

Exploring the potential of touch-screen computer technology in promoting enjoyable activities with people living with dementia: A visual ethnography

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Glossary

Acetyl cholinesterase inhibitors – pharmacological intervention that increases the amount of the chemical acetylcholine to aid messages to travel around the brain

Cochrane reviews – systematic literature reviews of primary research in health care and policy

Early on set dementia – diagnosis received before the age of 65

Formal care – support that is provided as paid work in various settings (community, day care, residential care)

Informal care – support that is provided unpaid by family, friends or neighbours

Abbreviations

ACE	-	Addenbrookes Cognitive Examination
CANE	-	Camberwell Assessment of Need for the Elderly
CIRCA	-	Computer Interactive Reminiscence & Conversation Aid
DDG	-	Darnall Dementia Group
ESRC	-	Economic and Social Research Council
ICD	-	International Classification of Diseases
ICT	-	Information and Communication Technology
MCI	-	Mild Cognitive Impairment
MMSE	-	Mini Mental State Examination
NICE	-	National Institute of Clinical Excellence
NRES	-	National Research Ethics Service
RCT	-	Randomised Controlled Trial
ScHaRR	-	School of Health & Related Research
SCIE	-	Social Care Institute of Excellence
SHSC	-	Sheffield Health and Social Care NHS Foundation Trust

Abstract

The potential of developing new technologies that may assist people living with dementia to successfully navigate their day is increasingly recognised. Interventions include prompts and reminders to support memory function as well as safety detectors and activity monitors. Few however, have recognised the potential of using existing technologies as an intervention to support social interactions and enjoyable activities. This thesis explored the potential of touch screen computer technology in facilitating enjoyable activities with people with dementia who live in the community. The project premise that technology may facilitate enjoyable activity by those with a dementia diagnosis was explored through two successive studies. The first involved attendees at a community day care centre. They were living with moderate to later manifestations of the condition but still lived at home, some alone. The second study involved people with a recent diagnosis of dementia and participants took part in their own homes.

The methodology employed was a focused visual ethnography and data collection methods comprised of video-based participant observations and in-depth interviews. Data analysis required the development of a novel technique drawing on concepts of multimodality and visual ethnographic methods which enabled non-verbal behaviour to be represented as equally significant to verbal behaviour. Findings from study 1 indicate that activities were enjoyed 'in the moment'. Although familiarity of the devices and applications was observed within sessions this did not extend between sessions. Further, the group context in study 1 provides regular social contact for people experiencing life in similar ways. In contrast, findings from study 2 indicated that the use of new knowledge and retained learning occurred across sessions for all participants, irrespective of the style of technology engagement. Nevertheless, the majority of participants in study 2 reported feeling lonely as a consequence of the condition and in need of increased social contact. The conclusions reached suggest that touch screen technology can facilitate enjoyable activities with people living with dementia, irrespective of the level of impairment, if supported appropriately.

Chapter 1: Introduction

1.1 Introduction

The advances in and successes of medical science, sanitation and nutrition mean that the population is living longer and one consequence is an increase in the numbers of people with dementia (Department of Health, 2012a). Dementia has been described as the most significant health and social care crisis of the twenty-first century, directly affecting over 820,000 people in the UK (Gore, Amanda and Ostrom, 2011). Another perspective describes '*on the one hand, the most complex condition humans can face, and on the other, individuals in all their diversity*' (Killick, 2013 p.13).

Two thirds of people with dementia in the UK live in their own homes, either on their own or with care from a spouse, relative, friend or neighbour (Luengo-Fernandez, Leal & Gray, 2010). This informal, unpaid care is essential in delaying residential care, enabling the person with dementia to stay at home for longer thus reducing social and health care costs. Evidence suggests that 83% of people with a diagnosis of dementia would prefer to remain in their own homes, a desire that has been penned as 'ageing in place' (Beard, Sakhtah, Imse, & Galvin, 2012). This is important as the familiarity of home can take on significant meaning and is able to compensate for reductions in physical and mental functioning associated with dementia (Chadhury, 2008). On occasions when people are away from their familiar surroundings, due to hospital admittance for example, the potential for memory impairment to deteriorate increases due to distress, noise and becoming generally overwhelmed with the new environment (Thompson & Heath, 2013). Nevertheless, people with dementia that live independently report having significantly more unmet needs when compared with those living with informal care or in residential care (Miranda-Castillo, Woods, Galboda, et al., 2010). Although this is also problematic as people with dementia living at home may be assumed to retain the capability to voice their unmet needs in ways that those in residential care settings may not.

The needs of people with dementia are considered to encompass social, psychological, physical and environmental needs and have been measured using tools including the Camberwell Assessment of Need for the Elderly (CANE) (Slade, Phelan, Thornicroft & Parkman, 1996) for example. A recent cross-sectional survey involving one-hundred and fifty two interviews with people with dementia and their carers using the CANE suggest that the priorities and perspectives of the two are not in accordance with one another (Miranda-Castillo, Woods, & Orrell, 2013). In fact, it was concluded that the

actual reported needs and requirements from the perspective of the person with dementia were not represented sufficiently by the instrument of measurement.

It has been argued that the most meaningful interventions are those applicable to both the individual with the condition and their informal caregiver (Brodaty, & Arasaratnam, 2012). Yet, if the needs and requirements of the individual and caregiver differ dramatically then relying on proxy accounts can significantly underestimate the person with dementias' subjective opinions of wellbeing (Cahill, Begley, Faulkner, & Hagen, 2007). Disquiet can also arise when the professional support that is offered is directed predominantly at the carer rendering the person with dementia feeling powerless and side-lined (Mountain & Craig, 2012). This intensifies the necessity to identify a balance between the needs and requirements of the dyad without compromising the relationship between the two (Mountain & Craig, 2012).

Daily activities that are meaningful to the person are considered to be one of the most frequently identified unmet needs for people living with dementia (Miranda-Castillo, Woods, & Orrell, 2013; Smits, Lange, Droes, Meiland, Vernooij-Dassen & Pot, 2007; van der Roest et al., 2009) and specifically, social and leisure activity for those living at home (Wherton & Monk, 2008). People with dementia are often keen to stay socially connected as well as being involved with activities that are meaningful to them (Droes et al., 2006; Phinney, 2006) and that those opportunities for activity may enable continued engagement in life (Genoe & Dupuis, 2012). Meaningful activities are highly valued by people living with dementia as many report such activities provide a purpose in life (Droes et al., 2006).

However, dementia lessens a person's ability to continue creating their own enjoyable activities which in consequence may lead to social isolation, insecurity and anxiety (Vernooij-Dassen, 2007). This situation is further exacerbated as those with dementia are more likely than the general population to suffer from depression (Robert et al., 2005). Teri et al., (2012) demonstrated an association between a lack of *pleasant activities* and increased symptoms of depression in both the person with dementia and their carer. Interventions to increase pleasant activities for people with dementia have illustrated decreased levels of depression (Downs & Bowers, 2008). Nevertheless, Phinney & Moody (2011) observed that many people with a recent diagnosis of dementia are still sitting at home with nothing to do.

The challenge is to determine what the unmet needs of the individual are and how they can be addressed. It has been proposed that technology offers the potential to increase quality of life for older adults living with long term conditions in the community (Mulvenna, Nugent, Moelaert, Craig, Droes & Bengtsson, 2010). Thus, research is required to identify effective technological based interventions that have the potential to perpetuate engagement and self-efficacy with people with dementia living in their own homes.

1.2 Thesis structure

This thesis consists of eight chapters, chapter 1 provides an introduction to the topic and chapter 2 explores the definition of dementia, the prevalence and the economics. The trajectory of the condition is described and how dementia is understood at a biological, psychological and social level. Chapter 3 is an examination of the relevant literature involving two distinct reviews of the existing evidence. The first review is focused on enjoyable activities and the second on technology use, both in the context of living with dementia. The reviews of the literature gave rise to various research gaps which are then identified and followed by the overall research aim, objectives and research questions of this thesis. The methodology is described in detail in chapter 4 which also provides the philosophical underpinnings of the research project. Chapters 5 and 6 focus on studies 1 and 2 respectively. Study 1 involved group members attending a day care centre who were experiencing moderate to later manifestations of the condition and study 2 involved those with a recent diagnosis of dementia and took place in their own homes. Chapter 7 is a synthesis of findings from study 1 and 2 which enables a discussion of the similarities and differences observed within and between people and their technology use when experiencing varying cognitive impairments associated with dementia. Chapter 7 will propose a model to promote technology participation despite dementia aiming to illustrate the convergent findings from the two studies which will then be situated within existing dementia studies. Chapter 8 is the final chapter in this thesis and discusses the contribution to new knowledge in the areas of methodology, dementia studies, dementia practice, and recommendations for policy implementation and agendas for future research.

Chapter 2: Background

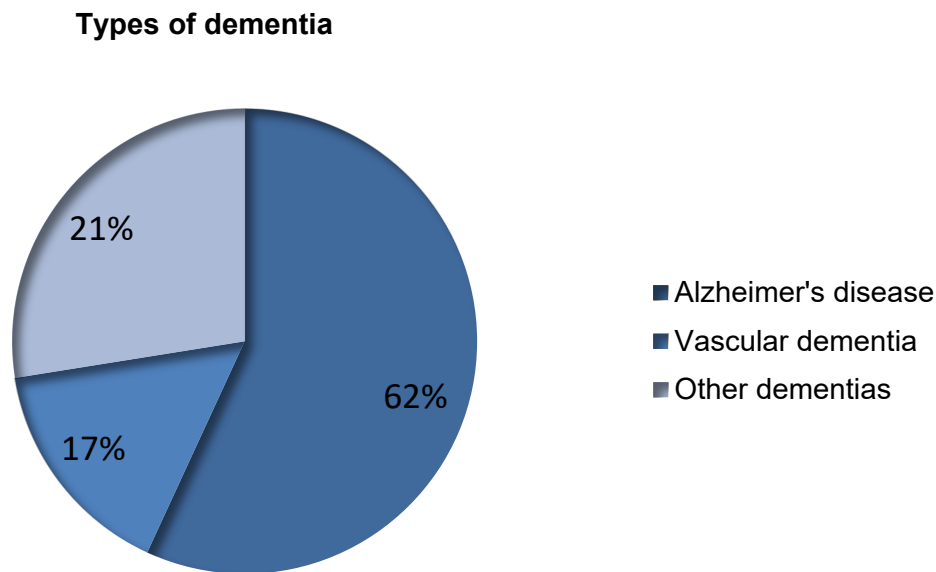
2.1 Introduction

This chapter begins by defining dementia the condition, the history, the prevalence, risk factors, symptomatology and diagnosis. Section 2.3 describes a trajectory of the biological, psychological and social manifestations of the condition. The economic costs of the condition in UK society and the recent policy push to address the increasing prevalence of dementia are then explored in section 2.4. and 2.5 respectively. As this thesis is focussed on people with dementia that live in the community, section 2.6 then describes some examples of the characteristics of this demographic. The individual, medical and social understandings of dementia are then explored by way of existing conceptual models of dementia. Given these varying approaches to the topic of dementia section 2.8 will conclude this chapter by situating this thesis in context.

2.2 Defining dementia

Dementia describes a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is a disturbance of higher cognitive functions including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement (World Health Organisation, 1992). Dementia typically presents itself through the gradual decline of short-term memory whilst the progression of the condition results in other cognitive domains becoming affected including space and time orientation and attention (Alzheimer's Society, 2012c). Dementia is an umbrella term for a group of brain conditions and diseases that cause structural and chemical changes in the brain, the most common of which is Alzheimer's disease accounting for 62% followed by vascular dementia accounting for 17% of all dementias (Alzheimer's Society, 2012c). Alzheimer's disease was penned by Dr Alois Alzheimer, a German psychiatrist in the early 20th Century in reaction to one patient who was exhibiting unusual behaviours. The pathological condition of dementia was diagnosed and the psychiatrists name endured until the 1970's when the condition began to gain recognition and beyond to present day. The World Alzheimer's Report suggests that Alzheimer's disease is currently the most feared condition worldwide, overtaking cancer and other long term conditions including heart disease and stroke (Prince et al. 2014).

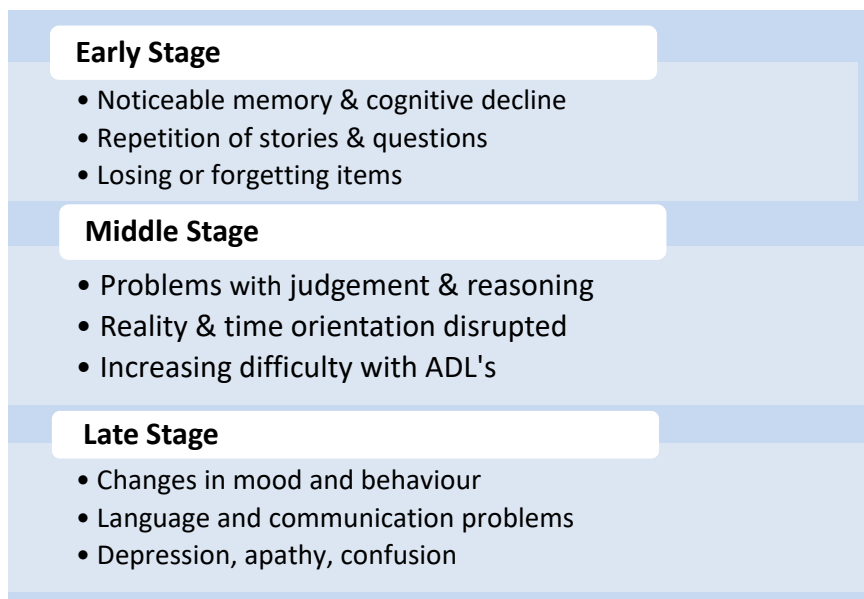
Figure 2.1: Types of dementia, adapted from Alzheimer's society (2012)



Numerous factors, including genetics, medical background, education and lifestyle can contribute towards the onset of the condition although age is the greatest risk factor for dementia (Knapp & Prince, 2007). Overall 10% of deaths in men over 65 years and 15% of deaths in women over 65 years may be attributed to dementia whilst delaying the onset of the condition by five years would halve the number of deaths due to dementia in the UK (Knapp et al. 2011). Dementia is categorised into three clinical stages, each identifiable by certain characteristics as seen in figure 2.2.

People receiving a diagnosis of dementia between the age of 65-69 survive an average of 10 years whereas people receiving a diagnosis between the ages of 80-89 are only expected to survive a further 3-4 years (Xie, Brayne, & Matthews, 2008). Two thirds of diagnoses are received by women which reflects the difference in longevity between males and females, which is estimated at 6 years longer for women (FUTURAGE, 2011).

Figure 2.2: Stages of dementia, adapted from (Alzheimer's Society, 2012b)



The biomedical approach to dementia favours stage theories to explain the progressive nature of dementia and the accompanying cognitive impairments (Innes, 2009). This approach understands dementia as a disease of three stages, early, middle and later (as seen in figure 2.2) in order to investigate causes and cures by determining the symptoms and when they are likely to occur in the dementia trajectory. Biomedical explanations assume a causal relationship between the pathology of the brain and the condition itself (Bond, 1992) thus relying on symptoms of the 'disease' as markers of a certain stage of dementia. Whilst still described by many as a series of stages, the course of dementia is increasingly considered to be a personal and unique journey (Kitwood, 1997; Sabat, 2001) and far more nuanced and complex than stage theories portray.

