear it inside her jumper so she couldn't get at it, and I felt comforTable that I'd got it there (327-329)

I was able to see where she was. All right she was with me, but I was able to see that the device was working (332-334)

Now having that device in the hotel in quite a big area, these hotels have got 200 or 300 bedrooms, you know, outdoor activities, so she'll be wearing that all the time (334-338)

I can't say it gives me anything other than a degree of concern. (373-374)

4. "It shouldn't be too complicated": choosing a tracker with functions he didn't need or use

Ivor is keen to adopt technology

I am teaching myself as fast as I can. I'm quite … when I learn to use things I'm quite au fait with them (162-163)

I've even got my thumb print on there you see, with my thumb, and I know how to switch it on and off and get the emails and suchlike (180-182)

So the company … I think the company from where this guy got his information and his technology, when you Google it there's a company doing vehicle tracking, equipment tracking, you know, JCB for instance, that I know they have trackers in all their bits of kit, you know. (223-227)

Ivor wants to use 'the best'

I can't remember how it went, but I think it was the policeman that mentioned it to me but certainly we exchanged bits of information and then I … he showed me one bit of kit which I wasn't that impressed with. (233-236)

Eventually I sourced two or three of them and this one appeared to be the one that would do the job for me, and I think to be fair, used correctly, it will be okay (238-241)

It alerts when the person goes outside that particular map reference, then yeah, the telephone rings and it says the person's outside the perimeter, get on with it. (284-287)

Getting help to use the tracker

I was hoping it would be a little less complicated (291)

If I can master the resetting, which isn't too complicated and I've never done it yet, I wanted to get it done in Spain but the bloke never rang me back (304-306)

He's rung me back when I first had it very quickly, you know; he's not available all the time, but he did ring fairly frequently when I was asking about the settings previously (307-310)
So I'm going to give it another go, we're going away on holiday next week and I shall do it again, and get him to give me another lesson on resetting. (311-312)
Yes, it's just a new thing. I'm very disappointed in my lack of ability to master it. So I rate myself reasonably clever but, you know, technology is sort of … anyway. (318-320)

Many functions of the tracker not used
I've told Xxxxx about it but she can't remember to press it, and we've never had to use it in anger yet. I've tried it with her, and I've said "that's yours, press it and let's have a chat, and I'm going to go in the other room", and she follows me. (254-258)

Appendix 25 Study 1 Participant Themes

	Participant Theme	**Participant**
1	"I find he doesn't seem to like being in the house at all": Father always liked to be busy	Annabel
2	"It's like having a baby": A changing relationship	
3	"What on earths that around your neck": A difficult introduction to the buddi system	
4	"I knew I could find him if I needed to": Helpful to Annabel but not necessarily her father	
5	"Tomorrow they'll forget it" : Negative attitude towards technology for people living with dementia	
6	"He was oblivious to it": Barbara's husband lacked insight into his condition	Barbara
7	"He was obviously in a different world to me": The life they lived together not recognised anymore	
8	"If he could get out of the house he was off": Husband frequently tries to get 'home' and gets lost in the local area	
9	"At least we'll know where he is": The buddi 'tracker' offers reassurance for Barbara	
10	"We do a lot of walking together, always have" : Walking is a consistent feature in their shared identity	Carl
11	"There's been quite a change": Adjusting and changing their lives	
12	"If you can get used to this, you know for the future": providing the tracker at the right time	
13	"It's not as easy to learn now": Finds technology increasingly difficult	
14	"The Birdman": Husbands professional and personal identity linked to nature and the outdoors	Diane
15	"It might as well have been a banana in his hand": Inappropriate technology provided for husband	
16	"People are afraid of it": Husbands illness stigmatised them both	
17	"The saddest time of our lives": The challenges of being a carer	
18	"Dad always came with us": Family relationships are based upon give and take	Emma
19	"Better not get back on my bike": A shrinking world	
20	"Do you have to lie to get this stuff?": Let down by services	

21	“Timing is important”: The importance of developing habits	
22	“He’s always been a keen cyclist”: Fathers well-being	
23	“Now she knows for sure that there is something”: a recent diagnosis of dementia	Francis
24	““He would take the pressure off by organising or cooking a meal”: Early (young) onset with a close family network	
25	“You can’t go taking him for a walk by yourself then”: Stigma impacts upon outdoor occupations	
26	“We were given some brochures and some literature”: A lack of professional support or guidance	
27	“We have no faith in it”: Not the right technology solution for them	
28	“They are there to be mastered”: Differing views on technology	
29	“We need to do something”: A time of change	Greg
30	“Even though it wasn’t cheap”: Important to get the right technology	
31	“He likes going out and visiting places”: Important to Father-in-law to get outside	
32	“Peace of mind”: how it helps them as a family	
33	“Because he can relate to it and not make mistakes”: Feels at home in the outdoors and with nature	Helen
34	“I know I know you, but I’ve got dementia and I can’t remember your name”: insightful into the impact of his dementia	
35	“If anything happens to me, I’m not sure, that’s much more difficult.”: The challenges of being an older carer	
36	“Trying to introduce something new, in my experience, is very hard”: Introducing technology at the right time	
37	“There are some things which go astray, but they are not worth making a fuss about”: Adapting to changes whilst promoting independence	
38	“You never know what the times are until it’s too late”: Regrets and losses	Ivor
39	““She still has the odd whack on the practice field” : Adapting to changing lives	
40	“It gives me a degree of confidence” : Benefits of using the tracker	

41	“It shouldn’t be too complicated”: choosing a tracker with functions he didn’t need or use	

Appendix 26 Study 2 Individual participant analysis

Adrian - Individual Participant Data Analysis

Adrian - Interview Summary

Technology used	Outdoor activity engaged with
Sat Nav	Social Walking
Googlemaps	Biking
Tracker	Dog Walking

Adrian has an early onset dementia and so the impact of his illness was felt by his employee's as well as family and friends. On receiving his diagnosis, he was forced to close his business and make all staff redundant, a situation that he finds difficult to deal with. He therefore struggled with both coming to terms with the diagnosis itself and the impact it had on his social standing within his community and the significantly reduced financial situation he and his wife were left in.

Immediately after his diagnosis Adrian experienced a period of depression and did not go out at all. He found this time in his life very difficult and it took a long time for him to piece together an understanding of how to move forward. A significant part of his recovery and his continued well-being is supported by regular access to the outdoors. He visits the woodland area near his home twice daily and undertakes a range of activities there including dog walking, social walking and biking with friends. He describes the natural environment as a restorative feature of his life and uses technology to enable him to continue with these activities independently. He uses a range of technologies, including a satnav on his bike and google maps on his phone. He finds the interactive nature of his different smartphone apps particularly helpful and his calendar will remind him when to go out and where he is due to be, linking up with his google maps to help him locate himself and the destination he is heading to.

Adrian has a practical and pragmatic approach to managing the challenges of his symptoms and processing difficulties. He seeks simple solutions and applies a consistent and organised approach to his tasks, enabling his to achieve a number of impressive tasks, including restoration of a prized motorbike. He is very keen to adopt technology in his life where it can help him but is concerned about the cost implications of the most up to date technology, such as iphones. He is aware of his limitations and finds it difficult to adapt when software updates are introduced on his existing devices.

Having been a carer for his parents, who both had dementia, Adrian is often concerned by the stigma and discrimination he sees against people living with dementia in society. He would also like to see greater access to practical support and technology to enable people to continue carrying on with activities that are meaningful. He has at times taken on both a dementia activist role and advocate role for others, whilst campaigning to get better services for people living with dementia in his local area.

Adrian - Emergent Themes

- Technology not widely available
- Significant financial impact
- Experience of barriers and stigma in society
- Difficulty with costs
- Changing software is a challenge
- Lack of information available
- Connectedness to nature
- Disillusionment with services
- Recovery from depression
- Impact of emotional and spiritual health
- Change in roles and society status
- Poor mental health
- Decreased physical health
- Functional skill loss

- Routine
- Humour
- Organised
- Connectivity within technologies helpful
- Resilient
- Practical Coping Strategies
- Family experience of dementia
- Different from person to person
- Dementia activism
- Advocate for others
- Technology compensates for lost processing skills
- Empowerment
- Reduced stress for carers
- Positive attitude towards adapting technology to support dementia
- Acceptance by society
- Positive view of tracking
- Positive Risk Taking
- Goes outdoors to walk with family
- Goes outdoors to bike with friends
- Enjoys dog walking twice daily
- Importance of everyday activities
- Living in the moment

Adrian - Theme Development

From the emergent themes 5 individual participant themes were developed:

- “Anybody can afford free.”: technology brings new challenges
- “Lets you connect with the stuff that’s really important”: enabling recovery from diagnosis
- “We have always been very outdoor; in a sedate way” : identity linked to nature
- “If it’s going to help you to live a proper life, isn’t that as useful as a stick to somebody who has a bad leg” : technology as an enabler

- “Everybody’s Dementia is different” : How I live with my Dementia

Within these themes a further 22 themes were identified, with each individual participant theme having between 3 and 6 themes each.

Adrian - Thematic Table

	Individual participant Themes		**Themes**	**Line no**
1	“Anybody can afford free.”: technology brings new challenges	1	Technology not widely available	1210-1212
		2	Lack of guidance information	866-869
		3	Significant financial implications	134-143 729-733 874-882 861 874 – 882 1369-1371
		4	Experience of barriers / stigma in society	139-132 145 -148 192-198 471-485
		5	Technology is often expensive	455 -458 693-670 729-723 866-869 861 874 - 882
		6	Changing software is a challenge	636-641 19 345 - 356
2	“Lets you connect with the stuff that’s really important: enabling recovery from diagnosis	7	Disillusionment with services	471-485 519 -542 526-530 532-540
		8	Impact on health	237 -253 170 173 1015-1023 1036-1042 1122-1126 255-257 116-121 175-184 435-438
		9	Change in roles and society status	99-109 874-882 123 -127 134 -135 192- 195
		10	Connectedness to nature	234 -236 301-307 1156-1165

				1165-1175
		11	Recovery from depression	1036-1042 1156-1162 301-307
3	“We have always been very outdoor; in a sedate way” :identity linked to nature	12	Living in the moment, everyday activities	2-10 301-309 505-511 1058-1065 1084-1088
		13	Twice daily dog walks in the woods	298 -299 304
		14	Goes to woods on bikes or walking with friends	228-232 232-236 313-315
4	“If its going to help you to live a proper life isnt that as useful as a stick to somebody who has a bad leg” : technology as an enabler	15	Positive attitude towards adapting technology to support dementia	631-633 678-684 740 – 746 758-761 993-998
		16	Reduced stress for carers	654-658 678 -684
		17	Acceptance by society	758-761 1053-1055 314-315 578 - 584
		18	Positive risk taking	678-684 700-701 705-707 709-716
		19	Empowerment	359 – 366 377 419 – 420 920 -940 589 – 596 1093-1095 1099-1101 561-567 573-608 582 -587
5	“Everybodys Dementia is different” : How I live with my Dementia	20	Humour	319-323 631 661 808 -810 1041-1042 1041-1042
		21	Connectivity within technologies is very helpful	377-379 582-587 589 -596 1099-1113
		22	Organised Routines	246 – 250 746 – 750 1036-1042

		23	Practical Coping strategies and Resilience	2-10 162-167 199-208 826-828 631-633 1193-1204 1425-1436
		24	Experiences of others with dementia	664-680 714-719 1269-1280 1292-1310 1321-1326 1337-1346 136 -143 920 -940 959 – 974 971 - 974
		25	Dementia Activism and an advocate role	429-433 463-471 740 – 744 490 – 494 1189-1191

<u>Adrian - Key data extracts</u>

1. *“Anybody can afford free.”: technology brings new challenges*

“And the other thing is when you’re diagnosed, you know, you sit in a room with a guy or a lady and they’ll say ‘I’m very sorry Mr XXX you’ve got Alzheimer’s’ and then you say ‘well what can I do’ and they’ll say ‘well, nothing’ you know they’ve given you a death sentence. (471 – 473)

“So overnight I lost my livelihood, I mean since that day my wife had done two jobs and my life has been a continuous struggle to try and find somebody who would let me work and I tried all kinds of jobs, you know, I haven’t been idle by any means, I started looking for a paid employment and I went from sort of things within my own personal skill set so I wouldn’t have to learn new things because obviously learning new things is a fairly large no-no, down to collecting trolleys at Tesco’s. I couldn’t get a job doing anything, not even sweeping up, not that there’s anything wrong with sweeping up… (134 -143)”

“No I mean some technology I need help for and new technology is very difficult, you know, it’s when they bring a new version of software out and they change quite a lot I struggle with

that quite a lot, I do find it difficult to…I don't remember new sequences and things very well. So I tend to stick to what I have rather than change it." (636-641)

"Technology doesn't have to be expensive, it doesn't have to be elaborate and I found very often the simple things are so much better and they're cheap, you know, some bits even free, anybody can afford free." (455-458)

2. "Lets you connect with the stuff that's really important": enabling recovery from diagnosis

"Or I would complete a contract and forget to invoice it and…I mean when we were doing quite well I had three teams of guys working for me [pause] and so obviously when all this happened I had a lady in the office and these three teams of guys and they all lost their jobs, overnight." (123- 127)

"I rebuilt the engine. I found out you see I can do that, I can read that and I could probably read another dozen words as well. So I've been doing something and I'd leave myself a note saying what I was up to and left it and when I went out back I knew what I was doing and things like that. So that was probably the very, very first coping strategy I do a lot." (162-167)

"Behind where we live we have a small wood, so I was advised a long time ago for stress you should meditate and I've never been able to work out how you meditate but I honestly think walking in the woods with the dogs, listening the birds, watching the squirrels…made me feel…it's absolutely fantastic, calms you down, makes you feel good, let's you connect with stuff that's really important. I do that twice every day, which is great." (301-307)

3. "We have always been very outdoor; in a sedate way" : identity linked to nature

"Up until my diagnosis I was relatively fit and used to go to the gym quite often. It was just that after my diagnosis, well obviously before my diagnosis as well I didn't know that the part of my brain that told me I was full wasn't working and I couldn't remember whether I'd eaten…"(236-242)

“Because I mean what I personally wanted to know after my diagnosis was, you know, will I be able to do stuff with the family, will I still be able to ride a bike, can I go for a pint, can I go on holiday, can we go shopping. This is what’s really important on a day to day basis. The big picture doesn’t really matter, it’s all the little things that are really important to you that matter…”(505-511)

“Well I actually go outdoors twice every day, even if I…because I have a big hairy old dog.” (298)

“We’ve always been very outdoor in a sedate way and never been into mountain climbing or anything like that.”(235-236)

4. “If it’s going to help you to live a proper life, isn’t that as useful as a stick to somebody who has a bad leg” : technology as an enabler

“She bought…she actually bought this tracker and said will you put this in your car, but I found out it’s actually…it is a…you can leave it in the car but you can take it off and put it in your pocket and I think that for, you know, your partner, your supportive, whoever is quite useful.” (654-658)

“ I’ve got a sat nav on the bike, so I’m not going to get lost” (314-315)

“Well, you know, stress is a huge killer, if you’re not stressed about getting lost you’re not stressed about getting lost [laughs] and so why give yourself a problem?” (631-633)

“We live in a modern world and the only people that would find this technology invasive I think are people who have something to hide.” (706-707)

“Cos I’ve seen both sides of the coin, from the point of view having somebody you care about deeply and not, you know, losing them, the very small inconvenience of having somebody find out…I mean it doesn’t matter, I’m not going to go anywhere that’s secret, I mean what’s the point?” (678 – 682)

“Essential, it’s absolutely essential. I mean, you know, [pause] if you can have this [holds up smartphone] and it’s going to help you to live a proper life isn’t that as useful as a stick to somebody who has a bad leg?”(359-362)

5. “Everybody’s Dementia is different” : How I live with my Dementia

“I don’t know. I don’t know. I’ve only been using this satnav, the app, the free app would you believe for probably 2 or 3 years “(582 -584)

“Once you’ve met one person with dementia you’ve met one person, everybody’s dementia is different, you know, it effects everybody in very different ways.” (962-964)

“If you have no hope, you have no reason to be and if you have no reason to be you have no…and it’s a progressive thing, you know? “(490-491)

Brian - Individual Participant Data Analysis

Brian -Interview Summary

Technology used	Outdoor activity engaged with
Googlemaps app on ipad	Dog walking
Sat nav	

Brian lives with his wife and their dogs in a small town outside of Birmingham. He experienced a diagnosis and treatment for cancer in his younger years, this caused him to give up an interesting career abroad as an engineer. After a short period as a landlord, he moved into the automobile industry and stayed working for the same company for some 30 years until his retirement.

Brian began to notice difficulties with his short term memory whilst still at work and initially managed these with a range of practical coping strategies. Because both of Brian's parents had lived with dementia prior to their deaths, he was keen to know if these symptoms were attributable to a dementia or simply ageing. After some difficulty Brian was finally diagnosed with a mixed dementia of both Alzheimer's disease and vascular dementia. He has a very positive outlook, partly as he feels he "had his shock all those years ago" and appears to have built some resilience from these early experiences of living with ill health. And partly because both of his parents were very 'happy' during their illnesses and although they both lived with advanced dementia for some time, they retained a good quality of life and had mainly positive experiences. This in turn seems to have enabled Brian to adopt a very pragmatic and optimistic view of his current situation and the potential changes he might face in the future.

Brian is very open about his dementia, telling everyone within his family and local community straight away and seeking help and support whenever needed. Consequently he feels he has experienced no stigma about his dementia or the challenges it poses to him. He has adopted a range of coping strategies, including the use of a car sat nav and the google maps app on his ipad. He sees the sat nav exclusively in his car, but uses his ipad both at home and when out and about in the local area. He is particularly keen on the way that the ipad syncs his email and calendar with other apps. This enables him to keep checking re-checking his daily itinerary. He uses this in conjunction with the google maps app both to plan trips out and frequently throughout the day.

Although he was quite adventurous and travelled widely in his youth, Brian does not travel far now. He has stopped going on holidays completely and he found that he became restless and uneasy when away from home and attributes this to his dementia. He no longer likes to be in unfamiliar surroundings. He does however enjoy visiting local parks and green open spaces, where goes with his wife and dogs. Brian has not always had dogs, but after inheriting his mother's dog, he found it difficult to be without one when this dog died; he felt he missed the outdoor walks. He now walks his dogs twice daily in a local green area near to his home. He does not see this as a hobby as such, but instead a part of his daily life. He also talks about the importance of getting out to maintain his physical health stating he has 'got to' do this. This personal responsibility for maintaining his own health and well-being is repeated throughout the interview when talking about getting out and keeping up with technology to 'maintain the brain'.

Technology and home computing in particular has always been important to Brian, and he would like to keep adopting new technology, but finds this increasingly difficult at present. He plans to continue using google maps on his ipad to plan his outings and to locate himself when out.

Brian - Emergent Themes

- Earlier healthcare
- Resilience
- Wanted diagnosis
- Process of getting diagnosed was difficult
- Community engagement is important to him
- Pride in involvement in charities
- Importance of keeping using technology
- Would like multifunctional smart technology
- Unaware of most recent technology developments

- Keen to adopt new technology
- Takes ipad out with him as a prompt
- Positive outlook
- Planning to support others to support him
- Importance of understanding a person’s history
- Parents were both happy despite advanced dementia
- Would like all technology on his phone
- Ill health as a young man changed career
- Everyday dog walker
- Dog connects to lost family members
- Dog walking in local parks
- History of getting outdoors regularly since childhood
- Missed dog walking when dog died
- Walks dog locally
- Unaware of current technology
- Would like ‘SMART’ technology
- Uses home computing
- Dog walking not a hobby
- Got to keep on walking
- Technology keeps your brain going
- Walks dog on familiar routes
- Struggles with new environments / change
- Adopting new technology is challenging

<u>Brian - Theme development</u>

From these emergent themes 5 main themes were developed

1. “I knew something was wrong”: knowledge enables planning
2. “I had my shock years ago” : positive open attitude
3. “I missed taking him for a walk” : the importance of dog walking
4. “I was out of me comfort zone” : adapting to change
5. “I do all the normal things” : how the technology works for him

Within these themes a further 22 sub themes were identified, with each main theme having between 4 and 5 sub themes each.

Brian - Thematic Table

	Super -ordinate Themes		**Themes**	**Line no**
1	I knew something was wrong : knowledge enables planning	1	The process of getting diagnosis was difficult	622-634 637-639
		2	Wanted diagnosis	625-627 637
		3	Importance of understanding a person's history	453-455 460-462 466-468
		4	Parents positive experience of living with advanced dementia	424-434 438-441 450-451
2	I had my shock years ago :positive open attitude	5	Earlier health scare made him resilient	80-84 666
		6	Humour	204 231-237 240-243 247-248 393 421 440-441 498-499 832
		7	Open with people about diagnosis	220-223 225-229
		8	Positive Outlook	231-237 490-491 495-496
		9	Community engagement is important for him	681-683 689-690 694-697

				730-734
3	I missed taking him for a walk :the importance of dog walking	10	Everyday dog walker in local area	182-183 186-187
		11	Dog connects him with lost mother	197-200
		12	Missed dog walking/ being outside after mothers dog died	200-204
		13	Dog walking not a hobby	254-258 261-265
4	I was out of me comfort zone : adapting to change	14	Adopting new technology is now challenging	533-534
		15	Walks dogs on a familiar route	273-275
		16	Struggles with new environments and change	177-180
		17	Technology keeps your brain going	840-843
		18	Got to keep walking	287
5	I do all the normal things : how the technology works for him	19	Would like technology that is SMART	316 413-415 506-507 548-552
		20	Keen to adopt new technology	53-54 292-294 297-298 308-309 327-328 331-332 508-510 541-542
		21	Takes ipad out with him as a prompt	353-356 514-516
		22	Uses apps for planning	383-386

<u>Brian Key Data Extracts</u>

1. *"I knew something was wrong": knowledge enables planning*

"I: So in terms of…

P: …and my dad was in a different world but he was happy.
I: Well that's a very good thing.
P: I mean my mum was happy and every way so I've got no qualms providing they've given me that [laughs]." (438 – 441)

"P: I intend to…I haven't got round to doing it now but I intend to do a portfolio if you like of my life and where I've been, what I've done, family and all the rest of it and so it's there. Somebody to take on.
I: It's a great idea. That's a really good idea and do you hope, what is it you hope that will achieve, I mean?"
P: I hope it will help them when I am in the area of where I'm not sure where I am [laughs]. It will help them to understand what I'm saying and what I'm referring or doing." (460 – 468)

"But I think this is where a lot of people in the caring industry up to now haven't realised that the most important thing is to down to the history of the person that they're caring for to be able to react to things happen." (452 – 455)

2. "I had my shock years ago" : positive open attitude

"When I was diagnosed I made the decision that I would tell everybody. I thought well they might think something wrong with me and they don't know so I've told them, I've told everybody "(220-223)

"Both my mum and dad passed away with the disease. My mum had vascular. My dad had Alzheimer's and they've given me a bit of both [laughs] in the genes and they don't…it runs in the family [laughs]." (233 – 237)

Well I had my shock years ago when I had the cancer and that was, I must admit I cried at the time, you know, I was really upset but I thought come on you got to pull yourself out." (666-668)

3. "I missed taking him for a walk" : the importance of dog walking

"So we just have a days out or take the dogs and go wherever in the car." (182-183)

"Well the family has. Mum and Dad had dogs and we and XXX mum had dogs and when XXX mum was getting, was ill, we had the dog over here and then she passed away so the dog was with us" (197-200)

"The dog went. I was taking it for walks and all the rest of it and after you've been gone for about 3 months I said to my wife I think we ought to have another dog. I said I miss taking him for a walk so that's what happened so we ended up with two" [laughs].(200-204)

4. "I was out of me comfort zone" : adapting to change

"At the moment we don't go on holiday's cause the last holiday we had I became not disorientated but I wasn't happy. Do you understand what I'm saying? I was out of me comfort zone, yeah?" (177-180)

"No but this technology in that you're using it , providing you're using it on regular basis will stay with you quite a long time. Quite a long time and I think the fact that I'm using it is keeping me ticked over." (840-843)

"Well I've got to. If I don't walk it'll stop working." (287)

5. "I do all the normal things" : how the technology works for him

"I've always had a computer obviously at work and then eventually I decided to have one for home and XXX doesn't use it. She's not technical at all [laughs] and I use it to do all my emails and everything through it and I've got to keep my records on there, everything there like my presentation. It's all on there. That's basically it and I search anything I want to find out. General things." (292-298)

"Well, well I would say, me schedules, where I'm going next, if I've got 2 appointments like I got today I've got that and I can click into it to just remind myself where I'm going and why." (541-544)

“My calendar. That’s all, that’s what I basically use it for. The most important thing for me is that and lets go, that’s months, goes through, see what’s next. As you’ll see I’ve got another appointment this afternoon. Diabetic” (353-358)

“When we’re going on holiday or something like that or if I’m visiting somewhere I’ve never been before and I’m, I know but I don’t know the address where I’m going so I’ll put that into me into google to see where it is. I probably put it in there but I will also put my tom-tom up to take me there.“(383-387)

Cynthia - Individual Participant Data Analysis

Cynthia - Interview Summary

Technology used	Outdoor activity engaged with
Pendant Alarm	Gardening

Cynthia describes her upbring as working class, but that her husband came from a higher social circle. She talks joyfully about the transition from living in a small cottage with her parents to attending large society balls and events as a young married woman. Throughout her married life there were periods where they struggled financially, and she returned to living in a small cottage with her own small children. She feels these experiences have enabled her to feel grounded and to take a non-judgemental stance when dealing with people from all walks of life.