It is a challenge when attempting to 'label' people in terms of a particular stage of the condition and defining people's experiences of dementia in this way are not helpful. Approaches focusing on the psychological and social aspects of dementia, although not competing with biomedical explanations, are focusing on the multiple ways the condition can manifest from different perspectives. In section 2.3, these varying approaches will be explored further but clarification is required here concerning the approach taken throughout this thesis. It will become clear in forthcoming chapters (specifically chapters 5 & 6) that dementia is not experienced in pre-defined stages as proposed by biomedical approaches but rather manifests differently, for different people at different points in time. Thus, more holistic understandings of the person and

the complex ways the condition is experienced are required that consider the psychological and social factors as equally influential as the person's own biology. Therefore, the approach to exploring and understanding dementia that will be adopted within this thesis will emphasise these complexities and refer to the 'experiences' of the condition rather than stages of the disease, and how the impairments may manifest differently.

Recognition of symptoms and delays in receiving an early diagnosis also impact upon the length of time a person is aware of the condition. A number of people coping with dementia may prefer not to actively seek a diagnosis and can choose to cope with the symptoms possibly with spousal or family support. This can be influenced by factors including denial, the stigma associated with dementia or lack of knowledge concerning the availability of interventions post diagnosis or the attitudes and beliefs of GP's preventing or delaying early diagnosis (All-Party Parliamentary Group on Dementia, 2014). It is estimated that 59% of people with dementia in the UK have a formal diagnosis (Department of Health, 2015a) a figure that was only 42% three years ago (Department of Health, 2012b). Furthermore, other reasons may explain why people become forgetful including depression, anxiety and physical illness thus receiving the correct diagnosis is essential. There are no definitive tests that can diagnose dementia and the condition is most commonly clinically diagnosed using the Addenbrookes Cognitive Examination III (ACE-III) (Larner, 2012), self-report, observation and individual history leading to a diagnosis of 'probable dementia'. More recently, structural and functional imaging of the brain has improved the accuracy of diagnosis although these procedures are expensive which can limit their use.

Until recently, people rarely obtained a diagnosis until their symptoms were well established by which time it was assumed little could be done for them. This is changing and increasing evidence suggests that people experiencing the earlier manifestations of the condition might retain the ability to take an active role in managing their own condition and developing relevant coping strategies (Beard, Sakhtah, Imse, & Galvin, 2012; Phinney, 2006; Sorensen, Waldorff, & Waldemar, 2008). However, as a cure is not likely in the foreseeable future increased information and services are also required including non-pharmacological interventions (All-Party Parliamentary Group on Dementia, 2014).

2.3 A trajectory of the biological, psychological and social manifestations of dementia

Research efforts have advanced our understandings beyond clinical symptoms and neuropathological correlates towards risk factors and disease mechanisms associated with dementia leading to new treatments (Grand, Caspar, & Macdonald, 2011). The progressive nature of the condition dictates that the person will deteriorate over time although dementia is experienced differently by each individual and not everyone will progress at the same rate nor experience the same symptoms at the same point in the trajectory of the condition. The dementia experience could be the result of physical and emotional resilience as well as the support that is available to each individual (Alzheimer's Society, 2011). Furthermore, the biological disruptions to the brain caused by the disease can manifest as psychological and behavioural disturbances that can then lead to a loss of initiative, independence and wellbeing (Mulvenna, et al. 2010). This illustrates the interplay between pathology, psychology and sociology as some symptoms may affect the way the person feels about their condition and their responses can manifest into behaviours that are misunderstood by others (Spector & Orrell, 2010). The following sections describe the ways that the condition can manifest and the interventions that have been developed in response.

2.3.1 Biological manifestations of dementia

From a biomedical perspective, dementia is defined as a group of neurodegenerative disorders that are characterised by a progressive decline in cognitive function. Pharmacological interventions are available once people receive a diagnosis of dementia and are targeted at relieving the progression of neurological impairment which can be achieved for a limited period. Such interventions have been found to be most effective post diagnosis (Department of Health, 2012a). There are three acetyl cholinesterase (AChE) inhibitors (donepezil, galantamine and rivastigmine) that are recommended by the National Institute of Clinical Excellence (NICE, 2011) for the management of mild to moderate Alzheimer's disease. Memantine is recommended as an alternative for people in the moderate to later levels of cognitive impairment who react negatively to the AChE inhibitors described above.

However, the majority of people with dementia experience impairment over and above that stemming from neurological impairment and biological factors (Spector & Orrell,

2010). Yet, pharmacological interventions that target these psychological and behavioural problems, including anti-psychotic drugs, have illustrated limited efficacy as well as causing adverse reactions in numerous people (Ballard et al., 2009). Evidence now suggests that the way a person experiences the condition can be explained by a combination of the individual's psychology and the wider social context (Bartlett & Connor, 2007; MacRae, 2011). It is for these reasons that additional explanations have been sought that may enable a more comprehensive understanding of the lived experience of dementia.

2.3.2 Psychological and behavioural manifestations of dementia

The impact of dementia can include psychological effects which are described as non-cognitive such as depression, apathy, delusions and hallucinations. Behavioural challenges can include agitation, wandering and aggression and deficits in functional ability as a consequence of dementia which can impact the person's ability to carry out activities of daily living. The psychological and behavioural manifestations of dementia have been reported by family caregivers as being more burdensome than cognitive dysfunction, physical dependence or functional impairment (Brodaty & Arasaratnam, 2012).

Psychosocial interventions are non-pharmacological approaches to support people in the maintenance of self-esteem and wellbeing and are designed to target the psychological and behavioural manifestations of dementia that do not involve pharmacological treatments (Myrra Vernooij-Dassen, Vasse, Zuidema, Cohen-Mansfield, & Moyle, 2010). Such interventions have been applied in numerous areas, for example, to support the family carer (Brodaty & Arasaratnam, 2012), in the context of residential care homes (Vernooij-Dassen et al 2010), and for the dyad living in the community (Van't Leven et al., 2013). Increasing evidence suggests that psychosocial interventions can target the frequency and severity of both psychological and behavioural problems associated with the condition. Recent evidence from a meta-analysis suggests that psychosocial interventions that have been tailored to the person with dementia and their carer can be effective in two distinct ways (Brodaty & Arasaratnam, 2012). First, such engagement can promote wellbeing in the person with dementia and reduce the psychological manifestations associated with the condition. Second, involvement can reduce carer burden and stress (Brodaty and Arasaratnam, 2012). Nevertheless, the interests and needs of the person and their family carer will

not always correspond and they will each have very different and sometimes inconsistent experiences of the condition (Beard et al 2012).

Furthermore, systematic reviews documenting the efficacy of psychosocial interventions have indicated that one of the most reported desires for people living with dementia is a sense of wellbeing (Brodaty and Arasaratnam, 2012; Phung et al., 2013; Van't Leven et al., 2013a). Wellbeing has been associated with quality of life encompassing how people feel about themselves and how satisfied they are with their lives rather than how others might assess their lives from a clinical perspective (Phung et al., 2013). Wellbeing in dementia includes life satisfaction, self-esteem, mastery and achievement and a sense of belonging and support (Kitwood, 1997).

2.3.3 Social manifestations of dementia

The social consequences of dementia include stigma, marginalisation, isolation, loneliness, discrimination and an imbalance of power which views people with dementia as disabled in their capabilities to continue participating fully in society (Bartlett & Connor, 2007; Bond, 1992; Downs, 2000; Lyman, 1989). People with dementia remain in many ways as understood in terms of what they can no longer achieve (Sabat, 2001) even though individuals who have the diagnosis are likely to focus upon the abilities that remain intact and adopt strategies to preserve their dignity (Sorensen et al 2008). Those with a diagnosis consistently report that their attitudes, beliefs, opinions and preferences are the same as they always were, despite dementia, and it is the reactions of others to their diagnosis that makes them feel different (Sabat, 2001). Recent improvements in societal awareness and in dementia services are leading to an appreciation of the need to work with and build upon retained skills rather than solely focussing upon deficits. The recent policy push has illustrated a significant move to try and ensure the social inclusion of people with dementia with enhanced participation being one means of achieving this (DASNI, 2000; Department of Health, 2012b, 2015a; Williamson, 2012).

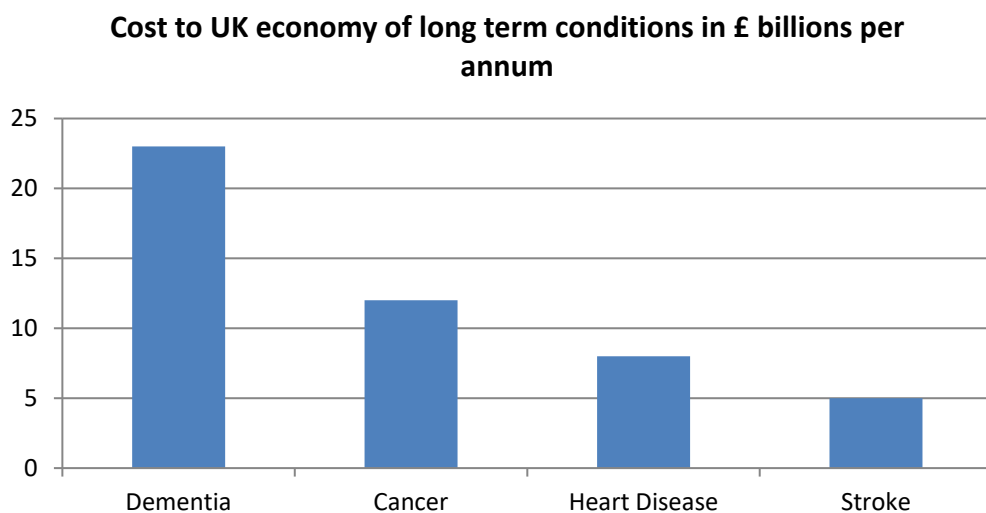
More recently this area of research has witnessed a shift from topics of 'inclusion' for the person with dementia to topics of 'participation' (Bartlett & Connor, 2007). This is important as the concept of 'inclusion' could infer that the individual with dementia is a passive addition to the research process rather than actively participating in decisions because their opinions and perspectives are essential (Bartlett & Connor, 2007). The

Dementia Care Advocacy and Support Network International (DASNI) were established in the year 2000 and are a clear example of an advocacy community that promotes ‘participation’ as a fundamental right for everyone, irrespective of dementia. Recently emerging networks include Dementia Engagement and Empowerment Project (DEEP) that aim to support groups across the UK in changing services and policies using the by-line ‘nothing about us without us’ (Williamson, 2012).

2.4 Economic costs of dementia

Dementia is one of four major conditions including cancer, heart disease and stroke with regard to healthcare consumption as well as being chronic and progressive (Graff, 2008). Dementia costs the UK economy £ 23 billion per year, twice that of cancer, three times that of heart disease and four times that of stroke (Luengo-Fernandez, Leal & Gray, 2010). The graph in figure 2.3 shows the UK economic cost of the four major long term health conditions.

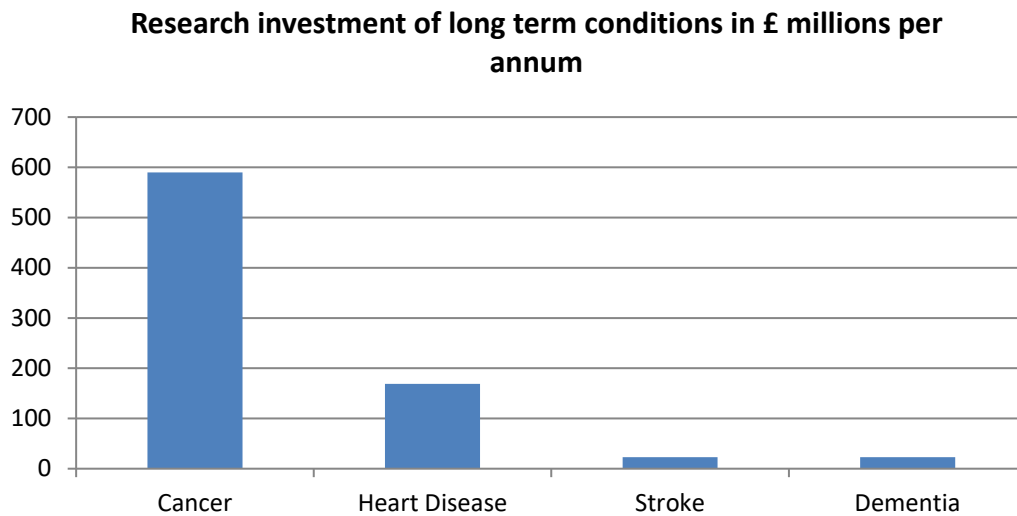
Figure 2.3: UK cost of long term conditions, adapted from (Luengo-Fernandez et al 2010)



Dementia has increasing costs to the UK economy, this cost is £23 billion per year of which £12.4 billion (55%) is met by unpaid carers (Luengo-Fernandez, et al. 2010).

The graph in figure 2.4 illustrates that research investment in the UK is largely dominated by cancer; in contrast, dementia research receives just 6% of funding in comparison to contributing 52% to the costs of health and social care.

Figure 2.4: UK research investment of long term conditions, adapted from (Luengo-Fernandez et al 2010)



There has been a history of poor investment in the past and UK investment for dementia research was £50 million in 2012 compared with £590 million for cancer research in the same year. However, investment in dementia research is now improving following the Prime Ministers Challenge on Dementia (Department of Health, 2012b, 2015a) and the G8 summit (Department of Health, 2013) in response to Government policy.

2.5 Recent Government Policy

The National Dementia Strategy (Department of Health, 2009) was a policy watershed in the Governmental push to ensure that dementia became a national priority. The strategy aimed to demonstrate how investment in dementia through prevention, early intervention and community-based support could enable people to 'live well with dementia'. The strategy emphasises that physical and mental stimulation should play a key role in this care (Department of Health, 2009). The Prime Minister's Challenge on Dementia (Department of Health, 2012b), supports the advancement in the area made by the National Dementia Strategy but outlines the need to make quicker and more effective progress. The report identifies that 42% of the UK population know a close friend or family member with dementia, a figure that will continue to rise as life expectancy increases. The key commitments to The Prime Minister's Challenge on Dementia campaign are to make a difference to current dementia diagnosis rates, improve healthcare, create dementia friendly communities and double overall research

investment by 2015 (Department of Health, 2012b). The National Dementia Strategy came to an end in March 2014 and the implementation of The Prime Minister's Challenge on Dementia will conclude in May 2015 by which time the new intended measures would mean every person living with dementia will be able to say:-

“I get the treatment and support which are best for my dementia and my life.”

“I know what I can do to help myself and who else can help me. My community is working to help me to live well with dementia.”

“I wanted to take part in research and was able to do so.” (Department of Health, 2012 p. 19).