Cynthia is 85 years old and is now a widow. Her son lives in their family home, but often works away. She has a good support network of friends and family around her and lives in a large country house. Cynthia is retired, but previously worked in a challenging social care environment, which she retired from when she felt her emotional resilience was reducing. She has lived in her current home for many years with her husband and experienced a period of depression after his death which appears to have preceded a deterioration in her memory. Although Cynthia has a diagnosis of dementia, she was reluctant to admit this, describing only mild memory difficulties. Despite this she has made several reasonable adjustments to her daily life and routine, such as driving only in the local area on familiar routes and getting help to manage her large garden.

Cynthia does not use any technology to support her location finding when driving or when out and about away from her home. Inside the home and within her large garden she wears a small alarm pendant. This alarm is an advanced version of a typical ‘falls pendant alarm’ designed for use within range of the home. Cynthia describes this pendant as giving her reassurance to get out into her garden and it reduces her feelings of isolation. Although she has never had to use it in an emergency, she regularly checks its functioning and is reassured to find someone at the call entre system, available to talk to her straight away when she presses the button. Cynthia is clear that she always wears her pendant and would not be without it.

Cynthia has always accessed green outdoor spaces, growing up in the countryside and enjoying cycling from village to village as a girl. She lives in a very rural location and has a large garden which she enjoys daily. She can no longer manage these now, and has hired two gardeners to help, but she has left a small area close to her house where she alone still gardens. She talks of the spiritual connection she feels with God when spending time in her garden and the importance she places on being able to do this. She also describes using time in the garden as a coping strategy when she is upset. It appears Cynthia had a serious period of depression following her husband's death and that this preceded her developing significant memory problems.

Although she lives in an extremely rural location, Cynthia feels that connection with other people is key to her well-being and makes the effort to talk to her neighbours, postman, local policeman and relatives frequently. She feels a sense of social responsibility and is keen to highlight that she regularly checks with this local policeman that her driving abilities are still safe as she would be 'devastated' to cause harm to anyone else if unsafe on the roads.

Cynthia - Emergent Themes

- Goes outdoors everyday
- Uses pendant inside and outside the home
- Really enjoys reading
- Spiritual connection to God in garden
- Idolises husband
- Moving between social classes
- Worked in a difficult area of Social Care
- Dismissive of sons help
- Human connections with people vital to her well-being
- Guilt/ Embarrassment at 'indulging in' reminiscence of past
- Enjoyed cycling outdoors in youth
- Gains help with big garden now
- Varied life experience
- Close support network family and community
- Always wears pendant

- Doesn’t like exercise, but walks in garden everyday
- Aware of driving risks to self and others
- Periods of financial hardship
- Husbands illness was devastating
- Uses time in garden as a coping strategy when upset
- Romantic courtship
- Reluctant to discuss diagnosis of dementia
- Feels she grew from difficult experiences and adversity
- Garden gives a sense of permanency through adversity
- Reluctant to discuss depression diagnosis
- Drives only in familiar local area
- Rural identity
- Having pendant prevents restrictions
- Pendent gives security despite rural isolation
- Rural upbringing
- Always enjoyed adopting kitchen gadgets
- Always gone outdoors
- Reluctant to admit fall
- Suspicious of family concerns
- Only part of a continuum
- Keeps area of garden for herself
- Gadgets useful to make life easier in the home
- Physical health limitations
- Finds pendant reassuring
- Seeks advice on driving from local policeman
- Dismissive of sons concerns for welfare

Cynthia - Theme development

From these emergent themes 6 main themes were developed

1. “The first thing I do in the morning”: Fiercely independent

2. “Every bit in life, I think if you handle it, it makes you less judgemental”: Social conscience
3. “It was nothing”: Doesn’t like to show weakness
4. “I always wear this”: Accepting of change and the need to adapt
5. “We are only part of a continuum”: the value of being in the garden
6. “She’s as close to me as she could be”: Connections to people vital

Within these themes a further 24 sub themes were identified, with each main theme having between 3 and 6 sub themes each.

Cynthia - Thematic Table

	Themes		**Sub Themes**	**Line no**
1	“The first thing I do in the morning”: Fiercely Independent	1		
		2	Finds pendant reassuring	493-501 611-618
		3	Adopts gadgets that make life easier	416-428 435-450
		4	Goes outdoors everyday	339-342
		5	Feels she grew from difficult experiences and adversity	175-176
		6	Pendant prevents restrictions	514-523
2	“Every bit in life, I think if you handle it, it makes you less judgemental”: Social conscience	7	Rural upbringing and sense of community	195-205 323-327
		8	Worked in difficult are of social care	126-150
		9	Seeks advice on driving from local policeman re: driving	377-389
		10	Varied life experience	175-176 566-572 584-591
		11	Concerned about her driving impacting others	369-375
3	“It was nothing”: Doesn’t like to show weakness	12	Reluctant to discuss diagnoses or general health complaints	167-173 254-263 678-681
		13	Suspicious/ dismissive of family concerns for welfare	266-271 281-287 299-303
		14	Guilt/ embarrassment at ‘indulging’ in reminiscence of her past	601
4	“I always wear this” :Accepting of change and the need to adapt	15	Drives only in familiar areas	397-304
		16	Arranged help to manage the big garden	660-663
		17	Uses pendant everyday inside and outside	289-294
		18	Aware of mobility limitations	678-681

5	“We are only part of a continuum”: the value of being in the garden	19	Garden represents a continuum of life	354 -359
		20	Maintains physical health in the garden, despite dislike of exercise	691-693
		21	Keeps a small area of the garden to work on herself	668-671
		22	Spiritual connection to God in the garden	344-346 349-352
6	“She’s as close to me as she could be”: connections to people vital	23	Relationship with husband very meaningful	162-165 538-544 577-582
		24	Devastated by husband’s death	167-177 717-728
		25	Close community connections important to her well-being	238-241

Cynthia - Key Data Extracts

1. *“The first thing I do in the morning”: Fiercely independent*

“It was a good lesson really cos…but it just, every bit in life I think if you handle it, it makes you less judgemental.” (175-176)

“Oh it [the pendant alarm] gives me great sense of security and although we’re stuck away down here” (499-500)

2. *“Every bit in life, I think if you handle it, it makes you less judgemental”: Social conscience*

“Cos’ when I was there it was rural, and I could remember…I knowingly I’d just identify as XXX’s granddaughter and that kind of thing [interviewer laughs] but in a way looking back was a very secure kind of upbringing.” (202-205)

“And I said well I was going to ask you for my sake and cos I would be devastated if I killed somebody you know…” (373 – 375)

“It stops you; I think the good thing looking back is that it does stop you being judgemental about people. I’ve bet you find that?” (589-590)

3. *“It was nothing”: Doesn’t like to show weakness*

"He started worrying about making meals for me [laughs] and I can't say I resented it because I'm truly grateful to him [laughs]…but it wasn't necessary, it was I'm not going to starve.…and you know its fine. I went into town, had some coffee, had some lunch or some other." (300-306)

"I have to say it's a bit self-indulgent." (601)

4. *"I always wear this": Accepting of change and the need to adapt*

"I'm not the least bit worried about being on my own…..I am [pause] I was quite careful if I went down the garden I took a walking stick or something, as you can see I always wear this…" (289-294)

5. *"We are only part of a continuum": the value of being in the garden*

"At least once a day and if ever anything upsets me it will be several times a day. I just go and walk round the little garden you know." (344-351)

"I'm quite religious and there's a biblical sentimental poem but there's a line which says you're nearer Gods heart in a garden than any place that's on earth." (349-351)

"It's sort of a sign of permanency or no matter what happens to me or around me things will go on……we're only part of a continuum." (356-359)

"I cut out all except this little bit in the front so, just before you came I was looking up and thinking will I go and buy a few bedding plants and that means paying for a dozen bedding plants, it's nothing and so that's nice." (668-671)

"I don't like doing exercise, walking around but I did go down as long as its fine or even if it isn't I go outside, walk up the garden or whatever that's almost every day." (691-693)

6. *"She's as close to me as she could be": Connections to people vital*

“Yeah, yeah and XXX was an incredible person who was very different to me cos I come from a very working class background and scholarships and all the rest of it and he was prep school and public school.” (538 – 540)

David - Individual Participant Data Analysis

David - Interview Introduction

Technology used	Outdoor activity engaged with
Garmin Car Sat nav	Walking
Phone App – Google maps	

David is a retired educational consultant who now volunteers as a PI. He live with his wife in a house they recently downsized to and has regular contact with his grandchildren. David denies ever being aware of any symptoms of his dementia but understands that he has an early stage Alzheimer's disease.

David prides himself on being an 'early adopter' of technology, including home computing and microwaves in the past. He used computers extensively in his work and feels that he has the right 'mindset' for technology. However, he does not embrace new technologies so easily now. He uses a smartphone, but has a limited understanding of its functional capability. When he does adopt new technology David now seeks advice and support from his grandchildren, whom he feels are experts.

David uses a satnav in his car and is very familiar with this type of technology. He has recently started to use the navigation app on his phone to support him when out on foot as well, although he finds tis more difficult to master. He reports using it to locate himself when in busy cities and when out walking.

David walks every day, but often this is to undertake functional tasks such as getting the shopping. He is proud of his 'fast and purposeful' walking pace. David does walk in local parks and for pleasure, often with his grandchildren. As a child he played in green spaces created in abandoned bomb sites after the war. He enjoys getting outdoors and used to walk a lot in his youth to get to and from places, but he does this out of choice now he is retired.

David is aware that his dementia may deteriorate in the future but has a limited understanding of what this may entail. However, he is aware of the importance of routine and developing habits that will safeguard him in the future. He talks about ways in which he could adopt both his sat nav and phone app into his everyday routine, but has not yet done this.

David - Emergent Themes

- Supporter not supported

- Reasonable adjustments
- Family history
- Distances himself from diagnosis
- No longer up to date
- Rejects new technology
- Technology is essential
- Excited by new technology
- City life and green spaces
- Walks to a target
- Not a rambler
- Walking out of choice
- Long life expectancy
- Knee problems
- Bleak view
- Developing habits
- City life and green spaces
- Walks to a target
- Not a rambler
- Walking out of choice

David - Theme Development

From these emergent themes 5 main themes were developed

1. "Now I do it out of choice": Walking with Purpose
2. "My international reputation" : an expert
3. "I use what I use" : New technology
4. "I don't anticipate becoming housebound" : later life
5. "Age-related slowing down of mind and body" : gentle deterioration

Within these themes a further 19 sub themes were identified, with each main theme having between 3 and 4 sub themes each.