Since concluding in May 2015, The Prime Minister's Challenge on Dementia 2012 has been refined and refreshed and the work achieved in the last three years will be now taken to the next level in the Challenge on Dementia 2020 (Department of Health, 2015a). By 2020, the aim is for England to be:-

- The best country in the world for dementia care and support and for people with dementia, their carers and families to live; and
- The best place in the world to undertake research into dementia and other neurodegenerative diseases (Department of Health, 2015a, p. 4).

2.6 Living at home with dementia

Nearly 822,000 people in the UK live with dementia and almost two thirds live at home and are either cared for informally by a spouse or family member or live independently (Luengo-Fernandez, et al. 2010). Living at home is the preference for the majority which is important and as indicated earlier the familiarity of home can compensate for reductions in physical and mental functioning associated with the condition (Chadhury, 2008). It is estimated that 63% of people with dementia live in their own homes and 37% live in residential care facilities (Knapp & Prince, 2007). There are clear economic advantages for society if people remain for longer in their own homes and interventions provided as early as possible, post-diagnosis will ultimately be one of the most cost effective solutions (Donnelly, Nugent, Craig, Passmore, & Mulvenna, 2008).

Of those people living at home, a further third do so independently with no informal care. Thus, for some home does not necessarily provide the ideal environment

particularly as the cognitive losses characteristic of dementia often lead to a lack of autonomy and decreased interest in social activity (Graff et al., 2008). This decline in self-efficacy affects the extent of social contact with a consequent negative impact upon wellbeing (van der Wardt et al. 2012). Further, the financial burden of residential care means that the majority of people with dementia will have no choice but to stay in their own homes without the care provided in residential settings (Mulvenna et al. 2010) which can result in increased stress for both the person with dementia and their informal carer if they have one, as the disease progresses (Phinney et al. 2007).

Dementia 2012 was the first in a series of annual reports undertaken by the Alzheimer's Society (2012a) to assess how well people are living with dementia. Living well is assessed through seven outcomes and the report concluded that people with dementia and their carers are still not living well with dementia. One of the questions directed to those living at home with a diagnosis of dementia was 'are you living well with dementia'? People gave the following responses:-

77% of all people with dementia feel anxious or depressed

75% of people in the UK consider society to be ignorant regarding dementia

67% of people with dementia do not always feel part of the community

61% of people with dementia feel lonely always or some of the time

48% of people with dementia feel like a burden to their family

Access to quality information about dementia is essential for both the person and their family carer post diagnosis so that they are able to understand the condition and use this knowledge to identify and adopt new ways of approaching life. As well as providing details of what to expect and how to self-manage the symptoms, information should also include details of local resources that might be able to help and/ or provide outlets for participation and leisure. For example, Reid et al (2013) compiled the Sheffield Dementia Information Pack as a resource to support people living with memory problems and the Alzheimer's Society provide factsheets of information on their website

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2580

It is important that such information is not necessarily dementia specific and incorporates resources that are mainstream and willing to provide the necessary assistance. Maintaining an up to date record is of prime importance so that the person with dementia and their carer can be confident in the accuracy of the information.

Creating supportive environments involving information and services can be enabling for the person through continued communication as well as maintaining relationships and social inclusion, despite dementia (Schweitzer and Bruce, 2008).

2.7 Conceptual models of dementia

Numerous models of dementia have been proposed as a way of exploring and understanding the condition and those living with it. These models are sometimes referred to as conceptual frameworks which are collections of ideas dedicated to the topic of dementia. Table 2.1 provides examples of how various concepts have been developed and refined in order to capture the nature of the phenomenon being explored (Blumer, 1969 cited in Hammersley, 1989). Referred to as 'sensitising concepts', rather than being prescriptive, can be described as guiding our understandings of dementia. The models of dementia described below can also be viewed as an historical timeline as understandings of the person and the condition progress.

2.7.1 The Biomedical Model of dementia

The Biomedical model of dementia explains dementia in terms of pathology which attracts the majority of research funding in the search for treatments and a cure for the 'disease'. Traditionally, the bio-medical model of dementia has been the dominant paradigm and the prevailing focus on pathology and symptoms has also been most influential on dementia care policy and practice in the UK (Innes & Manthorpe, 2012). Not surprisingly, the search for a cure is the number one research priority for the person with dementia and their families (Alzheimer's Society, 2012a). The bio-medical focus also includes diagnosis of the condition and the pharmacological interventions that can allay the progression of the dementia. Acquiring a diagnosis is essential in enabling people with dementia and their families to access services and the necessary support and information as the condition develops. Despite the importance of identifying treatments and the need for accurate diagnosis, connotations associated with the 'biomedicalisation' of dementia have viewed the person as 'a sufferer of the disease' and a 'care receiver' (Bond, 1992; Lyman, 1989). Thus, dominance of the biomedical model of dementia has been questioned as a cure is not imminent and

biological explanations of the condition fail to address quality of life issues, thus providing an incomplete explanation of the condition and people experiencing it.

2.7.2 The psychosocial model of dementia

The psychosocial model of dementia emerged in reaction to the biomedical model providing humanistic explanations that considered psychosocial factors as influential, including the individual reactions to the effects of cognitive impairment or how they were now viewed by 'healthy' others (Kitwood, 1997; Sabat, 2001). The views of healthy 'others' was considered to negatively impact the individual through the loss of personhood, a term Kitwood (1997) penned 'malignant social psychology'. Personhood can be defined as *'a standing or status that is bestowed upon one human being by others in the context of particular social relationships and institutional arrangements.....it implies recognition, respect and trust'* (Kitwood, 1997, p 7). Kitwood argued that the interaction between personality, biography, physical health, neurological impairment and social psychology can afford understandings of the person's unique experiences and perspectives. Psychosocial approaches and the concept of personhood focus on cognitive disability, wellbeing and identity, individualising the experience of dementia yet highlighting the importance of promoting 'voice' for the person with the condition (Cahill, 2004; Harris, 2002; Kitwood, 1997; Sabat, 2001; Williamson, 2012).

However, critical debate exists regarding the individualistic nature of person-centred approaches which some argue denies the view of the person as belonging to a network of social relationships (Nolan, Davies, Brown, Keady, & Nolan, 2004). Although grounded in the concepts surrounding the individuals quality of life, relationship-centred approaches view the quality of 'lives' as essential and the person with dementia in the context of significant relationships (Ryan, Nolan, Reid, & Enderby, 2008). In consequence, the 'senses framework' was developed to understand how relationships between the person with dementia, the family caregiver and the professional are established and sustained within a context of dementia care triads. Yet others argue that this conventional focus still views the person as a passive recipient of care (Bartlett & Connor, 2007) and may just not be 'social enough'.

2.7.3 Sociological models of dementia

Sociological models of dementia take a socio-political perspective by addressing wider social and structural factors including issues of stigma, discrimination, power inequalities and the ways people are treated by society. Critical social gerontology promotes a social science perspective by bridging the gap between individualistic explanations of the condition and the ways wider social structures can shape the experience of dementia (Innes and Manthorpe, 2012) thus rejecting assumptions that the individual is passive in the face of external forces (Bartlett & Connor, 2007). This is important as it redirects the responsibility of dementia onto society as a whole rather than assuming that change must occur at an individual level. Bartlett & Connor (2007) developed a conceptual framework to understand the contextual experiences of people with dementia. Bio-medical and psychosocial perspectives have been comprehensively relayed and in reaction a socio-political perspective is considered to provide a more relational picture of dementia. Referred to as ‘social citizenship’, the aim is to acknowledge the potential contribution that people living with dementia can bring to everyday social situations including self-advocacy groups, community groups and research studies. The motivations of social citizenship are becoming increasingly popular in contemporary research studies promoting the view that is ‘*more consistent with the reality of many people with dementia as active, engaged and socially contributing to society*’ (Bartlett & Connor, 2007p. 7). Models to assist with our understandings of dementia are continually being developed and extended. Table 2.1 illustrates how the concepts central to the approaches discussed above are continually evolving in relation to each other.

Table 2.1: Conceptual models of dementia

Personhood (Kitwood 1997)	Relationship-Centred care (Nolan 2008)	Citizenship (Bartlett & O’Connor 2010)
Comfort	Security	Growth
Identity	Continuity	Social positions
Occupation	Belonging	Purpose
Inclusion	Purpose	Participation
Attachment	Achievement	Community
Love	Significance	Freedom from discrimination

2.7.4 Multidisciplinary models of dementia

There are increasing efforts that acknowledge the situated nature of dementia the condition as an interplay between theory, policy, practice and research (Innes, 2009). Multifaceted ways of thinking about dementia are necessary as explanations of the condition from an individual perspective (micro level) provide incomplete accounts unless they are understood within a societal context (macro level) (Innes, 2009). It is well established that the impairment caused by dementia reaches beyond biological factors and Biopsychosocial explanations are increasing our understandings of the condition (Clare et al., 2012; Downs et al. 2008; Sabat, 2011; Spector & Orrell, 2010). The Biopsychosocial model of dementia specifies that the experience of dementia is influenced by biological, psychological and sociological factors, yet it is the dynamic interplay between all three that is of greater importance (Downs et al. 2008). Thus people living with dementia are not only affected by the neuropathology of the brain but also by their own reactions to its effects, by the environment within which they live and the ways they are treated by society (Scholl & Sabat, 2007).

A Biopsychosocial model is now a broadly accepted framework within the World Health Organisation's understanding of dementia, postulating a synthesis between medical and social models whereby the condition can be understood in terms of psychological factors and social systems (WHO, 2002). The same model has informed and shaped the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) 'dementia' guideline (NICE-SCIE, 2006). One key implication of a Biopsychosocial model of dementia is how the inclusion of psychological, social and environmental factors can highlight the individual experiences of dementia including differences in the progression of the condition, the manifestation of symptoms or the sudden unexplained improvement of the condition (Downs et al. 2008).

Spector & Orrell, (2010) have recently added 'mechanisms of change' to existing Biopsychosocial models viewing dementia as a process (trajectory) beginning with ageing and ending in death. Although the Biopsychosocial model of dementia can enable understandings of the interplay between the biology, psychology and sociology of the individual, it was ultimately developed as a need for a new medical model to aid decisions within clinical practice (Engel, 1977). The process of dementia will be unique to each individual thus there will be no obvious point on the trajectory that an intervention will be guaranteed to be beneficial for everyone.

2.8 Situating this thesis in context

Dementia research is focussed on discovering a cure for the condition and far fewer resources have been given to the examination and exploration of the care of those living with dementia. Dementia is a multifaceted topic requiring explanations from a multidisciplinary perspective in order to comprehensively understand the condition and the impact it has on the lives of over 820,000 people in the UK alone.

Health Services Research is a multidisciplinary endeavour and unites the social and behavioural sciences, epidemiology, statistics and clinical expertise (Bond & Corner, 2001). This thesis is multidisciplinary and rooted in the context of applied Health Services Research yet draws on existing sensitising concepts and theoretical thinking from additional disciplines including Sociology and Psychology. This multidisciplinary approach is therefore influenced by theoretical concepts that are interpretative in nature and pragmatically applicable to real life contexts.

This project is funded by the Economic and Social Research Council (ESRC) reflecting the social science challenges of an ageing population that are influenced by current political policy. The applied nature of the project is influenced by the discipline within which the researcher is working and ultimately the findings reflect the researcher's perspective.

Chapter 3: Reviewing the literature

3.1 Introduction

The aim of the two literature reviews described in this chapter is to provide an overview of the current nature and extent of research evidence surrounding the topic of dementia, enjoyable activities and technology use. From the existing literature, conclusions will be drawn regarding the quality and content of the evidence base and in consequence, research gaps will be identified. The knowledge gained from undertaking the two reviews will underpin the design and execution of the research that follows. These reviews may be considered as an assessment of the potential breadth of literature and although not exhaustive, the aim was to 'scope' the existing evidence in the topics of interest. The research questions to be addressed in this chapter are:-

What evidence exists concerning people living with dementia and activities enjoyed during leisure time?

To what extent has a diagnosis of dementia altered 'others' perceptions of activities that may be pursued now and in the future?

How is technology currently being appropriated for the purpose of promoting enjoyable activity by people with dementia?

What forms of enjoyable activity can be experienced through technology?

Section 3.2 of this chapter describes the first review which focuses on the existing evidence concerning the activities enjoyed by people with dementia and the perceptions of significant 'others'. Section 3.3 explores technology use and the evidence that exists concerning how enjoyable activity is currently being promoted through technological intervention with people living with dementia. Section 3.4 combines the findings from the two reviews and consequently enables the identification of research gaps in the evidence base.

3.1.1 Methodology

The methodological framework adopted for this scoping review is the 'York framework' (Arksey & O'Malley, 2005). This framework requires a broad approach to be maintained throughout allowing coverage to be comprehensive, rigorous, and transparent thus making it replicable. The review method of scoping the literature requires the identification of all literature that may be relevant providing a descriptive

overview of the topic at a particular point in time. Unlike a systematic review, the search yield was not critically appraised although a systematic approach to searching the literature was adopted ensuring the transparency of the search process.

3.2 Dementia and enjoyable activities – Review 1

3.2.1 Search methods

Ten electronic databases were searched using the key terms described in table 1. They were: Cochrane Library, MEDLINE, EMBASE, Applied Social Sciences Index & Abstracts (ASSIA), Social Care Online, Cumulative Index to Nursing & Allied Health Literature (CINAHL), PsycINFO, Science Citation Index (SCI), Social Sciences Citation Index (SSCI) and ProQuest Dissertations and Theses (grey literature). The search extended to other non-electronic sources including bibliographies of relevant papers, hand searching key journals (Ageing & Society, Gerontechnology, Ageing & Mental Health) book chapters, conference proceedings and relevant websites (NICE, SCIE, DASNI, WHO, Alzheimer’s Society, DOH).

Table 3.1: Search terms

Dementia or Alzheimer’s disease (AD)	NOT pharmacological or drug trials or clinical evaluation/assessment or neuroimaging or mild cognitive impairment (MCI) or memory loss
Living in the community or community dwelling or living at home or living in own home or residing at home.	NOT residential care/accommodation, care homes, interventions for carers, day care, respite care, assisted living.
Social and leisure activity or meaningful activity or meaningful interactions or social interactions or enjoyable activity or achievements or leisure and recreation or free time or fun.	NOT housework or activities of daily living (ADL) or instrumental activities of daily living (IADL) or employment or paid jobs or cognitive training or cognitive rehabilitation.

3.2.2 Definitions of the key constructs within the review

Dementia describes a progressive decline in brain function including memory, understanding, judgement, language and reasoning (Luengo-Fernandez et al. 2010). Dementia is a chronic and degenerative brain condition that typically presents itself through the gradual decline of short-term memory whilst the progression of the

condition results in other cognitive domains becoming affected including space and time orientation, attention and comprehension (Alzheimer's Society, 2012c).