David - Thematic Table

	Themes		**Sub Themes**	**Line no**
1	"Now I do it out of choice: Walking with Purpose	1	City life and green spaces	60-63 69 289-297 328-330
		2	Walks to a target	74-77
		3	Not a rambler	73-74 78-79 370
		4	Walking out of choice	84-86 94
2	"My International reputation": An expert	5	Working identity	13-14 23-26 39-40
		6	Technology expert	159-166 198-201 202 216-218
		7	Volunteering role	107-111 188-195
3	"I use what I use" New technology	8	No longer up to date	167-169 205-207 281-284 290-291
		9	Rejects new technology	171-173 192-195 225-231 236-239 440-441
		10	Technology is essential	178
		11	Excited by new technology	217 322-325 336-345 452-456 472-473 510
4	"I don't anticipate becoming housebound": Later Life	12	Long life expectancy	94-97 99-100
		13	Knee problems	89-91 294
		14	Bleak view	94-97 375-383
		15	Developing habits	235-231 265 269
5	"Age-related slowing down of mind and body": Gentle deterioration	16	Distances himself from diagnosis	35-43 48-49 114-118 119-122 124-125 390-391 415-423

		17	Family history	143-149
		18	Reasonable adjustments	130-136
		19	Supporter not supported	54-55 313-320 358-360

David - Key Data Extracts

1. "Now I do it out of choice": Walking with Purpose

"Yes, absolutely. I would say childhood, it was after the war and stuff and kids running round wild the whole times, it was smashing." (60-61)

"I've always gone out a lot. I've often had to but now I do it out of choice." (63)

"I've not particularly rambled as such, in a group, I walk. If there's a target, then I walk to the target, otherwise I try to walk for an hour every day." (73-75)

"I walk very fast and make myself out of breath when I'm walking, just round the corner or something like that. That will go on forever, I presume, I will get more and more out of breath, so I have to slow down, that will hurt but there it is, and I accept that that's going to happen, I probably have slowed down. In fact, one of the grandchildren, one of our children says, you're not walking as fast as you used to because we often go out on walks together." (366-374)

"I don't want to get so frail that I can't go out, so I can see that eventually I might only be able to make it up to the park and round the park once or twice, which is okay, it gets a bit boring after a while" (380-383).

2. "My international reputation" : an expert

"I don't work for money anymore, but I work full-time in voluntary activities." (13)…………….

"My first career was teaching and teacher training, my second career was an educational consultant, international education consultant and now I've retired from that and moved into this." (25-26)

"I do a lot of work with Alzheimer's Society and some of the senior people there know that I've been diagnosed, the sort of work I do, they want people living with dementia as well and carers as well as human beings."(107-111)

"I have been, I suppose I was an early adopter of home computers and stuff like that, I began to get an international reputation for educational computing, using computers for teaching and learning. So, in those days, I had a good enough reputation and if a new computer came out, I could write to the manufacturer, they would send me one for free in order to do that sort of work. So, yes, we ended up with about 50 BBC computers and things like that. "(159-166)

3. "I use what I use" : New technology

"I use what I use, I don't use it as a phone very much, I don't make many phone calls, I hate the phone, so I don't think I'm a fast adopter, if a new smart phone comes out, a new Blackberry comes out, I don't rush out and get it." (169 – 173)

"So, word processing to me is second nature, totally second nature but if I had to do that, if I was encouraged to do that, as something totally new, I'm sure I would find that very difficult. Like if someone gave me an iPhone and I said, right well I'm going to use this, I'm not sure how well I could do that." (202-206)

"People do find new kinds of things difficult and then with dementia, people are encouraged to keep the person concerned in familiar surroundings." (220-221)

"Changing habits becomes harder and harder, getting into new habits gets harder and harder and therefore adopting new approaches to life and technology could totally change your life, so it's not like getting a posher television or something like that. It's potentially a total change of life that people are expecting, and I imagine that might be difficult." (225-231)

His fear of not managing the potential changes has inhibited his desire to take on or adopt the new technologies. Although this may be a protective strategy, it may also have come from an aspect of trial and error with is blackberry phone, itself somewhat outdated now.
"However, despite these set-backs David still feels technology is important and that
I don't think I could manage without it." (178).

"Would I ever extend it? I don't know. I could extend the use of it if I was going on a long circular type walk when I was in a strange place, which I do sometimes do" (336 – 338)

"Well it's possible that, what's that new Google glass type thing that's just come out? It's possible that something like that would be easy enough to use where it was superimpose on what you – That would be particularly easy because getting your phone out and switching that on and finding out where I am, the map is already, it's there, that is a pain and if you've got to carry shopping, that is even more of a pain. " (472-480)

4. "I don't anticipate becoming housebound" : later life

"I would say quite a lot, it's difficult to define purely for the pleasure, as walking is sometimes not as pleasurable, my legs will start aching and stuff like that. "(89-90)

"R: Extremely important otherwise, if that becomes one of the difficulties in later life, that's something that I will miss most, I guess, going out. If I do become housebound or whatever, I don't anticipate becoming housebound.
I: No, there's no reason you should.
R: No but or too frail, which may be ten or twenty years, who knows, I may not be able to go out so much, I will miss that."

5. "Age-related slowing down of mind and body" : gentle deterioration

"I can't say I ever felt I had memory problems, but my wife became insistent that I had worse and worse ones," (35-36)

"So, the GP referred to the memory service and they did various tests, memory tests and so I and I did extremely well but when they did the scan, a MRI scan, there was, what they call …

there are signs of atrophy, there was signs of brain atrophy consistent with the early start of Alzheimer's. "(38-43)

"I believe, as I have age-related slowing down of mind and body" (113-114).

"All those cognitive things, do they, gentle deteriorate," (125)

"I'm getting into new routines, I have new routines in many cases, compared to old ones because I could multi-task much more than I can now, therefore I have to try to remember specifically why I'm carrying this and carrying that at the same time, going to this room and then into that room, sort of thing. So, I'm trying to do that more, but I hope that I succeed, and new habits will be ingrained including working things out." (132 -138)

Edward- Individual Participant Data Analysis

Edward - Interview Summary

Technology used	Outdoor activity engaged with
Googlemaps app	Dog walking
Google Earth app	Gardening

Edward lives in a very rural location with his wife and dog. He enjoys getting outdoors and feels that it is essential to a healthy and enriched life. He walks his dog twice a day and manages a large flower and vegetable garden at his home. His love of the outdoors stems from early childhood when he spent all of his school holidays with his grandparents in rural Wales and felt that this helped him escape an otherwise unhappy childhood.

Edward has experienced symptoms of ‘brain disease’ as he prefers to label his dementia for around 20 years. He worked previously as a business manager in education but had to leave his job because of deterioration in his abilities, due to the development of early onset dementia. This went undiagnosed for some years and he feel he had to fight to get that diagnosis, but once he was diagnosed and provided with medication, he has been able to stabilise the decline of his cognitive functions and establish a more structured and stable life. Edward no longer works but is a dementia activist, appearing in steering groups, public engagements and advising in a number of local and national capacities about the importance of early diagnosis. He is also a campaigner for the voice of people living with dementia to appear in publications, legislation and research about the condition and has a particularly popular twitter following.

Edward does not feel he has ever been keen on ‘gadgets’ but has always adopted technology and computing where he sees a use for it, for example within this work. He describes himself as confident with adopting new technologies and draws on his previous experience of successfully learning about new technologies when trying something new. He has adopted both a smartphone and ipad and now relies on them every day to manage his poor short-term memory, orientation and planning deficits. He says he adopted them because it made things easier for him and because he wished to remain independent for as long as he can.

In particular he uses his smartphone to plan journeys and outdoor walks. He looks at the map function to plan the actual walk, but also to determine how long it will take him, as he no longer feels able to judge times effectively. When out he feels he could no longer use a traditional map as he would not be able to locate his current location, whereas the app enables him to see where he is now as well as where he needs to go. Participant F also uses google earth as he feels he benefits considerably from the ability to look up a picture of the place he is at. He feels that using these apps on his smartphone in this way gives him confidence and reassurance. Edward feels that it is lack of confidence that is the greatest barrier for people like him to accessing the outdoors.

Edward - Emergent Themes

- Adjusts expectations
- Escapes unhappy childhood by going outdoors
- Increased confidence when going out
- Helpful in urban settings
- Viewing pictures is useful for confirming where you are
- Uses app for planning
- Good awareness and coping skills
- Uses technology where it is useful to him
- Patient expert
- Doesn't use the label dementia
- Critical incident in supermarket
- Early signs and symptoms
- Want knowledge and ownership of diagnosis
- Many challenges of his dementia
- Doesn't like risk adverse strategies
- Activism gives him purpose
- Will use technology in the future
- Competent with technology
- Uses technology to locate himself
- Many coping mechanisms
- Already experiences some restrictions
- Technology should be provided
- Should avoid withdrawal from the outdoors
- Technology supports independence

- Love of outdoors
- Early adoption of technology important
- Positive view of navigation technology
- Technology enables repeated checking because of poor short term memory
- Currently uses multiple apps, would like to see these combined
- Dislikes patronising risk adverse attitude from services
- Advocate for early diagnosis
- Diagnosis empowered him
- Diagnosis increased outdoor activity
- Diagnosis enabled access to medication that ‘woke him up’
- Long time before diagnosis
- Dismissive of dementia nurse
- Engaged with online dementia community
- Using technology is a coping strategy
- Doesn’t love gadgets
- Relies on technology
- Balance of privacy versus need/ independence
- History of adventurous outdoor pursuits
- Decreased confidence results in getting outdoor

Theme development

From these emergent themes 6 main themes were developed

1. “We want to know”: the long journey to diagnosis
2. “ My Brain Disease”: empowerment and role as an activist
3. “Wherever I am, I can find where I am”: technology compensating for lost skills
4. It’s hugely increased the confidence I feel :technology enabling access to outdoors
5. “I just love to be outside” :the meaning of getting outdoors
6. “I can work it out”: confident with technology

Within these themes a further 26 sub themes were identified, with each main theme having between 3 and 5 sub themes each.

Edward - Thematic Table

	Themes		**Sub Themes**	**Line no**
1	“We want to know”: the long journey to diagnosis	1	Critical incident in supermarket	228-234
		2	Many challenges of his dementia	210-214 236-239

		3	Want knowledge and ownership of diagnosis	54-55 58-59 17-19 27-30
		4	Early signs and symptoms	216-220 222-224
		5	Diagnosis empowered and enabled	60-63 89-100 256-257
2	"My Brain Disease": empowerment and role as an activist	6	Patient expert	70-72 80-82 80-82
		7	Doesn't use the label dementia	18-19 90-91 240-241
		8	Doesn't like risk adverse strategies	362-364 119-120 112 119-122 126-128
		9	Activism gives him purpose	84-86 100 446-449
		10	Engaged with online dementia community	110-111 128-132 576-583
3	"Wherever I am, I can find where I am": technology compensating for lost skills	11	Future developments of technology	457-463 601-608 622-624
		12	Currently uses multiple apps – would like 1 that does it all	601-608 622-624
		13	Enables checking, locating and planning	47-48 384-386 452-453 431-436
4	"It's hugely increased the confidence I feel: technology enabling access to outdoors	14	Increases confidence to go out	445-446 489-493 469-470 500-501
		15	Early adoption of technology	341-342 344-347 567-569 567-573
		16	Connected to others even when alone	531-536 683-687
		17	Balance of intrusive nature and need	353-358 362-364 370-372
		18	Also, very helpful in urban areas	491-493 512-517
5	"I just love to be outside": the meaning of getting outdoors	19	Love of outdoors	155-159 160-163 165

				185-186 191-194 197-200 672-674
		20	Technology to support independence	356-358 362-365 369-371 370-372 685-687
		21	Avoiding withdrawal from outside	663-666 596-597 512-517
		22	History of using outdoor environments to cope with difficulties	178-183 160-163
6	"I can work it out": confident with technology	23	Relies on technology now	40-45 379-380 27-31 246-249
		24	Uses technology where it is useful to him	326-335 383-386 572-573
		25	Will use technology in the future	473 529-531 553-554
		26	Competent with technology	322-333 395-396 400-407 417-421