Social and leisure activity is subjective, meaning different things to different people within different contexts. For the purpose of this review, leisure activity is defined as free time away from domestic duties, Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) and paid work yet incorporating an activity that is deemed enjoyable as well as meaningful to the person. It should be acknowledged that activities considered enjoyable may be different from activities that are thought to be meaningful; this will depend on the individual. For example, leisure activities may be enjoyable because we get pleasure from doing them independently or with others. Leisure activities may also be meaningful, providing a purpose for our skills and abilities. Equally, activities may be enjoyable and meaningful but for the purposes of this review will not include ADL's. Activities might also be sedentary like completing a crossword or reading a book or active like going for a walk or playing golf. The definition used for this review also includes activities such as ball games, word games, reminiscence, dancing, role playing, crafts, volunteering, gardening and hobbies. Convergent with Shaw (1985), leisure is defined as enjoyable and involving an activity that has been freely chosen by the person rather than chosen for the person. Ultimately, activities should reflect the individuals past experiences, hobbies, interests and maintained abilities in order to facilitate meaning and engagement in the promotion of wellbeing (Cohen-Mansfield, Dakheel-Ali and Marx, 2009; Kolanowski and Richards, 2002; Leng et al., 2014).

Social interaction is often perceived as a central component of leisure activity (Auld & Case cited in Leung & Lee 2005). For the purpose of this review the term 'social' describes time spent engaged in leisure activities that incorporate interactions with others either face-to-face, on the telephone or through the use of ICT. Interactions with others can be one of the first 'social causalities' disrupted by the effects of dementia and has been described by some as a devastating challenge that includes social isolation, changes in relationships and loss of independence (Dementia Advocacy and Support Network (DASNI, 2000)).

Community describes the living arrangements of the study population and defining the term was considered important. This is because studies in the USA consider the word 'community' to encompass older adults living together in some form of housing with warden type care, referred to as residential care or assisted living in the UK. In

contrast the term community in the UK would describe people who live in their own homes with a spouse or family member or alone. The term community in this review does not include assisted living, designated housing, sheltered housing or extra care housing. This is because estimated figures suggest that two thirds of people with dementia live in their own home without assisted living arrangements (Alzheimer's Society, 2014b)

3.2.3 Search outcome

As this is a scoping review there were few exclusion criteria thus the search pertained to;

1. All health care disciplines
2. All countries
3. All available years
4. All published, unpublished and on-going studies

Due to available time and resources only papers printed in English were included. Advice was sought to identify databases that were most likely to contain relevant studies. Literature searching took place between the 15th and the 31st May 2012 and was updated between 25th and 29th August 2014 and again between 20th and 23rd June 2015.

The initial search identified a total of 103 potentially relevant articles. Of these articles, 49 were immediately excluded based on title and abstract leaving 54 articles that were potentially relevant. All 54 articles were read in full and despite the defined search terms further exclusions were required based on the meaning of activity and how it is defined in a multitude of ways depending on the topic, population and context being researched. For example, articles were excluded based on individuals participation with leisure activities in populations of healthy older adults (Glei et al., 2005; Kattenstroth, Kolankowska, Kalisch, & Dinse, 2010; McMunn, Nazroo, Wahrendorf, Breeze, & Zaninotto, 2009; Paillard-Borg, Wang, Winblad, & Fratiglioni, 2009; Silverstein & Parker, 2002); cognitive leisure activities as protective factors or as effective strategies in the prevention of dementia (Hall et al., 2009; Stern & Munn, 2010; Wang, Xu, & Pei, 2012) or in preserving cognitive function (Iwasa et al., 2012; Leung et al., 2010); leisure activities that may reduce the risk of dementia (Crowe, Andel, Pedersen, Johansson, & Gatz, 2003; Hughes, Chang, Vander Bilt, & Ganguli, 2010; Verghese et al., 2006).

Further exclusions included activities of daily living (Cooper et al., 2012; Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010; Graff et al., 2008; Ji, 2013; Nygård, 2004; Olazarán et al., 2010; Vikstrom, Josephsson, Stigsdotter-Neely, & Nygard, 2008) and studies undertaken in residential care settings (Cohen, Firth, Biddle, Lloyd Lewis, & Simmens, 2009; Fernández-mayoralas et al., 2014; Gerritsen et al., 2007; Kolanowski & Richards, 2002; Trahan, Kuo, Carlson, & Gitlin, 2014; Myrra Vernooij-Dassen et al., 2010; Volicer, Simard, Pupa, Medrek, & Riordan, 2006); physical activity to reduce cognitive decline and induce wellbeing (Cedervall & Aberg, 2010; Venturelli, Scarsini, & Schena, 2011; Volkers & Scherder, 2011); midlife activity predicting the risk of dementia in later life (Carlson et al., 2008; Rovio et al., 2005) and activities for cognitive stimulation and rehabilitation (Aguirre, Woods, Spector, & Orrell, 2013; Liberati, Raffone, & Olivetti Belardinelli, 2011).

After exclusions, twenty articles met the inclusion criteria and the focus clearly describes activities as enjoyable, meaningful, social or recreational involving participation in leisure time with people living with dementia at home. The characteristics of the eighteen included studies have been defined and charted in table 3.2 below.

Figure 3.1: Search outcome

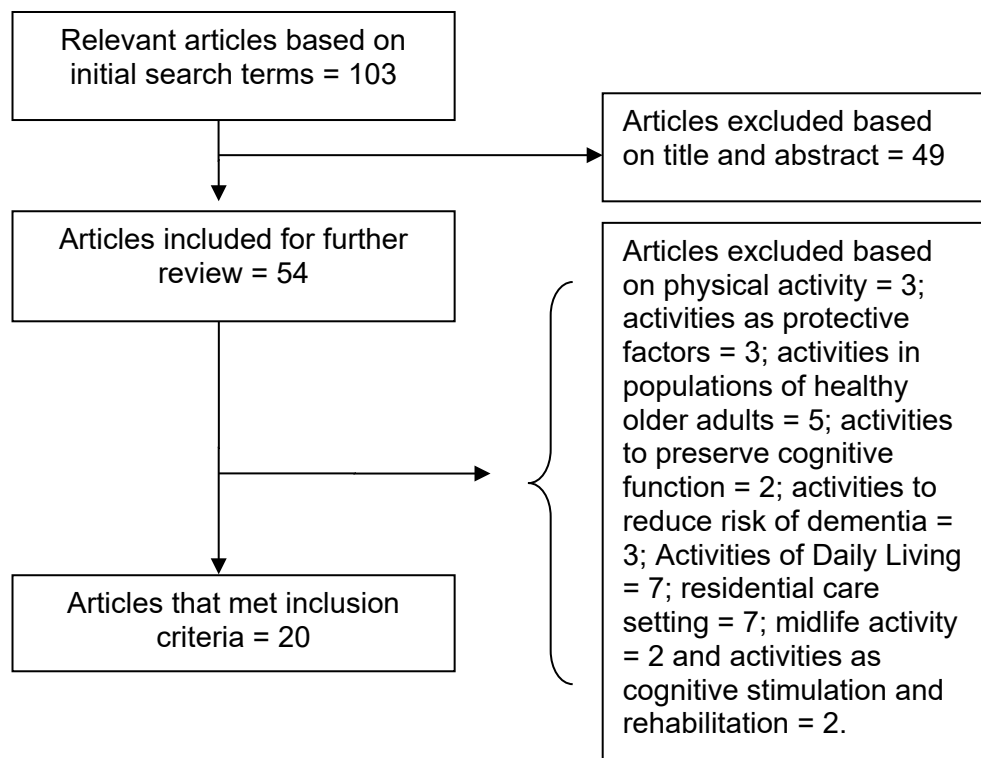


Table 3.2: Charting the data – review 1 – dementia and enjoyable social activities

Author	Research Aim	Context	Participants	Method	Dementia	Main Findings
Brooker & Duce (2000) UK	A comparison of reminiscence, arts & crafts and unstructured time	Day care	25	Dementia Care Mapping (DCM)	Mild to moderate	Individuals experienced greater sense of wellbeing during group reminiscence
Cassolato et al (2010) Canada	Exploring the meaning of eating out	Community	26 dyads	Qualitative interviews	Mild	Eating out can balance life with dementia but restrictions exist
Cook et al (2008) Canada	Decreased initiation of usual activities	Community	130	Semi-structured interviews	Mild to moderate	Decreased initiation in 85/130
Genoe & Dupuis (2009) Canada	Leisure in the context of dementia	Community	4	Interviews and observations	Mild	Leisure used to reduce stigma associated with dementia
Hanser et al (2011) USA	Home based music strategies	Community	14	Self-report	Not specified	Caregivers reported more benefit than person with dementia
Hewitt et al (2013) UK	Therapeutic gardening program	Community	12	Rating scales	Early on-set	Renewed wellbeing
Kinney et al. (2011) USA	Evaluation of volunteer program	Community	6	Interviews and observations	Early on-set	Volunteering allows sharing of experiences
Langdon et al. (2007) UK	Reactions of others	Community	12	Semi-structured interviews	Mild	Social responses from others may hinder adjustment to condition

Author	Research Aim	Context	Participants	Method	Dementia	Main Findings
MacRae (2011) Canada	Social interactions & relationships	Community & residential care	9	Semi-structured interviews	Not specified	Access to support gives meaning and purpose
Menne et al. (2012) USA	Activities currently enjoyed	Community & residential care	267	Interviews and observations	All	Activities enjoyed similar to health older adults
Phinney & Moody (2011) Canada	Social recreation groups	Community	10	Self-report questionnaires	Mild	Activities meaningful in context of past experiences
Rosenberg et al (2009) U.S.A	Art as educational and enjoyable	Community	37	Interviews	Mild	Importance of social interaction over art
Searson et al (2008) UK	Activities enjoyed by the dyad	Community	46	Pleasant Events Schedule	Mild to moderate	Activities reported most popular are those that encourage mutual enjoyment
Sixsmith & Gibson (2006) UK	Meaning of music	Community & residential care	26	Interviews	All	Music enables participation in meaningful enjoyable activities
Sorensen et al. (2008) Denmark	Everyday life & social situations	Community	11	Cochrane Review of RCT's	Mild to moderate	Highlighted the importance of spouse
Vink et al. (2010) Netherlands	Music therapy	Community & residential care	10 trials for review	Cochrane Review of RCT's	All	Methodological quality and reporting poor of all trials reviewed

Author	Research Aim	Context	Participants	Method	Dementia	Main Findings
Woods et al. (2009) UK	Reminiscence therapy	Community & residential care	4 trials for review	Eight centred RCT	All	Small trials of relatively low quality
Woods et a. (2012) UK	REMCARE	Community	350 dyads		Mild to moderate	No support for effectiveness of intervention
Young et al (2015) UK	Art-based interventions	Community	17 articles for review	Systematic review	Not specified	Positive effects in areas of cognitive function
Zeilig et al (2014) UK	Participatory art	Not specified	63 articles for review	Critical review	Not specified	Art creates a space to engage outside the demands of daily life

3.2.4 Synthesis of findings from review 1

The evidence base concerning leisure activity and people with dementia living in the community was found to be limited. Those articles that were included in the review were also diverse in methodology, design, sample size and focus regarding their definition of enjoyable activity. For this reason each study is described individually and then synthesised together under the following headings; activities currently enjoyed during leisure time, 'others' perceptions of activity and activities as therapeutic modalities. A discussion of the findings from review 1 can be found in section 3.2.5.

Activities enjoyed during leisure time

This section explores the evidence that exists regarding activities that are currently enjoyed by people living with dementia including a social recreation group, a volunteer programme and a photo voice study, museums and art and 'eating out' as an enjoyable activity. All studies were qualitative involving relatively small sample sizes. One longitudinal study consisted of qualitative interviews with 267 people living with dementia.

In their qualitative study to explore the impact of a social recreation group, Phinney and Moody, (2011) carried out 10 separate interviews and 40 hours of observations of people with a recent diagnosis of dementia. The focus was on participant's own experiences of a Canadian community-based intervention and how they perceived themselves to have changed because of their involvement in their programme. The overall aim of the programme was to encourage, motivate and educate people through social interaction, enjoyment, fun and friendship. The leisure activities provided included exercise, ball games, word games, reminiscence, dancing, role playing and crafts and the conclusions reached suggested this type of intervention filled an important gap for this population. This study illustrates the important role that contributing to a social group may have had on the participant's experiences and how socially interacting with others through leisure activity provided something fun to look forward to. However, contrary to exploring participants own experiences of the group, only one out of the 10 interviews was undertaken with a person with dementia, the rest consisted of family members and staff. This was because five of the participants had communication difficulties or were too far advanced in the condition to participate. The authors acknowledge the limitations of these findings in gaining the perspectives of

people with dementia which has resulted in an incomplete picture of the phenomenon. Although they stress that utilising observational methods enabled the perspectives of those less able to communicate their experiences. Further, video recordings of the group sessions may have highlighted the spontaneous verbal and non-verbal expressions that were missed during interviews and field notes. Nevertheless, this study is methodologically weak as people experiencing later manifestations of the condition were recruited when the research aim specifically stated that perceptions of those post diagnosis were required. The researchers concur that the study provided a 'snapshot' of activities undertaken in a social recreation group and that alternative methodologies are required to examine this further.

Kinney et al. (2011) evaluated a UK volunteer program at the local zoo for people with early-onset dementia. Semi-structured interviews were conducted with six male participants and this data was supplemented with data from a focus group involving wives of the participants who were asked about their perceptions of the program. The findings indicated that the program provided positive experiences for those involved including extended family and the wider community. Limitations acknowledged by the researchers are the relatively high costs of developing a volunteer program for such a small sample of participants and the distorted representation of male participants only and with no female representation. The focus on early-onset dementia will also have dictated that the sample were younger and thus not representative of all older adults with dementia.

Utilising a photo voice method 4 participants were asked to take photographs of objects, places and people that were meaningful for their leisure using disposable cameras (Genoe & Dupuis, 2012). Subsequent discussions of the photos were analysed based on the individuals 'lived experience'. Results indicated that the participants were keen to emphasise their intact abilities keep their minds active and prolong their engagement in meaningful leisure activities. In addition they felt that leisure activities allowed them the space to resist the stereotypical images of social expectations (Genoe & Dupuis, 2012). It was concluded that leisure activity becomes more significant to people after they have received a diagnosis of dementia although some did retain old leisure pursuits and others began new ones. This study highlights the difficulties distinguishing between leisure experiences and routine daily life experiences but the authors also suggest that dementia practice needs to move beyond the rigid therapeutic activities that are characteristic of day centre groups and residential care. Rather, meaningful leisure activities should be unique to the individual,

maintaining a connection with activities that were once enjoyed thus using residual skills.