Edward - Key Data Extracts

1. *"We want to know": the long journey to diagnosis*

Yes, the diagnosis – well, I went to the GP, it must have been 2013 or 14 that I got diagnosed, probably summer of 2013. I'd been to the GP in 2011 and 12 saying "Look, my wife and I know there's something not right here." And both times he said, "Well, what's the point of knowing, there's nothing anybody could do." Anyway the third time we both went and said, "Please refer us, because if it's not dementia, fine, if it is, we want to know." And of course, what it was, I mean it's Alzheimer's and vascular, I immediately was put on Donepezil, which woke up my brain. " (52-63)

2. *"My Brain Disease": empowerment and role as an activist*

I mean, it's difficult to say, pinpoint what and where dementia, well, brain disease starts and where it doesn't (17-19)

Because they keep you in touch – people scoff about Twitter, but actually Twitter is a fantastic way of networking. You find out loads of stuff if you want to, but you also – I mean you mentioned my network. Well, some of it's through Twitter. I can't stand Facebook, I mean I use it just to post some stuff occasionally for my DEEP groups, but the Twitter, it's just a really helpful thing to keep in touch. As long as you don't let it overtake your life. (576-583)

3. "Wherever I am, I can find where I am": technology compensating for lost skills

Yes. If I took the dog for a walk in, I don't know, let's say XXXXXX just up the road, ten miles away, and I do sometimes. I will find where I'm going on the Google Map just because I feel happier, I know where I am. So it's just going to there, because (a) I'll avoid going round in circles and not getting to the right place and (b) I want to know how far I can go without having to retrace steps or whatever else. And just be confident where I am, simple as that.(429-436)

4. It's hugely increased the confidence I feel: technology enabling access to outdoors

I think people should start using it before they have to, because the sooner you get used to using it. I remember reading someone's blog some time about it and it makes perfect sense. If you try to introduce, I don't know, some whizzy reminder system when someone actually can't remember to set the damn thing or whatever, then it's too late. (341-346)

I mean, it's interesting that, in these DEEP groups that we have, peer groups, there are people who are further on than me and it's quite evident that they, and I will, eventually struggle with working out what to do with a smartphone, just as much as anything else. So when I say I will continue to use it, I'll continue to use it for as long as I can. But I can see other people becoming less confident and less able and therefore putting it aside because they think, "Oh, it's too much hassle, I don't want to do it anymore."(549-557)

5. "I just love to be outside": the meaning of getting outdoors

It just gives me pleasure. I love seeing things grow, I love trees. I love growing things from seed. It's difficult to say, really. I love birds, I do a lot of bird-watching. I just like being outside. (197-200)

It's interesting. I think that the outdoors in any and every form is really important to people living with dementia, because it's too easy and it too often happens, I'm sure, for people to just withdraw.(663-666)

And I would say because I think the biggest issue for people living with dementia in getting out is losing confidence, to be sure you'll be safe, in your own terms, I don't mean not taking risks, but you'll be able to get home, you'll be able to remember to buy what you want to buy or go where you want to go – catch the right bus, etc.(596 – 601)

6. "I can work it out": confident with technology

By and large, I won't say I love gadgets, but I have always embraced what computers can do for me. In my work, at school, I was one of the people who wanted to make use of very early internet type and email type stuff to do projects for the children.(322-326)

Fiona - Individual Participant Data Analysis

Fiona - Interview Introduction

Technology used	Outdoor activity engaged with
Garmin Running Watch	Running
Car Sat Nav	Dog Walking
Mobile Phone app - googlemaps	Hockey
	Mowing
	Social Walking

Fiona lives in a very rural location, she moved there in recent years to downsize and have more opportunities to get out and about in the surrounding countryside. She lives with her partner and has a wide support network of family and friends. They also have two dogs and she is currently training to run the London Marathon in a few months' time.

Fiona developed memory difficulties during a particularly stressful end to her working career; which resulted in a vascular event or TGI, which has left her with generalised atrophy and a gradually deteriorating vascular dementia. These events happened several years ago and she talks within the interview about her struggles to accept and then own her diagnosis and find her own identity within it.

Being outdoors and talking part in outdoor activities such as dog walking and running are part of her everyday life and she believes them to be beneficial to both her physical and mental health and overall wellbeing. She has a lifelong love of natural outdoor spaces and has always engaged in outdoor pursuits such as playing hockey and dog walking. In recent years she has also started enjoying the outdoors by sitting on her r ide on mower and spending time mowing a small nearby field, an activity which she finds very helpful to manage her stress levels.

Although admitting she is a little bit afraid of technology, Fiona uses it to enable her to get out and about and feels that it is an essential part of her running, stating that she could not imagine running without it. She uses a combination of devises to assist her, each providing a slightly different function that helps her manage the complex difficulties she faces in planning and organising because of her dementia.

Fiona has a positive outlook and is keen to ensure that the people around her understand her condition, its limitations and the 'truth' about how it really affects her and others like her. She is an advocate or better dementia awareness and volunteers running dementia friends' events in the local area as well as raising money for Dementia Research charities with her running.

Fiona - Emergent Themes

- Finds pleasure in nature
- Outdoors identity
- Freedom being active
- Always doing something
- Initial reaction to diagnosis
- Moving forward
- Stigma
- The little world in which you live
- Competitive
- Positive/ Proactive outlook
- Motivation
- Personal responsibility
- Everyday technology
- Compensates for difficulties
- Emotional security
- Not a gadget person
- Ideal technology

Fiona - Theme Development

From these emergent themes 4 main themes were developed

1. “They’re part of what makes me me” : a love of nature
2. “The little world that you live in”: I’m still me!
3. “A bloody good reason to be doing it”: Resilience
4. “It’s part of what I need to have a good run” : make it easy for me

Within these themes a further 17 sub themes were identified, with each main theme having between 3 and 4 sub themes each.

Fiona - Thematic Table

	Themes		Sub Themes	Line no
1	"They're part of what makes me me" : a love of nature	1	Finds pleasure in nature	144-146 192-194
		2	Outdoors identity	127-129 492 507-508
		3	Freedom being active	153-154 180-181 192-194 515-516
		4	Always doing something	133-135 148-150
2	"The little world that you live in": I'm still me!	5	Initial reaction to diagnosis	47 204-211 226-228 258-260 184-188
		6	Moving forward	188-193 348-349 644-647 652
		7	Stigma	105-106 112-115 224-225 233-235 242-244 649-650
		8	The little world in which you live	74-79 107-108 642-643 644-647
3	"A bloody good reason to be doing it": Resilience	9	Competitive	54-58 173 378-379 539-540
		10	Positive /Proactive Outlook	90-92 297-299 338-343
		11	Motivation	175-177 303-305 521-523
		12	Personal responsibility	69 93-94 294-297 492-498 526-529
4	"It's part of what I need to have a good run" : make it easy for me	13	Everyday technology	328 378-381
		14	Compensates for difficulties	387-392 403-406 409-412 413-414 422-425

				438
		15	Emotional security	443-445 449-452 465-466
		16	Not a gadget person	11-13 317-318 325-326 350-354 431-435 477 504 551-554
		17	Ideal technology	564-567

Fiona - Key Data Extracts

1. *“They’re part of what makes me me” : a love of nature*

“It’s such a beautiful environment, I can just sit on the mower and look at the beauty all around me” (144-145)

“As a child my parents used to encourage us. We used to go for walks a lot or the Sunday drive and then there would be a walk at the end of it, and a love of sort of nature and countryside has always been part of me.” (127-130)

“But whilst I can still do those things, I want to do them, because they’re part of what makes me me if that makes sense? “(506-508)

“And dog walking, because we’ve had dogs, we’ve been together 25 years, and we’ve had dogs, so we’ve always done dog walking, which again is getting outdoors. So yes it has always been part but it’s more so now probably than ever. “(133-136)

“The fresh air, the freedom, the nature that’s out there, the things that you can experience, and it’s doing something,” (180-181)

2. *“The little world that you live in”: I’m still me!*

"Then gradually as it became obvious that it was more serious, it did make me tend towards staying indoors a bit more and perhaps not bothering to go out because of the oh well if I've got some sort of illness," (206-210)

"I had two very clear reactions. One was relief because I knew there was something wrong and utter despair, because my experience of people with vascular dementia was not great." (226-228)

"I didn't do stuff, I would say to Sheila 'Oh I can't be bothered' or she would say 'Oh shall we walk the dog together today?' 'No I can't be bothered'." (286-288)

"Because one of the things that I have learnt is I'm still me, you know? The diagnosis doesn't … I can't remember the word now, but it doesn't … it has completely gone. In spite of the diagnosis, I'm still XXX, and that's what a lot of people have said, and that has given me back some positivity, and getting outside is very much part of that and getting out in the fresh air again." (288-293)

"Somebody said to me, "Gosh I'd rather have a cancer than a dementia". " (262-263)

"My philosophy in life is such that you can't change the world but you can make a difference in the little world that you live in." (641-643).

3. "A bloody good reason to be doing it": Resilience

"When I'm elderly I'll still be competitive. And with running you have to be competitive with yourself," (539 -541)

"I'm not a great walker, especially now I run, I don't want to walk, I want to get there quickly" (172-173)

"I am allowed to drive, and if I wasn't capable then I shouldn't be, but I have to have my licence renewed every year which living somewhere like this is scary. The idea that I might

have lost my licence was terrifying. That was part of the process that was most scary, so I went on a driving course to make sure that I was okay and I was." (338-343)

"So I have to keep exercising and doing these outdoor things otherwise it means that the likelihood of me getting another episode and then a step, so it's vital for my health that I keep doing those things, and that's a bloody good reason to be doing it." (526-529)

"Especially living somewhere like this, yes. I think that also adds to my wellbeing, you know? I think if I was cooped up in a flat in a town I think that would not help my mental state, I'm pretty sure of that, so I do count my blessings that we live somewhere so good." (174-177)

"Oh gosh. I think I could very easily get very depressed. " (521-523)

4. "It's part of what I need to have a good run" : make it easy for me

"My phone is usually glued to my hand." (328)

"The other girls in the running group had one and because I'm competitive I needed to be able to challenge myself. And some people use their phones, but this is much more accurate and it's much easier to look at while you're running, and if you're a proper runner you have one ."(378-381)

"It also helps me because when I was trying to increase my distances, I would look at where I had already run, and then I could plot where the next run would be to take me however many more kilometres I needed to go. "(389-392)

"Now I don't know whether other runners could do that without, but I absolutely couldn't because of the dementia. And I do sometimes try, when I'm looking at the watch, I try to predict things, like oh well if I'm doing this at the moment, and I have to stop doing that because I can't, whereas I think for other runners they can, they can look at the watch and say 'Oh well I've already done such and such and I'm going to be doing such and such, so I'll carry on at this pace'. I just plod on at the same pace and get there when I get there." (413-420)

"And one of the things it tells me is the … I think cadence is the word, but my feet. And I'm terribly predictable, I always run at the same pace, which is great for anyone who's coming out to meet me or find me, they know exactly where I will be, and I couldn't have done any of that without that watch." (408-412)

"It's more about if I didn't have it I would feel, not naked, but I would feel I couldn't have a proper run. It's part of my equipment, it's part of what I need to have a good run. So it gives me some sort of a security actually." (449-452)

"I'm slightly scared of technology, but I'm getting better if you like". (325 – 326)

"I'm fortunate to be in a relationship with somebody who can do that for me, so I don't rely on it. If I was on my own, it would be very different, but then I think this would all be very different if I was on my own, if I hadn't got the support." (551-554)

"It would be my brain. It would be implanted so that I could see in my mind where I'm going. I wouldn't have to fiddle with anything, it would just be something that would automatically … and I know that's ridiculous, but maybe it isn't……….That I could … I'm out walking and I'm thinking I'd quite like to walk for another half hour or so, but which direction do I need to go in in order to come back to the path that I am on? And it would automatically do it for me." (564-572)

Gary - Individual Participant Data Analysis

Gary - Interview Introduction

Technology used	Outdoor activity engaged with
Googlemaps	Walking for exercise
	Walking holidays

Gary grew up in an inner city area and had little opportunity to go outdoors and visit the countryside. However, he was sent away to boarding school and there enjoyed spending time in open fields. As an adult he has continued to live inner city areas, but has often travelled out to visit green spaces, particularly on the many walking holidays he and his wife have enjoyed over the years. They still go on a walking holiday each year and Gary tries to do at least 3 10 minute walks a day to remain fit. Whilst he does not feel it is particularly important to him to be able to get out to these the countryside anymore, he would resent being told that he couldn't go out at all.