An emerging area of research has been gathered recently by two reviews highlighting the positive impact that art interventions may have on people with dementias' health and wellbeing. A systematic review focused on art based interventions and cognitive processes defined the evidence into literary arts, performing arts and visual arts (Young, Camic, & Tischler, 2015). The evidence indicates wide ranging psychological and social benefits in cognitive functioning including recall, communication, attention, new learning and short-term memory. However, the authors indicate the majority of evidence to be methodologically weak but also report inconsistent measurement tools across studies making it challenging to integrate findings into a coherent review. In addition, many articles were excluded as they did not specifically consider the impact of the art intervention on any cognitive process. One particular exclusion was an evaluation involving the Museum of Modern Art explored the potential for self-awareness, expression and empowerment through the arts (Rosenberg, Parsa, Humble & McGee, 2009). Up to six small groups involving people with a recent diagnosis of dementia and their family carers were provided with a 90 minute tour of the museum by a trained educator in the arts. The tours took place when the museum was closed to other visitors. Through the development and evaluation of the programme it was considered that engagement with art offers participants an opportunity to enhance their quality of life through mental stimulation, communication, personal growth, and social engagement (Rosenberg et al 2009). Overall, 37 people with dementia and 37 informal carers took part and the evaluation measures comprised 4 self-report questionnaires which interestingly highlighted that 86.5% of participants were categorised as highly educated. The conclusions of the evaluation indicated that it was the style and approach of the art educator, rather than the art itself, that had the most positive impact on participation. Moreover, emphasis was placed on the importance of increased social interaction enabled by participation as opposed to education in the arts. This is confirmed by a recent critical review undertaken in the UK focusing on participative arts for people living with dementia (Zeilig, Killick, & Fox, 2014). Participative arts included singing and music groups, drawing, making and painting groups, dance projects, theatre and storytelling, poetry and writing, museums and art galleries. The review concluded that the evidence will continue to develop and be of value in meeting the needs of people with dementia. However, the authors suggest that it is a challenge to establish whether the positive effects reported were

intrinsically associated with the particular arts activity or the increased opportunity to socially participate and integrate with others (Zeilig et al., 2014).

Based on the premise that valued activities for people with dementia do “*not simply centre on personal care and domestic tasks but include opportunities to socialize, to engage in activities and to achieve a sense of social integration*” (Bamford & Bruce, 2000, p. 553), a Canadian study carried out qualitative interviews to explore the perspectives and meaning of eating out as an enjoyable leisure activity (Cassolato et al., 2010). Twenty six dyads involving people with a recent diagnosis of dementia and their spouse or family member reported that eating out was a way of balancing life in the face of living with dementia. Yet, it was also reported by those in a supporting role that the biological, physical and psychological changes associated with dementia placed further constraints and restrictions on such activities. These included crowded and noisy environments increasing the stress of both parties as well as demands on time, resources and energy (Cassolato et al., 2010).

A longitudinal study to explore the everyday, enjoyable activities’ people with dementia engaged with was undertaken by Menne et al. (2012). The study sample consisted of 267 people with dementia who completed up to 5 interviews each. The importance of encouraging continued engagement in activities that the person found enjoyable was acknowledged. The research team considered that declining cognition may dictate that enjoyable activities be modified, for example audio books instead of traditional books or rather introduce new activities altogether. During each interview participants were asked ‘What kinds of activities do you like to do now’ (Menne et al. 2012)? The results from analysis of the interview data showed that 50% of the respondents indicated preferences for the following social and leisure activities; socialising 19.77%, TV/music/radio 13.9%, exercise/recreation, 11.9% and cognitive stimulation for example crossword puzzles 10.28%. Conclusions suggest the importance of recognising activities that people with dementia already enjoy by engaging the person in the decision making before intervening with new or modified alternatives. However, questions are raised when categories of leisure activity are predefined by the researchers and participant responses are recorded to fit the ‘most likely’ category.

Significant ‘others’ perceptions of enjoyable activities

The following section is concerned with dyadic relationships and the reactions and perceptions of the person’s informal carer to leisure activity and the person they care for. All the identified studies involved people with dementia alongside an informal caregiver. These studies were mainly qualitative with small sample sizes. Only one study was larger (130 participants) and involved secondary qualitative analysis of descriptive data.

Sorensen et al. (2008) recruited eleven participants from the Danish Alzheimer Intervention Study (DAISY) (Waldemar, Waldorff, Buss, Eckermann, Keiding & Rishoej, 2006) and carried out a process evaluation. DAISY was a longitudinal, multi-centre randomized controlled trial investigating an intensive intervention programme specifically for people living at home with mild dementia and their informal carers. The eleven participants recruited from DAISY were asked to describe their experiences of everyday activities; recent changes in these activities; and their social life with spouse family and friends. Interview analysis found that people with dementia were aware of a decline and attempted to adjust their activities in order to preserve their dignity and value. People with dementia described how they began to feel uncomfortable around significant ‘others’ in case they might say something embarrassing which may lead to feelings of being undervalued. Others describe how friends stop calling, leaving fewer opportunities to stay socially integrated which may result in higher risks of depression and further declines in cognitive functioning (Sorensen et al. 2008). Participants with dementia described how they were now viewed by their spouse in relation to staying socially active, so attempts were made to develop coping strategies in order to maintain feelings of well-being (Sorensen et al., 2008). Importance was attached to ‘entertaining activities’ that included watching TV, crossword puzzles and reading. Participants were also supported by their spouse who it was reported may have contributed to the positive coping strategies of the person.

Similarly, Searson, Hendry, Ramachandran, Burns, & Purandare, (2008) recruited 46 people with mild to moderate dementia alongside their spouses in a cross-sectional two site study. The Pleasant Events Schedule – AD (PES-AD; Teri & Logsdon, 1991) was administered to rate the frequency of activity for the person, their spouse, and by the dyad together. The ten most frequently enjoyed activities reported by the dyad were:

1. Looking at photo albums
2. Being told I am loved
3. Having meals with friends and family
4. Being outside
5. Listening to music
6. Laughing
7. Reading or listening to the news
8. Recalling past events
9. Being with family
10. Watching T.V.

The findings suggest that activities reported as most popular were those that encouraged a sense of mutual enjoyment and companionship, as carers consider the loss of relationships as the most distressing when living with a spouse with dementia (Searson et al., 2008). The conclusions imply the need for future interventions that may support carers' wellbeing by encouraging activities through therapeutic interventions to maintain companionship and wellbeing for the dyad.

A Canadian study by Cook et al. (2008) explored decreased initiation in social and leisure activities in 130 community dwelling people with mild to moderate Alzheimer's disease. A secondary qualitative analysis of descriptive data was obtained from the Video Imaging Synthesis of Treating Alzheimer's disease (VISTA), a Randomised Controlled Trial undertaken two years previously. Data analysis illustrated that decreased initiation of functional, social or leisure activities was common and reported by 65% of participants. Social and leisure activities mostly referred to reading, crafts, walking, puzzles and gardening. Less popular were card games, carpentry, exercising, music, painting and writing. It was concluded that people with dementia, who can lack initiation to participate in a particular social or leisure activity, remain interested in that activity when it is initiated by others. Cook et al. (2008) explains these findings as indicative of executive dysfunction, a disruption to the cognitive structure of the brain that affects the decision making process commonly associated with dementia. An increased understanding of these results may have been gained had the researchers accounted and collected details of social and leisure activity participation before a diagnosis of dementia was received.

A qualitative UK study undertaken by Langdon et al. (2007) recruited 12 men and women, aged 66-87 with a recent diagnosis of dementia. Although this study does not

explore the views of others regarding leisure activity it was considered relevant due to the focus on 'others' reactions to the persons changing social status and the social effects of receiving a diagnosis of dementia. Using Interpretative Phenomenology as a theoretical perspective, the study explored how participants own perceptions of their condition and their understandings of others' reactions to them had changed since receiving a diagnosis. It was proposed that distinctions may be drawn between the two. Interviews were carried out in either a clinical environment or in the person's own home to elicit views on the reactions of others to their changing condition. Participants were aware and felt sensitive towards other people's concealment, avoidance and often denial of their condition, which they described as impacting upon their own attempts to adjust to their diagnosis. The authors concluded that people with a diagnosis of dementia are keen to be treated as normally as possible with clear, unambiguous and honest responses from others.

Similarly, a Canadian study by MacRae, (2011) recruited 9 people with early manifestations of Alzheimer's disease, living in their own homes and conducted semi-structured interviews to understand social interactions and social relationships. MacRae stresses that spouses and families play a crucial role in facilitating social interactions '*...by creating ways to be involved in meaningful activity and encouraging and facilitating the ability and desire of the person with dementia to use their remaining intact inabilities to their fullest potential*' (2011 p.447). Taking 'symbolic interactionism' (Mead, 1934) as a theoretical perspective, the findings suggest that positive social interactions and supportive relationships can diminish the potentially negative impact of dementia (MacRae, 2010). Participants agreed that significant others reactions to them had not changed after receiving a diagnosis and most continued to be very active socially whilst maintaining supportive connections with spouses, friends and family. It is a challenge to understand why the results from studies that are so closely related in population characteristics and focus of investigation (Langdon et al., 2007; MacRae, 2011) can illustrate such contrasting results. It could be that taking 'symbolic interactionism' (Mead, 1934) as a theoretical perspective, placed emphasis specifically on the meaning of social interactions, possibly illustrating the nuances of living with dementia in ways that phenomenological methodologies cannot. Alternatively it could be recruitment bias, involving particularly active participants with dementia who were keen to participate in research that were also enabled by continued spousal support.

Leisure activities as therapeutic modalities

Therapeutic modalities describe psychosocial interventions that are specifically applied to people with dementia as a therapy. Modalities identified through this review include reminiscence, gardening and music therapy. Research on therapeutic modalities place more emphasis on the treatment of 'symptoms' of dementia by focusing on the cognitive impairment and those memories that have been compromised rather than the 'lived experiences' of dementia.

A systematic review undertaken by Beard, (2011) focussed on art therapies as an intervention for people with dementia although included in this definition were dance, music, drama, gardening, physical exercise and aromatherapy. In general, it was found that art therapy interventions helped alleviate 'disruptive' behaviours and were largely applied in the context of residential care thus not included in this review. Nevertheless, the review highlighted an overemphasis on clinical outcomes at the expense of enjoyable activity and increased wellbeing. This crucial distinction between activity as something to be enjoyed and therapy to target symptoms needs to be recognised (Beard, 2011) although this review aimed to identify studies on the latter it was considered important to include this distinction.

Brooker & Duce, (2000) explored wellbeing and activity in dementia using a within subjects design to compare three types of activity in the promotion of wellbeing. Twenty five individuals with mild to moderate dementia attending day care facilities, participated in group reminiscence therapy (RT) using objects and photographs, group activities (GA) involving crafts and games and unstructured time (UT) whereby individuals were left to their own devices. Using Dementia Care Mapping (DCM) as an evaluation tool to measure wellbeing, the findings suggests that those involved in the reminiscence therapy group sustained a higher level of wellbeing when compared with the two other groups (Brooker & Duce, 2000). This implies that without planned activity, wellbeing can quickly deteriorate although this only demonstrates that wellbeing was sustained during reminiscence therapy and not necessarily maintained beyond the session.

A Cochrane review assessed the effects of music therapy as a non-pharmacological intervention for dementia (Vink, et al 2010). The review yielded ten randomised controlled trials that reported on clinically relevant outcomes to the treatment of behavioural, social, cognitive and emotional problems of people with dementia. The reviewed studies were concerned with people at varying levels of dementia, living

either in the community or residential care homes. All ten studies in the review reported music therapy as a beneficial treatment for dementia. However, conclusions from the review indicate that all ten studies had methodological limitations, poor reporting of results and inadequate statistical analysis which questions the validity of any reported benefits.

Sixsmith & Gibson (2006) undertook qualitative research to explore the meaning and importance of music in the everyday lives of people with dementia. In-depth interviews were conducted with 26 participants and their carers who resided either at home or in residential care. Unsurprisingly, participants living at home and those residing in residential care differed, with the former being more engaged, which may reflect the level of cognitive impairment. Analysis of the interviews indicates that those residing at home had problems accessing resources enabling them to engage with music. Nevertheless, the authors conclude that music could enable enjoyable participation and *'it is an important source of social cohesion and social contact.....and provides a degree of empowerment and control over their everyday situations'* (Sixsmith & Gibson 2006 p. 127).

A caregiver-administered music therapy programme was evaluated involving fourteen people with dementia and their family caregiver in their own homes (Hanser, Butterfield-Whitcomb, Kawata, & Collins, 2011). The intervention was designed to reduce stress and enhance the care giving role whilst offering the person with dementia opportunities to improve mood and psychological state (Hanser et al. 2011). It was reported that caregivers received the most benefit when compared with the person with dementia although caregiver satisfaction did not increase over the course of the intervention.

Woods et al. (2009) undertook a Cochrane review to determine the efficacy of reminiscence therapy for dementia. Only four randomised controlled trials were included in the review, three of which were carried out in residential care settings involving people with moderate to severe dementia. The one trial that addressed reminiscence with people living in the community was based on 11 participants and relied heavily on the proxy accounts from caregivers in regard to the individuals functioning (Thorgrimsen 2002, cited in Woods et al. 2009). The authors propose that the available trials for review were of relatively low quality mainly due to a lack of methodological consistency across studies. Based on this limited evidence a multicentre randomised control trial was undertaken to explore the effectiveness of joint

REMiniscence groups involving the person with dementia and their informal CAREgivers (REMCARE) compared with usual care (Woods et al., 2012). The intervention involved 350 dyads living in the community consisting of 12 consecutive weekly reminiscence groups followed by monthly maintenance sessions for a further 7 months. Dyads in the control group received usual care which varied depending upon the eight research centres. The results indicate no difference in quality of life outcome measures for the person with dementia although carers allocated to the intervention group reported significant increases in levels of anxiety compared to the control group. The conclusion drawn suggests the trial does not provide support for the effectiveness of joint reminiscence groups involving people with dementia and their informal carers (Woods et al., 2012).

Gardening has been considered to have therapeutic advantages in the promotion of general wellbeing, quality of life, increasing physical and cognitive ability as well as socialisation in health older adults (Wang & MacMillan, 2013). A structured gardening programme involving 12 participants with early onset dementia, aged under 65 years was found to have positive effects on well-being and therapeutic effects on self-esteem and confidence whilst recognising the physical constraints such activities may involve (Hewitt et al. 2013). No other articles were located involving adults over 65 years suggesting accessibility challenges to existing groups of older adults with dementia living in their own homes.

3.2.5 Discussion

The evidence that exists concerning people living with dementia and activities enjoyed during leisure time is limited. Almost a third of the research activity identified in this review remains dedicated to the possible ways that leisure may be delivered as a therapeutic intervention, including music, reminiscence and gardening. The Cochrane Reviews examining music therapy (Vink, et al 2011) and reminiscence therapy (Woods et al., 2009) both raised methodological concerns regarding the design and reporting of results in the limited number of existing randomised controlled trials identified rendering any positive effects as questionable. Furthermore, the multicentre randomised controlled trial of joint reminiscence groups could not provide support for such interventions when measuring quality of life or health related outcomes for the person with dementia or informal carers (Woods et al., 2012). Only one article was located that explored gardening as a therapeutic intervention for people with early-onset dementia

under the age of 65. Research on therapeutic modalities place more emphasis on the treatment of 'symptoms' of dementia rather than the 'lived experiences' of dementia. This review aimed to identify studies on the former but in addition found limited evidence for the effectiveness of the latter.

It is also clear that the research evidence is dominated by small scale qualitative studies. Qualitative studies that utilise small sample sizes can be critiqued thus limiting their empirical depth and detail of findings. Although, findings from a systematic review of art-based interventions considered methodological issues weaken the findings rather than small sample sizes (Young et al., 2015). For example, in their qualitative study exploring the impact of social recreation groups, Phinney & Moody (2011) utilised a convenience sample of participants that were not based on the inclusion or exclusion criteria of the study. The intention was to explore perceptions of leisure activity from the perspectives of people living with a recent diagnosis of the condition but ultimately recruited participants who had progressed beyond this and who were unable to verbally communicate their opinions. Small scale qualitative research is essential for exploring the experiences and perspectives of the individual but requires a strong methodological approach that is both appropriate and effective in doing so.

Not all qualitative research relies on small sample sizes and the study undertaken by Menne, et al (2012) recruited 267 participants to explore the leisure activities currently enjoyed by people living with dementia. The strengths of this study lie in the longitudinal design as well as highlighting the similarities with previous studies undertaken with healthy adults. The authors suggest that the preferences for social and leisure activities reported by people with dementia were consistent to those reported in the Baltimore Longitudinal Study of Aging undertaken with healthy older adults (Verbrugge et al. 1996). It is possible then that the leisure activities enjoyed by older adults do not necessarily change because of a diagnosis of dementia. Thus, the longitudinal design enabled an understanding of activities currently enjoyed by asking the person directly what they enjoy yet also acknowledges the progression of the disease as preferences, needs and capacities may alter over time.

In contrast, other studies conclude that a diagnosis of dementia does change the choice and access to certain leisure activities as constraints and constrictions, both individual and societal, increase as the condition progresses (Cassolato et al., 2010). Whereas others report that it is little to do with the specific activity and more to do with increasing opportunities to socially interact with others (Rosenberg, Parsa, Humble &

McGee, 2009; Zeilig et al., 2014). It is also argued that people with dementia have difficulty communicating their desired preference of leisure activity yet they remain interested in that activity if initiated by others (Cook et al., 2008). Yet supporting and maintaining these activities may also be time consuming requiring the carers imagination and creativity alongside having to continue with necessary routine caring tasks (Nygård, 2004). Thus, the evidence is contradictory and differences in preference or desire for specific activities varied considerably depending on the individual, the context and the possible support that was available.

Further contradictions were highlighted in the literature concerning the extent that a diagnosis of dementia had on the perceptions of significant 'others' regarding enjoyable activities and how these may have altered. It is suggested that 'others' reactions to the diagnosis has contributed to the person with dementia feeling undervalued and isolated (Sorensen et al., 2008). The research team carried out qualitative interviews involving participants already recruited to large randomised control trial that were considered to be particularly resourceful in their participation. Although resourceful participants could be considered to strengthen the validity of the findings it can also be limiting as these perspectives are isolated and are not necessarily reflective of all people with dementia. DAISY was the largest Randomised Controlled Trial (RCT) of psychosocial interventions involving the person with dementia and the family carer. Nevertheless, a three year follow-up of DAISY found no positive long term benefits from participation in the intervention (Phung et al., 2013).

Similarly, participants perspectives of 'others' reactions to their diagnosis was explored using qualitative interviews and found that social responses fail to take account of the persons own awareness of their condition resulting in the person feeling marginalised and infantilised (Langdon et al., 2007). The researchers were keen to point out the limitations of this study and stressed that the opinions of those interviewed were only representative of the participants' own observations of others' reactions to them. Yet, in contrast to the studies by Langdon et al., (2007) and Sorensen et al (2008) it has also been reported that receiving a diagnosis has made minimal difference to 'others' perceptions of their loved one or the activities that may be enjoyed (MacRae, 2010). From the perspective of 'others' people with dementia are understood in terms of activities that they can no longer do (Sabat 2001) when those with the diagnosis are more likely to focus on abilities that remain intact (MacRae 2008; Genoe et al 2009). Furthermore, it is possible that not all problems faced by people with dementia are a result of the disease but rather the way 'others' react to the person with the condition.

Sabat (2001) persuasively argues that the reactions of others can significantly influence how the person with dementia experiences their condition. This is important as the reactions of 'others' bestowed status upon the participants in the context of relationships and society as a whole (Kitwood, 1997).

Overall, the existing evidence focussing on enjoyable activity and people with dementia in the community is limited and contradictory. The majority of the larger scale trials focussed on enjoyable activities as therapeutic modalities but were reported by Cochrane reviews as methodologically weak in design and reporting of results as well as limited support for the effectiveness of the interventions. The smaller scale qualitative studies that were non-therapeutic in nature including social groups, volunteering, museums, art and eating out were generally exploratory focussing on the subjective experiences which were expectedly found to be contradictory across the reviewed studies. Although, a common theme occurred across these studies highlighting the importance of maintaining social connectivity within communities that may be enabled by participation with enjoyable leisure activities. The only identified longitudinal study aided understandings of preferred activities that were concluded to be similar to those reported by healthy older adults. Yet categories of leisure activities in the Menne et al (2012) study, and others (Searson et al., 2008) were predefined by the researchers using rating scales and participant responses were recorded to fit the 'most likely' category for the majority. The conclusions from this review indicate that ongoing assumptions remain suggesting that people with dementia are homogenous thus diversity in activity preference can be side-lined. It is considered that multiple differences exist between how people with dementia experience enjoyable activity and what is actually meaningful to the individual.

3.3 Dementia and technology use

3.3.1 Search methods

The same search method was adopted as described previously (see 3.2.1) although additional search terms were required to incorporate the technology focus of this review.

Table 3.3: Search terms

Dementia or Alzheimer’s disease (AD)	NOT pharmacological or drug trials or clinical evaluation/assessment or neuroimaging or mild cognitive impairment (MCI) or memory loss
Living in the community or community dwelling or living at home or living in own home or residing at home.	NOT residential care/accommodation, care homes, interventions for carers, day care, respite care, assisted living.
Information and Communication Technology (ICT) or touch screen technology or iPad or computing of Human Computer Interaction (HCI) or hand-held or tablet	NOT Telehealth or Telecare or Assistive Technology
Social and leisure activity or meaningful activity or meaningful interactions or social interactions or enjoyable activity or achievements or leisure and recreation or free time or fun.	NOT housework or activities of daily living (ADL) or instrumental activities of daily living (IADL) or employment or paid jobs or cognitive training or cognitive rehabilitation.

3.3.2 Definitions of the key constructs within the review

Information and Communication Technologies (ICT) describe computer-based communication devices and applications that provide a workspace, communication and entertainment platform including e-mail, the internet, chat rooms and discussion groups, internet and telephone based support groups, videoconferencing, Skype, blogging and online gaming.

Touch-screen technology describes a computer display screen that is also an input device. The screens are sensitive to pressure and a user interacts with the computer by touching pictures or words on the screen.

3.3.3 Search outcome

As this is a scoping review there were few exclusion criteria thus the search pertained to;

1. All health care disciplines
2. All countries
3. All available years
4. All published, unpublished and on-going studies

Due to available time and resources only papers printed in English were included. Advice was sought to identify databases that were most likely to contain relevant

studies. Literature searching took place between the 15th and the 31st May 2012 and was updated again between 25th and 29th August 2014 and again between 20th and 23rd June 2015. Despite the extensive search terms, the initial search identified a total of 856 potentially relevant articles. Of these articles, 806 were immediately excluded based on title and abstract leaving 50 articles that were potentially relevant. All 50 remaining articles were read in full and the further exclusions were applied.

People with dementia have been increasingly exposed to technologies to assist and enable in a number of life domains (Davies et al. 2009; Nygard 2008; Topo 2008). Although many benefits of technology have been identified in the review, the following were excluded as the interventions did not involve enjoyable activities. The facilitation of independence and autonomy for the person and their carer including GPS tracking and safer walking (Algase, 2003; Miskelly, 2004; Shoal et al. 2008; Robinson et al. 2009); technologies that may enable Instrumental /Activities of Daily Living (Orpwood et al. 2007; Meiland et al., 2014; Mountain, 2012; Nygard, 2008; Rosenberg & Nygard, 2011); to increase aspects of safety and security (Algase, 2003; Robinson, 2009; Shoal et al. 2008), technologies that provide cognitive stimulation and rehabilitation (Tárraga et al., 2006; Galante, Venturini, & Fiaccadori, 2007; Woods, Aguirre, Ae, & Orrell, 2012), technologies to enhance memory function and the recall of information (Hodges et al. 2011; Mulvenna, et al. 2010; Nygard, 2008) and to support shared decision making (Vernooij-dassen & Eefsting, 2014). Equally, interventions have been applied to benefit and reassure the carer by facilitating access to information and support websites via telephone and the internet (Beauchamp, et al. 2005, Smyth, et al. 2007, Chiu et al. 2009) also to benefit the dyad with access to information websites concerning available assistive technologies (Burrow & Brooks, 2012). Further exclusions were applied including articles that focused on residential care settings (Orpwood et al. 2009; McCallum, 2012; Sixsmith, Gibson, Hill, Orpwood, & Torrington, 2007; Waterworth, 2006; Astell, 2004; Cohene, Baecker, Marziali, & Mindy, 2005; Goodwin, 2012; Lazar, Demiris, & Thompson, 2015; Upton, Brooker, & Grove, 2011).

A conscious decision was made to **not** exclude two further articles that initially may have appeared to fall into the above criteria. First, an article by Sarne-Fleischmann & Tractinsky, (2008) was included despite the focus on multimedia technology to support memory function using reminiscence material. This is because the content of the system was personalised to the individual and although designed as a therapeutic intervention, it was also found to be a pleasurable and entertaining activity applied to people living at home. An article describing a similar multimedia intervention (Astell,

2004) has been excluded as the focus was on participation within residential care settings. Second, the article by (Karlsson, Axelsson, Zingmark, & Sävenstedt, 2011) has also **not** been excluded despite the focus on Activities of Daily Living (ADL) as oppose to enjoyable activities. This is because the intervention can be described as 'holistic' in order to account for the psychological, social and medical aspects of dementia. One domain of the intervention was to support social contact which is often perceived as a central component of leisure activity (Auld & Case cited in Leung & Lee 2005).

After exclusions (n = 32), 18 articles were considered to meet the inclusion criteria and are described in this review. The characteristics of each study have been charted and can be viewed in table 3.4 below.

Figure 3.2: search outcome

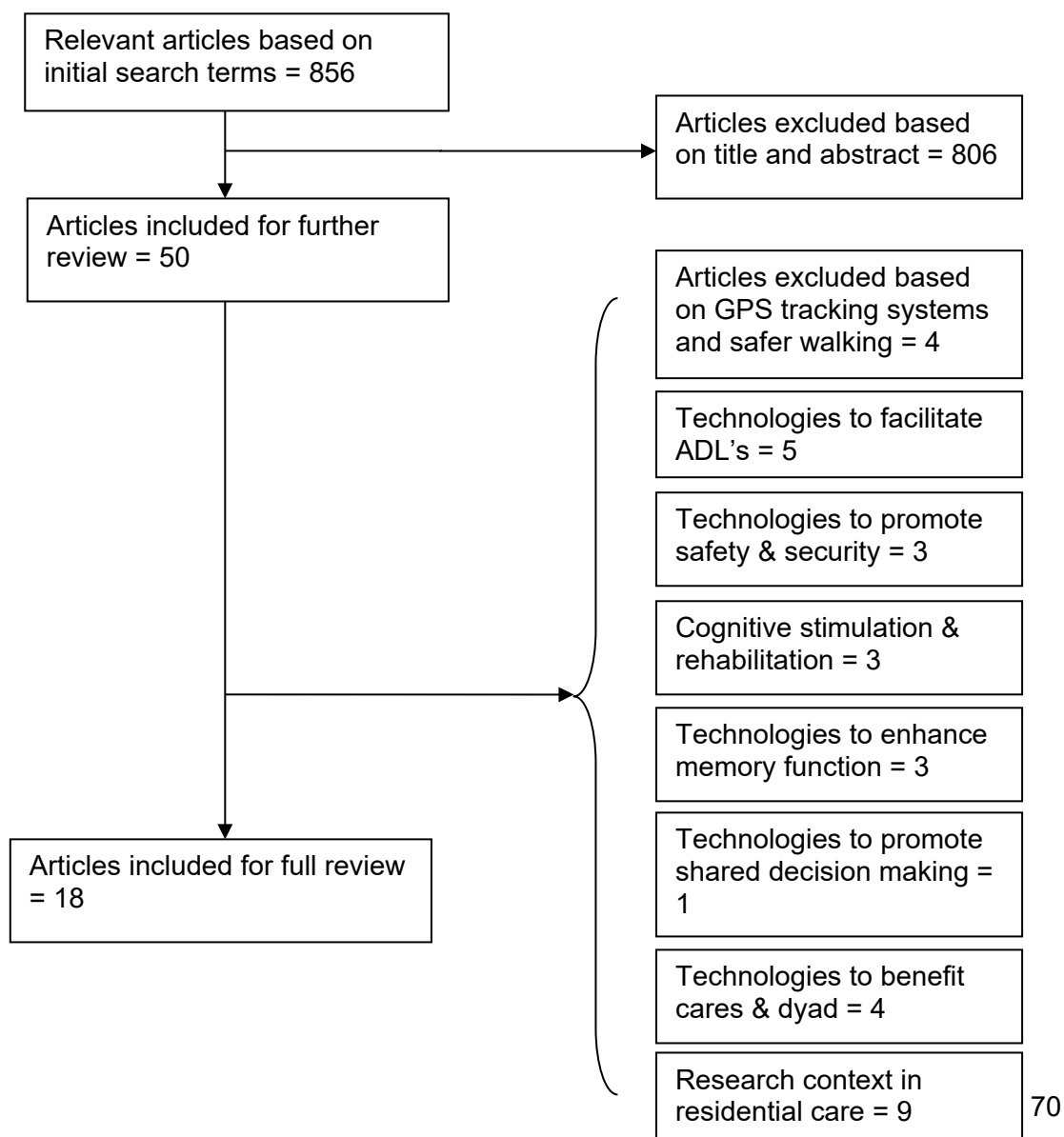


Table 3.4: Charting the data – review 2 – dementia and technology use

Author	Research Aim	Context	Participants	Method	Dementia	Main Findings
Askedal (2011) Norway	Reminiscence game using touch-screen	Day Care	5	Observations	All	Usability issues observed
BRAID (2012) Europe	Enabling environments	Both	0	Stakeholders & ICT experts surveyed	All	Technology can facilitate social & leisure activity
Brooks et al (2012) UK	Mylife supports independence	Community	2	Rating scales & questionnaires	Mild	Still in evaluation stage
Burrows & Brooks (2012) UK	Atdementia web based info for AT	All	0	Stakeholders survey	All	69% found site useful & 44% had obtained AT
Clare et al. (2008) UK	Impact of social identity on dementia	Community	7	Interviews via email	Mild	Change through collective strength
Cutler, Hicks & Innes, (2014) UK	Technology Club	Community and Assisted Living	2 x groups	Field notes, discussion and evaluation forms	All	People with Dementia can engage with technologies
Damianakis et al (2010) Canada	Multimedia biographies	Community	12 family members	Video recorded observations and interviews	MCI and AD	Multimedia biographies aid reminiscence
Hoey et al. (2010) Canada	Art therapy using touch-screen	Art group	71	Interviews with art therapists	No Dementia	Evaluation suggests appropriate for user group
Karlsson et al. (2011) Sweden	COGKNOW intervention	Community	2	Participant observations and interviews	Mild	Individuals rarely used the device

Author	Research Aim	Context	Participants	Method	Dementia	Main Findings
Kikhia (2011) Sweden	Digital reminiscence	Community	10	Unclear	Mild	Intervention can increase perceived QOL
Leng et al (2014) Australia	Comparison of iPad apps with traditional activities	Day care	6	Dementia Care Mapping (DCM)	Not specified	Greater variation of behaviours in technology activities
Magnusson & Hanson 2012 Sweden	ACTION project to support caregivers	Community	350	Focus groups	Caregivers only	Successful and mainstreamed in Sweden
Mitseva (2010) Denmark, Greece, Italy, UK	ISISEMED to support independence	Community	31 across 4 sites	Rating scales and questionnaires	Mild	Can have positive impact if technology accepted in to the home
Riley et al (2009) UK	Musical creativity	Day care	15	Observations	Not specified	Creating music is an enjoyable activity
Sarne-Fleischmann & Tractinsky (2008) Israel	Multimedia system for reminiscence	Day care	5	Observations and interview	Mild to moderate	Clear preference for personal content
Van Rijn et al (2010) Netherlands	Chitchatters game	Day care	12	Participant observation	Mild to moderate	Technological support for reminiscence
Van den Heuvel (2012) UK	Barriers of technology use	Alzheimer's society	0	Questionnaires	Family carers only	Leisure activities not well supported my AT
Van der Wardt et al (2012) UK	The use of ICT to sustain engagement	none	0	Literature Review	Not applicable	Some improvement in wellbeing, depression, cognition when using ICT

3.3.4 Synthesis of findings from review 2

A plethora of literature concerning people with dementia and technologies exists yet the evidence focussed specifically on enjoyable leisure activity was found to be limited. There is a clear divide in the literature between technologies that have been specifically designed for people with dementia or carers and existing 'off the shelf' technologies. The review comprises evidence focused on multimedia technologies and ICT's developed specifically for the person with dementia, technological interventions developed for carers only and existing technologies to promote enjoyable activity. Section 3.3.5 discusses the findings from review 2.