During his 50's Participant F first noticed a notable short term memory loss, but put this down to ageing. It was not until 10 years later when he found himself lost in his home city that he started to suspect something was wrong. The incident was upsetting and caused him to seek further advice and he was eventually diagnosed with a mixed vascular dementia and Alzheimer's disease. That was approx. 10 years ago and he does not feel his memory has deteriorated much since then.

Gary identifies himself as a 'geek' who had a long career in IT before returning to full time education and studying Philosophy at university in his 50's. He went on to study this at masters level with the Open University but couldn't complete the coursework because of short term memory problems that developed in his mid – late 50's. He continued to work setting up a small second hand textbook business until his retirement. Participnt G remains interested in technology, using a smart phone efficiently in his day to day life. However, he does have some difficulties adapting to a new technology or changes in existing technology, including problems operating a recently purchased smart TV.

Gary uses the google maps app on his smartphone to navigate when out in his car or on foot. He relies on this to find where he is, as well as to guide him to his destination. He uses this everywhere he goes, including in the streets immediately around his home. He states that he uses it because he needs it and has no concerns about this.

His wife has used the ‘find my iphone’ function of his phone to locate him several occasions. He finds this reassuring and does not have any concerns about privacy or being tracked. When asked about the se of this technology in his future he stated that he could not consider this as he ‘had no imagination’ and so could therefore not speculate about the future.

Gary - Emergent Themes

- Childhood experiences
- Walking Holidays
- Walking for exercise
- Previously good sense of direction
- Getting lost in familiar surroundings
- Impact of incident
- Just getting old
- Dismissive of past success
- Negative about self
- Negative view of future
- Technology career
- Open and positive about technology
- Practical solutions
- Changing abilities
- Technology to support carer
- Privacy not an issue
- People are helpful
- Technology idea
- Smart / resourceful
- Varied career
- Doesn’t like being told not to do things

Gary - Theme Development

From these emergent themes 6 main themes were developed

1. “We always get a map” : loves walking
2. “I had not a clue where I was” : there might be something wrong
3. “I’m a slight geek” : technology career
4. ”I shall carry on until I can’t” : social outlook
5. “I got rather fed up” : negativity
6. “They’re usually quite helpful” : support from others

Within these themes a further 21 sub themes were identified, with each main theme having between 3 and 4 sub themes each.

Gary - Thematic Table

	Themes		**Sub Themes**	**Line no**
1	“We always get a map” : loves walking	1	Childhood experiences	164-167 168-170
		2	Walking Holidays	156-158 185-194 199
		3	Walking for exercise	208-212 219-221
2	“I had not a clue where I was” : there might be something wrong	4	Previously good sense of direction	319-328 257-259
		5	Getting lost in familiar surroundings	65-81 240-248 257-262
		6	Impact of incident	96-97 504-509
3	“I’m a slight geek” : technology career	7	Technology career	9-10
		8	Open and positive about technology	284-285 308 352 390-391
		9	Practical solutions	262 333-336 354-355
		10	Changing abilities	85-91 290-292
4	”I shall carry on until I can’t” : social outlook	11	Smart/ resourceful	85-86 248-249 579
		12	Varied Career	9-14
		13	Doesn’t like being told not to do things	400-401

				407-408 457-459
5	“I got rather fed up” : negativity	14	Just getting old	92
		15	Dismissive of past success	18-19 50-51
		16	Negative about self	120-121 174-177 445-447 522 566-567
		17	Negative view of future	226 233-237
6	“They’re usually quite helpful” : support from others	18	Technology to support carer	472-473 478-482
		19	Privacy not an issue	486-488
		20	People are helpful	115-117 129-130 381-383
		21	Technology idea	602-610 643-648

Gary - Key Data Extracts

1. “”I shall carry on until I can’t” : social outlook

“Yes. Oh I love it, I love it, yes, yes. I’m a bit nervous now in case I get lost. It hasn’t really … well it has happened but I’ve been able to cope.” (156 – 158)

“But we always get a map so we know where we are so we can go out for a wander, even if it’s just a couple of miles.” (192 – 195)

2. “I’m a slight geek” : technology career

“I’ve been up it thousands of times. And I was coming down from a side road and I got to the junction and I looked and I had not a clue where I was, not … the whole … I’d never been there before, and I thought blimey.” (68-72)

“It didn’t matter, because as soon as I got a few hundred yards I recognised something. So that’s when we thought whoops there might be something wrong.” (79-81)

“And they fascinate me too and I’ve always been a slight geek.” (284-285)

"So you know that that's there and therefore that other place must be there, now I don't. So I just turn Google maps on." (260 – 262)

3. "I had not a clue where I was" : there might be something wrong

"Looking back I can see now it has been going for ten years or more." (84-85)

"So she was a bit worried that she had been sort of spying on me, but I said, "No do please, because you never know what I'm going to be up to"." (486 – 488)

"It takes away any anxiety. I just look on it and I know I'm going to get wherever I want to go." (390-391)

4. "We always get a map" : loves walking

"I shall carry on until I can't" (579)

"If I want to do something I do it. I get into terrible problems but I still try and do it." (407-408)

"I used to love going out, we used to go out in the fields and wander around, we were outside in the country and that was lovely. So I've always liked being out and I used to here actually go out a lot," (170 – 173)

5. "I got rather fed up" : negativity

And I think I just retired after that, got fed up." (51-52)

"We've been right open about it and up front right from the beginning, we tell anyone and talk about it, don't hide it." (110 -112)

6. "They're usually quite helpful" : support from others

"But there are a lot of people out there who know about it and would help and do help I think, but quietly, not making it obvious." (115 – 117)

“She did the other day wonder where I was and saw that I was making my way home (inaudible 00:22:14) some strange way, so she didn’t worry” (479 – 481)

Hugo - Individual Participant Data Analysis

Hugo - Interview Summary

Technology used	Outdoor activity engaged with
Phone App – Google maps	Dog walking
Phone App – Map my run	Walking for pleasure
	Social walking groups

Hugo is a gentleman in his early 70's with Vascular Dementia. He has a long history of diabetes and a number of related health conditions. He was first diagnosed 5 years ago after his wife noticed symptoms of memory loss, although he has never been aware of any symptomatic changes himself. His diagnosis was a big shock to him and although he is a positive, proactive person he continues to deny any awareness of symptoms or changes during this time. Hugo feels that his diagnosis was a catalyst for change and has since improved his overall health considerably by undertaking greater physical and cognitive activities in an attempt to 'level out' the impact of the dementia.

Hugo has always engaged in outdoor 'walking activities' since his late teens and is keen to identify as a walker and not a runner or jogger. He has also cycled in the past and has a group of close friends for whom walking is a common leisure pursuit. In his past work he was able to spend whole days away from his office travelling to visit sites and often spent large amounts of this time walking his dog (whom he always took away with him) at various locations around the UK.

As well as a positive and proactive outlook, Hugo likes to think things through logically and is good at problem solving. Although he denies that the diagnosis of dementia has impacted his life, he has made some decisions to change his life as a result of the diagnosis. This can be seen in the decision not to have another family dog and in the adoption of a greater physical exercise regime.

In addition to walking in local parks and natural spaces with his wife or with friends, he reports undertaking volunteer dog walking for a greyhound rescue charity based near his home. He appears to get a lot of pleasure from this activity and he reports it being vital to his well-being. During a bout of sciatic nerve pain last year he found the inability to undertake this activity detrimental to his mental health and used the volunteer dog walking as a graded recovery programme to build up both his physical stamina and his confidence following this period of ill-health. Reflecting upon this experience he describes the importance of getting outside and walking as being vital to life and makes comparisons to the traumatic loss of walking ability experienced by injured servicemen in recent conflicts.

Hugo uses a couple of different navigation/ mapping apps on his phone to locate himself when out walking. Although he initially states these are used only when getting lost, he then talks about their use more widely to support him manage and track his activity- as well as to locate himself when lost. He describes himself as having confidence with technology in general and feels that the use of technology is an essential part of modern life. He takes pride in comparing his perceived superior abilities using such technologies when comparing himself to peers such as his wife or friends. In particular he describes being able to use his app to take on an expert role in navigating when out walking in a group, even when his friend (whom he implies is an expert navigator with traditional maps) finds it difficult to navigate.

Despite acknowledging the likely software updates such apps will inevitably require over time, Hugo is reluctant to upgrade or change his smartphone. Possibly not wanting to face difficulties in adapting to new technologies or changes in the function that he will struggle to master. He sees a continued use for safer walking technology in his future and is keen to maintain his current engagement with the outdoors for as long as possible.

Hugo - Emergent Themes

- Shock of diagnosis
- Denial / not wanting to know
- Pro-active response
- Personal responsibility for health
- Improved physical health
- Humour -To enable difficult conversations
- Humour – deflect vulnerability
- Humour – coping mechanism
- Reluctance to upgrade technology
- Insightful of the needs of people living with dementia
- Struggle to adapt

- Limitations of technology
- Autonomy
- Essential to everyday life
- Social standing and individual expertise
- Access to leisure activities
- Everyday use, like you
- Positive outlook
- Problem solver / logical thinker
- Experiential leaner
- Enjoys the flexibility and autonomy of retirement
- Pro-active and independent
- Confident with technology
- Always been a walker
- Emotional need for pet
- Pride in past dogs
- Volunteer role reflects past identity
- Walker not a jogger
- Companionship of dogs
- Deteriorating indoors
- Outdoors and wellbeing
- Trauma of losing outdoor access
- Walking as a basis for life

Hugo - Theme Development

From these emergent themes 7 main themes were developed

1. "I used to spend hours walking" : dog walking as part of identity
2. "Going out and not vegetating" : indoors v outdoors
3. "It is life" : safer walking technology enables
4. "Like a bolt out of the blue" : response to diagnosis
5. "Then I shall use it" : limitations
6. "My brain hurts!" : using humour

7. “I’ve got over that” :personality traits

Within these themes a further 34 sub themes were identified, with each main theme having between 3 and 6 sub themes each.

Hugo – Thematic Table

	Themes		Sub Themes	Line no
1	“I’ve got over that” :personality traits	1	Positive outlook	380-384
		2	Problem solver / logical thinker	95-98 458- 461 470 - 473
		3	Experiential learner	276 - 290
		4	Enjoys the flexibility and autonomy of retirement	173-176 178 -183
		5	Pro-active and independent	60-68 85-86
		6	Confident with technology	232 - 235
2	Dog Walking as part of identity	7	Always been a walker	134-140
		8	Emotional need for pet	134 -140
		9	Pride in past dogs	114-118 212-213 430-432
		10	Volunteer role reflects past identity	108 –113 205 -211
		11	Walker not a jogger	153- 160
		12	Companionship of dogs	130-131 144-150
3	“Going out and not vegetating” : indoors v outdoors	13	Deteriorating indoors	205- 211 434 -438
		14	Avoiding indoors	172 –178 221 -225
		15	Outdoors and wellbeing	207-211
		16	Trauma of losing outdoor access	423-427 439-441
		17	Walking as a basis for life	447-448
4	“It is life” : safer walking technology enables	18	Autonomy	303-307
		19	Essential to everyday life	238-240 391-395
		20	Social standing and individual expertise	309-319
		21	Access to leisure activities	319-324 340-342 514-519
		22	Everyday use, like you	269-272 346-351
5	“Like a bolt out of the blue” : response to diagnosis	23	Shock of diagnosis	35-37 46-49
		24	Denial/ not wanting to know	11-17 20-25

				52-53 418-422
		25	Pro-active response	60-63 104-107
		26	Personal responsibility for health	63-68 148-149 221-225
		27	Improved physical health	69-72 114-118
6	"My brain hurts!" : using humour	28	To enable difficult conversation	127
		29	Deflect vulnerability	28-29
		30	Coping mechanism	504
7	"Then I shall use it" : limitations	31	Reluctance to upgrade technology	249-251
		32	Insightful of the needs of people living with dementia	260-268 358-360
		33	Struggle to adapt	292-299 391-395
		34	Limitations of technology	358-360