Multimedia technologies specifically developed for people living with dementia

Multimedia technology refers to a range of media including pictures, music, film and video generally presented on information and communication technology. Some interventions that utilise multimedia technologies have been specifically designed for people dementia and these studies will be described next.

In the evaluation of an interactive tool to promote musical creativity in people with dementia, Riley et al. (2009) carried out a pilot study with 10 people with mild to moderate levels of dementia. The technology has been categorised as 'leisure technology' and is a continuation of the CIRCA (Computer Interactive Reminiscence and Conversation Aid) (Alm et al., 2007) system that may provide new activities or new ways to participate in activities or hobbies previously enjoyed. Data collected from observations suggests that people with mild dementia are as capable as healthy older adults in their abilities to engage with the system. The researchers propose that this group may retain their creative abilities in spite of dementia and may even be able to create new abilities. It was concluded that the system was usable for people with dementia to actively create music at home, in day care centres or residential settings (Riley et al., 2009). These findings are supported by other studies using multimedia for leisure purposes including reminiscence (Alm et al., 2009, Astell et al., 2010; Mäki et al., 2004). Reminiscence interventions are biographical but memories are discussed generally in a group context often using multimedia tools including DVD's and CD's or digital representations of mementos from the past.

Sarne-Fleischmann & Tractinsky (2008) developed a multimedia system for reminiscence therapy within a day care centre in Israel with five people experiencing early to moderate levels of dementia. The system was web-based with a flexible interface and a touch screen containing general reminiscence material as well as an option to personalise the intervention. The findings illustrated that both general and personal content evoked memories effectively but there was a clear preference for the personal content. Equally, it was felt that people with dementia were able to navigate the system. However, the researchers did acknowledge that reminiscence could evoke memories that may be detrimental to the person. They conclude that this '*phenomenon seems to be inevitable since these kinds of memories constitute a significant part of the participants life memories and their meaning as it is perceived by them*' (Sarneck-Fleischmann & Tractinsky, 2008).

A technological intervention to support reminiscence was developed in the Netherlands by van Rijn, van Hoof, & Stappers, (2010). Referred to as the Chitchatters Game, the aim was to provide a game for people with dementia attending a day care facility that may stimulate social interaction. The intervention shares similarities with the CIRCA system described above yet uses 'old fashioned looking objects' including a television and wireless that enabled users to interact with technologies that may fit with their skills and abilities using group reminiscence activities. The system was evaluated with 12 people experiencing mild to moderate manifestations of dementia and was considered by the research team to be successful in the support of reminiscence therapy.

A multidisciplinary team of multimedia biographers and social workers interviewed 12 family members of people with dementia or Mild Cognitive Impairment (MCI) living at home (Damianakis, Crete-Nishihata, Smith, Baecker, & Marziali, 2010). The aim was to capture 'patients' life histories in order that biographies could be viewed together and family members would be enabled in the understanding of their loved ones. Yet, the person with dementia was not consulted during the development of their own biographies. Rather, people with dementia were filmed in order to capture responses when viewing the multimedia biographies that had been developed. Follow up interviews at 3 and 6 months were carried out with the family member and 'patient' and conclusions reached suggest such biographies can stimulate reminiscing.

Life story work is closely aligned with reminiscence therapy; both approaches are aimed at improving wellbeing for people living with dementia. Life story work is more person-centred and evidence suggests that creating individual life stories can bring

together the person with dementia and their formal or informal caregivers (McKeown, Clarke, Ingleton, Ryan, & Repper, 2010; Woods et al., 2009). For example, Kikhia, (2011) developed a system for life logging using reminiscence therapy methods with the aim of providing the person with dementia with a visual means for retrieving life experiences. Ten participants with a recent diagnosis of dementia and their caregivers were involved in the evaluation process and conclusions suggest that digital reminiscence systems can increase perceived quality of life for the person.

Technologies developed for the person with dementia using ICT

The growth of research and development in the area of ICT and ageing has illustrated the potential in providing interventions that can enhance quality of life for older people.

Bridging Research in Ageing and Information and Communication Technology

Development (BRAID, 2012) is a European funded project directed at empowering people, especially vulnerable groups, to realise their potential and to age with dignity within an inclusive society. The aim is to create *enabling environments* by 2020 for all citizens across Europe with the emphasis on sustainable ICT solutions whilst addressing existing barriers to usage. By focussing on active and healthy ageing, the project places emphasis on the impact and contribution of ICT in four areas:

independent living, health and care in life, occupation in life and recreation in life.

Recreation in life describes how *'technology can facilitate socialisation and participation of older people in leisure activities.....including: crafts and hobbies, sports and physical activity, entertainment, participation in cultural activities and playing games, family interaction and socialising, travel and leisure, political engagement, spiritual and faith groups, lifelong learning and passing on personal wisdom'* (BRAID, 2012, p.17). This initiative is also illustrative of why inequalities still remain in ICT use. The project alluded to an inclusive *vision*, particularly for those who are most vulnerable; unfortunately there is no reference to any potential benefits for people living with dementia.

COGKNOW (Meiland et al. 2007) was a European Commission supported project utilising a prototype ICT device developed to support people with dementia in four areas; remembering, maintaining social contacts, performing daily life activities (ADL's) and feeling safe (Nugent et al. 2008). It is these areas that Lauriks et al., (2007) identified as the most frequently unmet in people with dementia that reside in the community. The intervention can be described as 'holistic' in order to account for the

psychological, social and medical aspects of dementia. The importance of including both the person with dementia and their informal carer is being increasingly stressed and some have considered the target population as *active collaborators* in the research process (Nugent et al. 2008). The device was evaluated by forty two people with dementia and their caregivers. It was concluded that some success was achieved in the areas of memory, ADL's and social contact but additional research was needed that focussed on safety and security. There was also an observed need to ensure that the technology remained reliable as frequent issues of malfunction with the system arose during field tests. Nevertheless, given that the usability and functionality of the device gained positive feedback from the users, later evaluations observed that the devices were seldom used (Karlsson et al. 2011). It has since been concluded that the acceptance of the device is influenced by the persons self-image and the support received from their informal carer (Karlsson et al., 2011).

An ICT facilitated study reflecting the abilities and participatory nature of people with a diagnosis of dementia was carried out in the UK by Clare et al. (2008). The aim of this qualitative, longitudinal study was to explore the subjective experiences of belonging to a group from a psychological perspective. Seven people with dementia who were active members of the Dementia Advocacy and Support Network International (DASNI, 2000) were interviewed via email. The main aim of DASNI is to empower people to actively participate in their own condition whilst providing encouragement to improve their quality of life by advocating for others (Clare et al. 2008). Analysis of the data collected over 2 years indicated that people considered receiving a diagnosis of dementia to reflect feelings of loss, struggle and uncertainty. Yet, in contrast, participating in DASNI facilitated a 'collective strength' initiating feelings of value, contribution and the realisation that there was a life after diagnosis (Clare et al. 2008). The conclusions drawn propose that people with dementia are slowly rejecting the passive patient role and beginning to engage more with life by challenging social attitudes through self-help and mutual support and ICT can facilitate this (Clare et al. 2008). However, not every person with a diagnosis of dementia is going to have the ability or indeed the desire to participate in an advocacy website. Thus, by the authors own admission, those that do are by definition, exceptional individuals (Clare et al. 2008). The sample population for this study were well educated, high achievers, with an early diagnosis of the condition and relatively young in comparison to others with dementia.

Intelligent System for Independent living and Self-care of seniors with cognitive problems or Mild Dementia (ISISEMD) is a European project to support the independent living of elderly people, in particular those with cognitive impairments or mild dementia (Mitseva et al. 2010). This holistic solution utilises an ICT touch screen interface and is directed at both the person and their carer. The aim is to address issues of safety and security, ADL's, social interaction, object locator and GPS, caregiver burden, communication, memory and QOL. A strength of this project is the acknowledgement of the neglect that people with dementia have received as consumers of technology applications, especially people with mild dementia, living at home with informal care. Seventy one people with suspected dementia or a diagnosis of dementia and their informal carers took part in the evaluation although no statistical differences were found after the intermediate evaluation (six to ten months). It was concluded that the ISISEMD intervention can at least maintain QOL in family caregivers and help alleviate their burden (Mitseva et al., 2012). However, the research team stressed that the main challenge faced by the project was that each individual had specific needs and requirements dependent upon how the condition was progressing and the support the person receives from their family and friends.

Mylife project (Brooks et al. 2012) is a collaboration between researchers from Norway, the United Kingdom and Germany for people with cognitive disabilities. The aim of Mylife is to support time-orientation, sensory awareness, communication and recreational activities via internet based applications presented on existing touch screen technology. Mylife is flexible and can be continually modified and personalised, with support from a caregiver, to suit the users changing needs and requirements and enable independence for the user. The project is on-going and as yet there are no publications and no results available to report.

A recent review of 19 empirical studies investigated the relationship between cognition, well-being and the use of new technologies (van der Wardt et al. 2012). It was found that in order to use new technologies sufficiently the individual requires working memory, spatial abilities, reasoning and processing speed, all of which decrease with age and more so with dementia (van der Wardt et al. 2012). Importantly, the review also discovered that in contrast to the older adults in general, people with dementia illustrated improvements in wellbeing during Internet and computer training programmes. The reviewers noted that lifestyle factors including diet, physical and social activity had not been controlled for in many of the studies, an important oversight

considering that it has been demonstrated that these factors have the potential to significantly influence cognitive function in older adults (van der Wardt et al. 2012).

Technological interventions developed and applied to carers only

It is evident that a proportion of the technological solutions available for dementia have been largely developed to support and decrease the burden of those that provide informal care and not for the individual with dementia. For example, the recent study by McHugh et al. (2012) found that caregivers require more support because they feel socially isolated due to their caring role which in turn contributes to the breakdown of the relationship with the person they are caring for. Marshall therefore argues that *'few of us live without an interdependent relationship, dementia or not, thus anything technology can do to enhance relationships will clearly meet a very fundamental need'* (cited in Topo, 2008 p.3).

Sixteen focus groups were used in order to develop a questionnaire to be administered to carers by the Alzheimer's Society in the UK (van den Heuvel et al. 2012). The questionnaire was developed to understand how accessible technological interventions were for people with dementia and their carers. The informal carers were consulted rather than the people with dementia themselves for two main reasons, firstly *'many of the interventions provide reassurance for carers rather than provide help that would be immediately perceived as beneficial by the dementia sufferer'* and secondly, *'problems with memory and communication are classic symptoms of dementia and these problems could make it difficult for dementia sufferers to accurately report technology use'* (van den Heuvel et al. 2012, p. 141). The carers agreed that the main concern was the safety and security of the person with dementia. It was found that the areas of leisure, entertainment and social interaction were not well assisted by technologies, yet it was considered that these activities were paramount to maintaining quality of life thus new technologies in this area would be welcome. It was also noted by the researchers that the informal carers were all from economically privileged areas thus enabling better access and opportunities to purchase technology if required (van den Heuvel et al. 2012).

Assisting Carers using Telematics Interventions to meet Older people's Needs (ACTION) was an EU-funded project (1997-2000) that illustrated a collaboration between researchers, technicians and practitioners from Sweden who worked with

people in caring roles (Magnusson et al. 2005). The aim was to develop a user friendly computer based information, education and support network for informal carers. Observations of three hundred and fifty users over fourteen years indicated that the person with dementia required on-going support in order to maximise the potential gains of technology, and with adequate support from their carer the person can then benefit positively from interaction with user-friendly ICT (Hanson et al. 2007). The benefits included the empowering effects of contributing to the research process and the increased interaction with grandchildren that the newly acquired knowledge of ICT had brought the person with dementia. Other benefits reported increased wellbeing for the carers inducing feelings of control, enriching the caring situation. ACTION is currently running as a mainstream service in one municipality of Sweden as well as implementation projects in an additional 25 municipalities across Sweden (Magnusson & Hanson, 2012).

Some have realised the potential of *developing* ICT's and multimedia technologies to enable the person with dementia and their carer to participate with various activities. However, the following studies have recognised the possibilities that existing Information and Communication Technologies may hold in facilitating social and leisure activity.

Existing 'off the shelf' technologies appropriated for the purpose of enjoyable activity

Recent advances in mobile computing have enjoyed an explosion in popularity. Touch screen devices such as iPhones, iPads and tablets in general have become a familiar addition to the day-to-day lives of many in the population, providing a workspace and entertainment platform that offers a huge array of personalisable applications together in one convenient unit (Pedersen, 2010). The popularity of such devices has extended to the context of work and educational environments. Touch screen tablets in particular are increasingly encouraged in health care settings holding the potential to speed up the access to healthcare thus increasing patient satisfaction and reducing waiting times as well as medical errors (Age UK, 2008). Examples of touch screen computing in health care settings include the EU-funded MIRROR project which aims to capture information at the time of care on mobile touch screen devices in residential care homes (Karlsen-Pitts et al. 2011).