Hugo - Key Data Extracts

1. *"I used to spend hours walking" : dog walking as part of identity*

"I walk probably every day I suppose, but it might be, like yesterday, the day was even worse than today but I did walk to the village just to do some shopping, I mean it's about a mile away to the shops, so it's a 2-mile round trip. And although the car was sitting out there I thought, "No, we ain't taking the car, we're going to walk." That's the extent of my walking."(144-150)

"Walking, yes. I've never been into running or jogging, that's not my scene at all." (130- 131)

"That was always with the dog and I really enjoyed that as well, I mean I used to spend hours walking."(212 -213)

"We've always had pets and the dog died about 3 years ago, and we had a cat which died last year, and all of them have been elderly; we've only had 2 dogs during the course of our marriage, one lived to 17 and the other dog lived until he was 15 so that's 32 years, we've been married 47, so it isn't a bad innings really." (108-113)

"I used to take the dog with me, she travelled beautifully, you never knew she was in the car and every time I went somewhere I would always go and find either on the way there or on

the way back, a National Trust property or what have you and just walk the dog for a couple of hours, spend the entire day out, otherwise I had to get back to the office!" (205-211)

"Walking with the dog was the main activity, and I do miss that, and that's one of the reasons why I got involved with the greyhound re-homing, because at least I can go out and get some exercise and I can have some time with the dogs." (114-118)

"I took a long time, it took months to get past that, and one of the benefits or one of the things which got me past that was actually walking the dogs" (430 -432)

"I found it difficult to walk on uneven ground, actually where we walk the dogs is on uneven ground, so that I had to do a walk, which was on even ground, and everybody would go that way and I'd say, "I'm going this way." I mean the dogs didn't mind, they weren't bothered where they were walking to be honest."(432 -441)

2. "Going out and not vegetating" : indoors v outdoors

"Oh That's important [going outside]; I mean otherwise you're sort of in here and stale aren't you?" (172-178)

"No, I mean I still remain fairly active, and as I mentioned, it's quite the opposite, because of this problem I made a point of going out and not vegetating, mainly to keep active….."(221-225)

"Every time I went somewhere I would always go and find either on the way there or on the way back, a National Trust property or what have you and just walk the dog for a couple of hours, spend the entire day out, otherwise I had to get back to the office!"(207-211)

"Last year I obviously had very limited activity, walking activity until I got this back and really was a down side, not only medically for that, but it also affected everything else; because you couldn't walk … I lost confidence even just walking to the village. I don't have that problem now, that's gone, I've got over that, but that activity I thought brought me down mentally significantly, and it took a long time, it took months to get past that" (423 – 431)

"So I would imagine to answer your question: what effect would lack of walking be? I think it would be a deterioration in quality of life all-round, just not the activity of walking, it would affect everything to be honest, because that actually is the basis of life, being able to walk isn't it? (442-447)

" You ask anybody who has lost limbs in Afghanistan or whatever, it has a big effect."(447-448)

3. "It is life" : safer walking technology enables

"It's [technology] essential, it is life to be honest now; you can't separate one from the other, it is part of life and if you don't accept it you're in the last century and not this one to be honest."(238-240)

"That's where I do see a problem in as much as, if you're going to use this for general activity like going to the shops or what have you, then really that's got to be part of the activity……………… That's different to going out into the middle of the countryside where you don't know where you are and you're relying on that to get you to a place where you want to be."(321- 332)

The apps that I use are obviously Google Maps, I mean I use it probably most like you, getting here today, as a sat-nav system, if I wanted to go to XXXXXXX or whatever then I would plonk that in and then off we go (269-272)

"I found that useful in the past because a friend of mine, him and his wife are in a walking club, they actually run one, and he comes out with clipboards and his maps and his gadgets, and his hat – he looks the part he really does. He comes out, "I've got this route." And sometimes we look at each other and think, "Have you got your Map my Walk with you? I think we're going to get lost here." And it has happened in the past. He won't. He swears, "I know where we are." And we've got this thing here and you think, "No you're not." " (309-319)

4. “Like a bolt out of the blue” : response to diagnosis

“I sort of put that to the back of my mind,” (52-53)

“It just hit me like a bolt out of the blue”(35-36) and (49)

“It’s dementia. I’m never actually got to the bottom of exactly what dementia it is; to be honest, the differentials between one and another defeat me to be honest, a bit medical to me. I know there’s vascular dementia but what the definition of vascular dementia is I’ve never really bothered to delve into it, they just said, “You’ve got dementia.””(11-17)

“And yet if anything, the experience, oddly enough, has to be improve things, because I’m aware of the problem I have, or potentially have, you tend to do things to help, right, you get more exercise, you do more brain work, instead of sitting watching television all day and doing nothing and whatever, which I think improves things so you’ve got 2 counter-acting directions: 1) is improving things, but it’s going down, so you’re ending up at the same level sort of thing, hopefully that’s the plan anyway.” (63-68)

“And although the car was sitting out there I thought, “No, we ain’t taking the car, we’re going to walk.” That’s the extent of my walking.” (148-149)

“So if anything, over the last 5 years, physically I feel actually better than I did 5 years ago”(69-70)

5. “Then I shall use it” : limitations

I: That’s a smart phone isn’t it?

R: Yes; S4 I think it is.

I: It’s a good one.

R: It’s now up to S7 now and they keep trying to convince me that I really need a new one and I think, “No I don’t.”(246-250)

"It's [technology] part of life these days, so somebody might come out next week with a 'Map my Walk 2' sort of thing. Alright, well if Map my Walk 2 ends up better than what we've got here then I shall use it." (391-395)

6. "My brain hurts!" : using humour

"In actual fact it wasn't me, it was my wife. And I'm still convinced that my memory is better than hers." (29-29)

> *"My Brain hurts!" (504)*

"The flip side of that is when your battery goes and you haven't got it, there's a definite loss of security then! You think, "Oh, shit!" that's happened quite a few times, then you've got to go back to basics then: where's the sun? What time is it? That can be a bit of a problem, did we pass this tree an hour ago?" (358-363)

Ian - Individual Participant Data Analysis

Ian – Interview Summary

Technology used	Outdoor activity engaged with
Phone App – Google maps	Walking for pleasure
	Gardening

Ian was keen to be interviewed with his wife present and at times showed signs of expressive dysphasia, difficulty in organising his ideas and remembering dates. He was imaginative and enthusiastic in talking about his 'ideal' technology, but for most of the interview he was reserved and cautious, often thinking about a question for a moment or two before answering and then only providing a brief response.

Ian has an early onset dementia and is 57. He does not identify himself as retired, but no longer works. He was previously a postman and worked 6 days a week, with one rest day each week. Although he understands his diagnosis well he has not been aware of his symptoms or changing skills, these have been noticed more by his wife and 3 children who are now all young adults.

Ian has a good social network in his local area and engages in a number of hobbies, such as attending northern soul nights, gardening, walking and has a keen interest in aeroplanes. When thinking back to his childhood and adolescence Ian does not recall spending much time outside. During his working years and he went on many walking holidays with his family and enjoyed time in his garden. He currently goes walking at least once a week, but only in good weather. He is keen to stress that he is not a sporty person, but appreciates nature such as birds and trees when outside.

When Ian goes out walking he usually walks in local parks or a large local forestry area. He uses the 'google maps' app on his phone to support him to do this. He use the app for locating himself, wayfinding and identifying useful local facilities or sights. He feels that using the app is important to him and relies on it to find his way, but also as an emotional support. He describes the technology as being reassuring and preventing feelings of panic.

Ian acknowledges some difficulties he is having with the slow speed of the app when outdoors and would like to see the interface simplified. Although he is aware of the rapid pace that technology of this nature changes and has already moved from using a traditional sat nav to the app in recent years. During the interview Ian shows a good awareness of how his dementia might change in the future and sees a role for locating technology in his future.

Ian - Emergent Themes

- Passion for outdoors / nature
- Enthusiasm for other hobbies – planes, northern soul
- Enthusiasm for adoption of technology
- Sort of person who doesn’t lose things
- Access to green spaces important to him
- Not a sporty person
- Fair weather walker
- Doesn’t stop him from doing things
- Adapting the way he lives
- Adapting to changing technology
- Using technology to compensate for lost knowledge of local area
- Using technology to compensate for lost skills in orientating himself
- Adapting for the skills
- Little opportunity for leisure in working life
- Using technology out of necessity
- Reliance on technology
- Change of working identity
- Rejects the term ‘memory problems’
- Avoids saying dementia
- Technology for people living with dementia
- Fear of being lost
- No humour
- Tracking needed soon
- Evolving quickly

Ian - Theme Development

From these emergent themes 5 main themes were developed

1. “The sort of person I am” : occupation defines her identity
2. “I struggled with recognising that I’d got this” : disassociation with dementia
3. “I’m just not working” :lack of choice
4. “It isn’t anything that actually stops me doing anything” : adapting to change
5. “I’d be lost without it” : uncertain future

Within these themes a further 24 sub themes were identified, with each main theme having between 3 and 7 sub themes each.

Ian - Thematic Table

			Emergent Themes	Line no
1	“The sort of person I am” : occupation defines her identity	1	Passion for outdoors/ nature	82-83 99 133
		2	Enthusiasm for other hobbies – planes, northern soul	67-70 89-92 574 606-609
		3	Enthusiasm for adoption and use of technology	279
		4	Sort of person who doesn’t lose things	433-435
		5	Access to green spaces important to him	112 198
		6	Not a sporty person	127
		7	Fair weather walker	151-152 185
2	“It isn’t anything that actually stops me doing anything” : adapting to change	8	Doesn’t stop him from doing things	229-231
		9	Adapting the way he lives	211 240-242
		10	Adapting to changing technology	314-315 529
		11	Using technology to compensate for lost knowledge of local area	342-344 382-383
		12	Using technology to compensate for lost skills in orientating himself	337 409-410
		13	Adapting for the future	433
3	“I’m just not working” :lack of choice	14	Little opportunity for leisure in working life	146-149
		15	Using technology out of necessity	327
		16	Reliance on technology	476 551-554
		17	Change of working identity	10-11

				17
4	“I struggled with recognising that I’d got this” : disassociation with dementia	18	Rejects the term ‘memory problems’	223-224
		19	Avoids saying dementia	23-25 45-47 229-231 527-533
		20	Technology for people living with dementia	284
5	“I’d be lost without it” : uncertain future	21	Fear of being lost	468-470
		22	No humour	476
		23	Tracking needed soon	508-510
		24	Evolving quickly	433-436 45-47

Ian - Key Data Extracts

1. “The sort of person I am” : occupation defines her identity

If I’ve been outdoors it has been to go somewhere or whatever, but not sort of the outdoors specifically whereas now I appreciate a nice sunny day and we’ve been up to see trains, we love to see birds, you know? I like trees, I like all that. (129-133)

I’ve never been a sporty person or anything like that, so I’ve never really been an outdoors for entertainment wise like. (126-129)

2. “I struggled with recognising that I’d got this” : disassociation with dementia

It’s been diagnosed as mixed dementia which is basically a mix of vascular dementia, it’s tending to lead more to what they call frontal lobe dementia (23-25)

And for say 18 months, two years, I struggled with recognising that I’d got this, it was mainly my wife and my kids who was noticing it more. (45-47)

The thing that is sort of affecting me now, or has been for a few years, but obviously it will get worse ………..(529-531)

I: Yes? Oh that’s good, okay. And do you generally find them helpful in your life?
R: Yes, yes, yes.

I: Okay. How do you feel about the use of technology to support people living with dementia?

R: Fine.

I: Fine?

R: Yes. (276 – 288)

3. *"I'm just not working" :lack of choice*

Because I was a postman I worked six days a week, I only had one day off, and so it was quite a sort of a rest day sort of thing, so it [walking] tended to be holidays and things like that. There would be the occasional days out. (146-149)

I don't work at the moment, at the moment I'm just not working, (10-11)

Necessity. (327)

It's a lot to sort of ask for something that is so direct and yet to me it seems so simple really. Good light, good lighting, so you can rely on it, it is an important thing. (550-554)

4. *"It isn't anything that actually stops me doing anything" : adapting to change*

Memory wise it doesn't tend to be things that stop me doing things. I do have some memory issues but it isn't anything that actually stops me doing anything.(229-230)

I: That's great then. So have you had to adapt the way that you plan or undertake these activities at all?

R: Yes, yes, yes. We have to do that quite a lot. Sometimes I'll get my son to drive if it's a place that is a bit awkward for me. They'll take over. (237 – 242)

Yes because it's quite a big open area and you do sort of need to know your orientation.(409-410)

I have got a sat nav but I don't tend to use the sat nav quite as much……..Not that I couldn't use it, I just don't find it very much good so I don't tend to use it. But because I've got a phone on me all the time, I find that more useful. (314 -321).

5. "I'd be lost without it" : uncertain future

Reassurance and how would you describe it? Not being lost sort of thing, you know? I don't get that feeling of panic of being lost. (468 – 470)

I: And what about this kind of tracking and locating technology?

R: I think for me in the near future that possibly would be something that I would think is more appropriate for me (505 -510)

I would, but I'd be a bit lost without it. (47

Appendix 27 Study 2 Combined superordinate themes

	Superordinate Theme	**Participant**
1	Anybody can afford free.": technology brings new challenges	Adrian
2	"Lets you connect with the stuff that's really important": enabling recovery from diagnosis	
3	"We have always been very outdoor; in a sedate way": identity linked to nature	
4	"If it's going to help you to live a proper life, isn't that as useful as a stick to somebody who has a bad leg": technology as an enabler	
5	"Everybody's Dementia is different": How I live with my Dementia	
6	"I knew something was wrong": knowledge enables planning	Brian
7	"I had my shock years ago": positive open attitude	
8	"I missed taking him for a walk": the importance of dog walking	
9	"I was out of me comfort zone": adapting to change	
10	"I do all the normal things": how the technology works for him	
11	"The first thing I do in the morning": Fiercely independent	Cynthia
12	"Every bit in life, I think if you handle it, it makes you less judgemental": Social conscience	
13	"It was nothing": Doesn't like to show weakness	
14	"I always wear this": Accepting of change and the need to adapt	
15	"We are only part of a continuum": the value of being in the garden	
16	"She's as close to me as she could be": Connections to people vital	
17	"Now I do it out of choice": Walking with Purpose	David
18	"My International reputation": An expert	
19	"I use what I use" New technology	
20	"I don't anticipate becoming housebound": Later Life	
21	"Age-related slowing down of mind and body": Gentle deterioration	
22	"We want to know": the long journey to diagnosis	Edward
23	"My Brain Disease": empowerment and role as an activist	
24	"Wherever I am, I can find where I am": technology compensating for lost skills	
25	"I just love to be outside": the meaning of getting outdoors	
26	"I can work it out": confident with technology	

27	"It's hugely increased the confidence I feel": technology enabling access to outdoors	
28	"They're part of what makes me me": a love of nature	Fiona
29	"The little world that you live in": I'm still me!	
30	"A bloody good reason to be doing it": Resilience	
31	"It's part of what I need to have a good run": make it easy for me	
32	"We always get a map": loves walking	Gary
33	"I had not a clue where I was": there might be something wrong	
34	"I'm a slight geek": technology career	
35	"I shall carry on until I can't": social outlook	
36	"I got rather fed up": negativity	
37	"They're usually quite helpful": support from others	
38	"I used to spend hours walking": dog walking as part of identity	Hugo
39	"Going out and not vegetating": indoors v outdoors	
40	"It is life": safer walking technology enables	
41	"Like a bolt out of the blue": response to diagnosis	
42	"Then I shall use it": limitations	
43	"My brain hurts!": using humour	
44	"I've got over that": personality traits	
45	"The sort of person I am": occupation defines her identity	Ian
46	"I struggled with recognising that I'd got this": disassociation with dementia	
47	"I'm just not working": lack of choice	
48	"It isn't anything that actually stops me doing anything": adapting to change	
49	"I'd be lost without it": uncertain future	

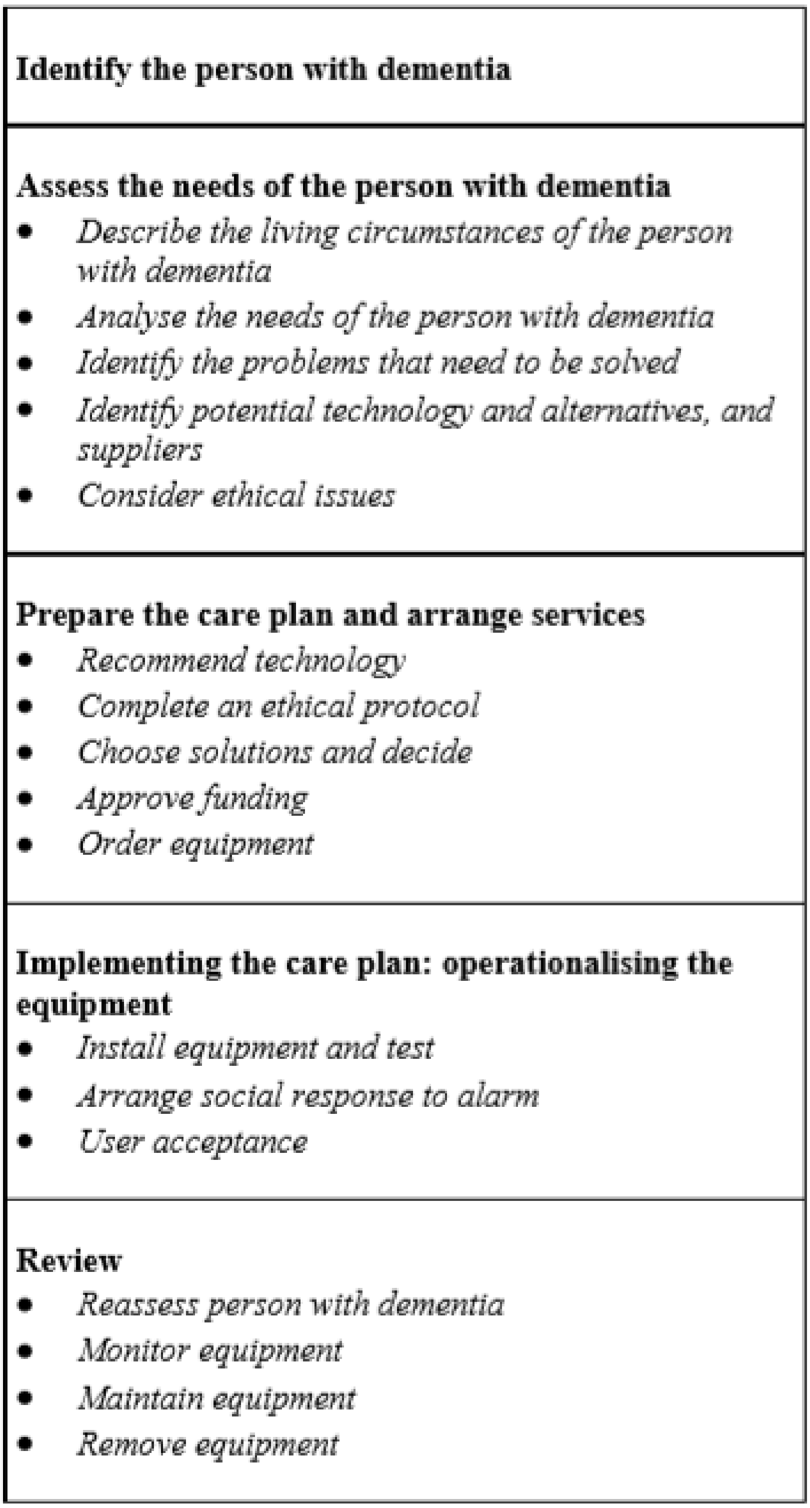
Appendix 28 Safer walking technology descriptions

	Safer walking Technology	Description
Identified by participants in study 1 (family carers)	Buddi tracker system	The Buddi system is a safer walking tracker that uses a GPS signal to locate itself and is commonly provided by social services in some areas of the UK. It consists of a box tracker that must be worn or carried by the person (usually on a cord around their neck) and charged each night. It has an emergency call button and allows a carer or nominated person to locate the tracker on the Buddi website. The tracker box is bulky and was reported to be quite heavy. Newer versions of this system have been developed and marketed since the original Buddi, although this newer range was not used by any of the participants interviewed in this study.
	Binatone 2-way radio	These handheld 'walkie talky' style sets enabled the carer to stay in touch with the person they were caring for when they went out. The radio allowed a two-way conversation and also featured an emergency button. Both handsets required charging and setting to the same channel.
	Small clip on Tracker	This very small basic tracking device has a limited range of around 200 meters and can be attached to a person or everyday item via a small clip. The tracker can be located by logging onto the app.
	Doro Phone Tracker	The Doro phone is a simplified mobile phone with just 4 pre-programmed numbers, but no wireless capability, SMART or text facilities. It has an emergency call button and an inbuilt GPS tracker system. To operate, the phone needs to have a mobile network SIM and all use is charged. This allows the phone to be located by logging onto the Doro App.
	Tracker expert	The tracker expert is a small clip-on tracker that can be worn or attached to an everyday item. It is very small, lightweight (35g) and has a battery life of 30-40 days dependent on use. It has a range of features including an emergency button to seek help, a movement alarm, GPS tracking facility through the app, the ability to set up perimeter 'geofences' and the ability to covertly listen in on the person carrying it. It requires a mobile network SIM and has a monthly usage fee.
Identified by participants in study 1	Phone App – Google maps	This is a downloadable phone app that enables the user to view real-time data. It provides maps and routes for traveling by foot, car, bicycle or by public transportation. The user can locate themselves and view their progress 'live' on the map as they travel.
	Tablet App- Google maps	This is a downloadable app identical to the phone version but used on a tablet device.
	Tablet App- Google Earth	Google Earth is a downloadable app using satellite imagery. The user can zoom in and out of specific safer walkings to see them photographed from above. This enables them to view images of safer walkings they wish to visit and a photographic style map.
	Phone app- Map my walk	'Map my walk' is a downloadable app that allows the user to track and record their walking routes, view statistical data on their performance and share routes with other users online.

	GPS Sat Nav system	A GPS sat-nav is a safer walking device reliant on receiving live information from satellites. It is typically used in the car to plan and monitor journeys but can be used by hand when walking (although with limited battery life). It is also possible to use the device to enable the user to locate themselves on the map or nearby places of interest.
	Garmin running watch	GPS running watches accurately track how far and how fast the wearer runs, whilst also collecting and recording a range of statistical data about their performance. On some versions, it is also possible to download information to a computer after a run to view maps and routes of runs recorded.
	Pendant alarm system	Pendant alarm systems are part of a range of telecare technologies that are used to support a person in their own home. They feature an emergency call button, which when pressed calls through to a 24-hour call center and a two-way connection is made enabling the user to speak to the call center directly. They have a limited range from their base hub, usually within and close the user's property.
	Small tracking device	This is a small piece of technology that can be placed in a car or a user’s bag or pocket. This enables a carer to log onto an online website and view safer walking information about the tracker in real time.
	Find my iPhone	This is a remote safer walking tracking service built into Apple devices such as iPhone, iPads and some MacBook computers. It allows users or family carers to view real-time data about the safer walking of the device on an app or website.

Appendix 29 Assistive Technology 5 -stage Process

Woolham, J. and Frisby, B. (2002) 'Building a Local Infrastructure that Supports the use of Assistive Technology in the Care of People with Dementia'. *Research Policy and Planning* 20 (1), 11-24



Identify the person with dementia

Assess the needs of the person with dementia

- *Describe the living circumstances of the person with dementia*
- *Analyse the needs of the person with dementia*
- *Identify the problems that need to be solved*
- *Identify potential technology and alternatives, and suppliers*
- *Consider ethical issues*

Prepare the care plan and arrange services

- *Recommend technology*
- *Complete an ethical protocol*
- *Choose solutions and decide*
- *Approve funding*
- *Order equipment*

Implementing the care plan: operationalising the equipment

- *Install equipment and test*
- *Arrange social response to alarm*
- *User acceptance*

Review

- *Reassess person with dementia*
- *Monitor equipment*
- *Maintain equipment*
- *Remove equipment*