Touch screen interfaces are increasingly utilised to assist in the usability of technology for older adults as they require direct input, have large button targets and eradicate the need for a monitor, mouse and keyboard (Jin et al. 2007). Further, Miura (2010, cited in Alpeyev & Eki, 2011) stresses that the iPad is a good tool for older adults as unlike traditional computers it does not require prior knowledge and is very forgiving of mistakes. Even though this population have been traditionally considered as less knowledgeable and thus less comfortable when introduced to new technologies, the Department of Health, (2011) has emphasised that older adults are not 'technophobes'. However, Newell (2008) argues that differences exist between mainstream technology and assistive technology thus those that infer universal usability are not being realistic.

A study from Norway developed a prototype reminiscence game compatible with the Samsung Galaxy tablet PC (Askedal, 2011). Five people with dementia were observed using the tablet and interviewed on their experience. Results showed that just over 52% of the questions on the reminiscence game were answered independently of carers and play became more independent as the game progressed. It was concluded that individual differences were apparent in the usability of the technology as not all of the users were able to navigate it successfully without help (Askedal, 2011). The researchers emphasised the user centred design aspect of the project yet the prototype was evaluated by software experts and not the intended user which does limit the applicability of game.

A Canadian study developed a tool to promote prolonged engagement in art therapy for people with dementia utilising a user-centred design process by means of a survey, focus group and interviews (Hoey et al. 2010). The aim is to promote creative activities via a touch screen interface that enables the user to engage in activities including painting, drawing and collage. The tool is flexible allowing the design and implementation of personalised therapeutic and goal orientated activities for the individual. The tool has yet to be evaluated with people with dementia but rather has been developed in collaboration with a group of creative arts therapists to illicit their views on whether the software would be appropriate for this population.

Commissioned by the local borough council, the Bournemouth University Dementia Institute (BUDI) evaluated two technology clubs, one in a residential care context and the other for community dwellers (Cutler, Hicks, & Innes, 2014). Contemporary touch screen devices were among the gaming technologies to be evaluated and preliminary results were positive. Differences were found between the groups in the ways

participants engaged with the activities and the technologies which the research team suggests could be explained by cultural and environmental factors.

An Australian study utilised Dementia Care Mapping (DCM) as a method to measure wellbeing in the comparison of iPad applications and traditional activities enjoyed by people with dementia (Leng, Yeo, George, & Barr, 2014). The findings from this study were limited as the design involved six participants over a period of only 2 days. Nevertheless, results did indicate that participants achieved a greater sense of wellbeing using iPad applications compared to traditional activities including cooking and crafts.

3.3.5 Discussion

Technology can take many forms and plays an important role in the lives of many people with dementia allowing for the continuous adaptation to changing circumstances, but it is not always the solution. This review has highlighted the popularity in applying technological solutions to people with dementia yet limited evidence exists regarding enjoyable leisure activity specifically, rather the focus remains on the ways technology may deliver therapeutic modalities including reminiscence, music and art for this population. The multimedia technologies (Damianakis et al., 2010; Riley et al., 2009; Sarne-Fleischmann & Tractinsky, 2008; van Rijn et al., 2010) have been developed specifically for people with dementia in the engagement of therapeutic activities including music and reminiscence. These are commonly applied in group settings with quite generic multimedia content thus applicable to all tastes. Multimedia technologies promoting life story work are more person-centred requiring the person with dementia to work with the researcher in the creation of multimedia biographies (Kikhia, 2011) but studies exploring this are limited. The majority of these studies are evaluating prototypes of intended technologies and are small scale and exploratory in nature thus pursuing the feasibility of larger scale studies in the future.

In contrast to the smaller scale evaluations of prototypes are the large European funded projects that have developed technologies for people with dementia using Information and Communication Technologies (Brooks et al., 2012; Karlsson et al., 2011; Magnusson & Hanson, 2012; Mitseva et al., 2010). The focus here is to develop a technological intervention that is more holistic and can meet the needs of the person

and the family carer in a variety of areas including Activities of Daily Living (ADL), social interaction, safety and security as well as supporting memory function, but again there is limited attention to activities that may be enjoyable.

Technologies that are designed specifically for people with dementia can sometimes fail to translate well in practice. There is a continued focus on developing new interventions, when only a small proportion of which get developed and mainstreamed in practice (Mountain, 2012). For example, only two of the systems in this review that were specifically developed for people with dementia have gone on to be mainstreamed (Alm et al., 2009; Magnusson & Hanson, 2012). Some technologies and applications have been developed with little, if any, input from the intended user group (Hoey et al., 2010; van den Heuvel, Jowitt & McIntyre, 2012; van Rijn et al., 2010) and design decisions have been made on behalf of people with dementia leading to inappropriate devices or applications that can be stigmatising resulting in limited uptake. It may be that eliciting the perspectives of people with dementia is more of a research challenge thus the probability is high that this population will have inappropriate technology thrust upon them (Dickinson & Gregor, 2006). For example, the Chitchatters game (van Rijn et al., 2010) was developed to disguise contemporary ICT into a simplified, recognisable and familiar form that may be in line with the persons decreasing cognitive abilities. The activities were passive and required limited input by the person with dementia other than sitting and listening or watching. In addition, the content of the system was assumed to be applicable to all people's histories and experiences. This a clear example of the tendency in dementia research to homogenise people's experiences, that is to regard them as all the same (Bartlett & O' Connor, 2007). Thus, if one person has difficulties navigating cotemporary ICT it is assumed that the whole population of people with dementia will have the same difficulty. Equally, if one person fails to feel stigmatised and marginalised by some of the developed technologies then ethically it is acceptable to proceed this way.

There have been recent political initiatives to decrease the digital divide and as described in some instances older adults have benefited from increased ICT usage. It could be that those who have benefited are high-functioning, physically able research volunteers who display a positive attitude towards ageing and ICT (Clare et al., 2008). This is not representative of older adults in general and certainly not all people living with dementia. Equally, an influencing factor in technology participation may be the personalisable design that enables the unique characteristics of the individual to be

reflected in the technology, as illustrated in the study undertaken by Sarne-Fleischmann & Tractinsky (2008).

The use of digital technologies is increasing in contemporary society from the workplace to schools, from supermarkets to train stations. In fact some go as far to say that *'almost every site of sociality in contemporary society includes interactive objects and technologies'* (Heath, Hindmarsh and Luff, 2010 p.93). In addition, older adults are the fastest growing group of internet users (Ofcom, 2012). Some argue that the issues surrounding the use of technology by people with dementia can range from memory decline to a lack of confidence and technical problems to a lack of support (Mitseva et al. 2010). Yet, understanding remains limited regarding the use of ICT by people with dementia and some suggest it is inadequate knowledge rather than fear of utilising new technologies (Nygard & Starkhammar, 2007). This lack of knowledge can act as a barrier and hinder opportunities in gaining access to the products and services that may be of benefit. Additionally, stereotypes linked to dementia drive society's preconceptions regarding the abilities, needs and requirements of this population (Brittain et al. 2010) which in turn become inextricably linked to the forms of technology developed specifically for them (Mountain, 2012). Undoubtedly, contemporary ICT's are not developed with people with dementia in mind and it has been argued that manufacturers and designers of technology fail to consider age-related changes in ability as the cognitive capabilities immediately place this group at a disadvantage (Czaja & Lee, 2006). Yet contemporary ICT's may have the potential to play an important role in common with the general population by providing the flexibility and capacity to allow for the continuous adaption to changing circumstances.

The potential of contemporary ICT's is beginning to be recognised in the dementia literature and there has been an exciting influx of research evidence that has utilised new forms of ICT in order to engage effectively with the person with dementia (Cutler et al., 2014, Leng, Yeo, George, & Barr, 2014;). These studies illustrate the avoidance of technologies that are complex, expensive or inflexible but rather exploit existing technologies that do not require development and that are easily accessible through retailers for the whole population. Utilising existing technologies could help address reliability and usability issues that are highlighted when technologies specifically developed for people with dementia are found to be inflexible or unreliable (Nugent et al., 2008). Equally, designers and manufacturers of technology often fail to acknowledge older adults as active users of technology thus their understanding can be limited regarding dementia specifically and the need for adaptive and flexible

devices (Brittain et al., 2010). Sabat (2001) argues that the stigma associated with dementia is related to the embarrassment, depression and frustration of the person over the cognitive losses coupled with the desire to maintain dignity and positive self-esteem. Thus, if technological interventions do not correspond with the individuals own self-image, if they are too simplistic, for example, they are likely to lose confidence in the device and discontinue use (Karlsson et al., 2011).

Finally, assumptions should not be made that all people with dementia will enjoy computer use. For example, Dickinson & Gregor, (2006) argue that the frequently cited assumption stating that technology holds the potential to change the lives of an ageing population is very misleading, a huge generalisation that can be inappropriately reported. Equally Burrow & Brooks (2012) propose that technologies have the capacity to be both enabling or disabling for people with dementia and it is information and support that is required that allow informed decisions to be made regarding use.

3.4 Conclusions from the two scoping reviews

The four research questions stated at the beginning of this chapter informed the search strategy for the two scoping reviews and the analysis of the subsequent yield. The literature reviews illustrate the extent of evidence and the complex nature of topics concerning dementia, technology use and enjoyable activities. Research gaps (section 3.5 of this chapter) were identified from this analysis which led to the rationale for the two subsequent studies. The nature of the evidence differs between the two reviews although both reviews shared similarities in their focus on reminiscence and music as a therapeutic intervention for the behavioural and psychological symptoms of dementia.

The first review of people with dementia living at home and enjoyable activities revealed inconsistencies in understanding regarding what constitutes activities enjoyed in leisure time and for whom. Some people with dementia report having little desire to continue with activities they enjoyed pre-diagnosis. Others report experiencing no change in activities enjoyed before or after a dementia diagnosis. Ultimately, activities enjoyed in leisure time differ between participants depending upon past and present hobbies and interests as well as the challenges that might directly or indirectly stem from living with a diagnosis of dementia. This review highlights the heterogeneity of people living with a diagnosis of dementia and the ways that the condition is experienced. These differences include the impact of cognitive impairment and how

this influences the person's motivation to socially engage with activities as well as the perceptions of significant 'others'.

The first review of people with dementia and enjoyable activities also highlighted further discrepancy in that those seeking to research this area can make different interpretations of enjoyable leisure activities compared with those of the individual. Consequently, some research questions have been asked based on the researchers own interpretation of what constitutes enjoyable activity including reminiscence, music, art, museums and eating out. Thus the research evidence does not always relate to what people with dementia are saying as some report that the opportunity to socially connect outweighs the importance of the actual activity. Thus, the evidence base demonstrated how methodologies that enable choice and the perspectives and opinions of the person living with dementia to be heard remain limited.

The second review on use of technologies for enjoyable activities with people with dementia living at home highlighted how technologies have been appropriated to address issues of safety and security and interventions aimed at therapeutic modalities and research conducted to examine this. Although these aspects remain important a disproportionate focus was found in the literature concerning what people with dementia have reported as important to them, which is something enjoyable to do during the day. Nevertheless, this review also highlights an increasing interest in research topics concerning the use of contemporary technologies that may encourage effective engagement with people with dementia.

The availability of technologies such as touch screen tablet computers is shifting the focus from the development of dementia specific technologies towards a consideration of how these commonly encountered devices might be used. This additional perspective illustrates increasing acknowledgment regarding the heterogeneity of people living with dementia and that 'one size does not fit all' regarding technological interventions. Thus, existing 'off the shelf' technologies are beginning to address some of the identified unmet needs as they are flexible and accessible to the wider population addressing the necessity of personalised interventions based on the individuals current and changing needs and requirements. Although touch-screen computers are designed with cognitively able users in mind the intuitive interface enables those with cognitive impairment to engage with contemporary ICT's thus working towards a positive self-image.

There is evidence to suggest that wellbeing, happiness and life satisfaction for older adults in general is associated with participation with informal social activities that are personally meaningful and valued (Adams, Leibbrandt, & Moon, 2010). Attempts are being made to identify how people with dementia may enjoy their leisure time through the continued participation in meaningful and enjoyable activity. This is coupled with an emergence of interest, due to the digital era, in understanding how technologies may facilitate such activity, specifically newer forms of Information and Communication Technology (ICT). Differences exist regarding the interpretations of what constitutes enjoyable social and leisure activity and some studies are quick to decide that activity can be an effective intervention without actually exploring which activities may be meaningful for the person. Consequently, the research evidence does not always correspond to what people with dementia are saying.

There is also evidence to suggest that participation in social and leisure activity, especially those activities facilitated by technology, may be indicative of available and consistent support. This illustrates a positive scenario but not one that is representative of all people living with dementia in the community. Also, the positive reflections and maintenance of wellbeing and self-esteem could be the result of those who have remained engaged socially, mentally and digitally throughout the life course. Positive interactions with technology could also reflect those who enjoyed an economically and educationally advantaged lifestyle allowing for rich and varied experiences, past and present.

Limited evidence suggests that people may engage in social and leisure activity for leisure's sake, just because it is enjoyed or gives them something meaningful to do to fill time and alleviate boredom. The idea that so many people living with dementia in their own homes are struggling to find something enjoyable to do suggests that urgent support is needed for this group to maintain participation with enjoyable activities. Particular focus needs to emphasise how contemporary technologies may address these needs. Abilities that remain intact need to be sustained and acknowledged over those that have been lost whilst recognising an understanding of the individual differences that arise within and between people with dementia. Some have acknowledged the need to personalise interventions to meet the needs and requirements of the individual although it is concluded that understanding in this area remains limited, although it is changing.

3.5 Identifying research gaps

Despite the research that has already taken place there remains significant gaps in the evidence base, the knowledge base and the use of technology in the provision of care in relation to dementia (Department of Health, 2011). These gaps have been identified by undertaking the two reviews described and discussed in sections 3.2 and 3.3 of this chapter and are as follows:-

Enjoyable activities - Daily activities that are meaningful to the person are considered to be one of the most frequently identified unmet needs for people living with dementia (Miranda-Castillo, Woods, & Orrell, 2013; Smits, Lange, Droes, Meiland, Vernooij-Dassen & Pot, 2007; van der Roest et al., 2009) specifically, social and leisure activity for those living at home (Wherton & Monk, 2008). Rather, the existing evidence emphasises the losses and deficits associated with condition as well as aspects of safety and security to keep people at home for longer. As important as these aspects are, it is considered that a sense of wellbeing depends on more than feeling safe and secure. Events and activities to look forward to are of equal importance, whether enjoyed in the persons own home or out and about in the community. There is a definite need for an increase in research toward activities that make life worth living.

Research setting - Bias exists regarding the contexts within which the majority of research has taken place (Topo, 2008). Long-term residential care has provided opportunities for researchers to recruit large quantities of people with dementia and their formal caregivers. This is a concern as it is estimated that 64% of people with dementia live at home with informal care (Alzheimer's Society, 2011). The evidence that has focused on community dwellers has tended to favour how technology may enhance the safety and security aspects of care to reassure carers and delay residential care admittance rather than enjoyable activity. If the majority of research remains focussed on residential settings it will render those with a recent diagnosis of the condition who reside in the community neglected. Therefore questions need raising that focus on people living in the community and how they would like to spend their leisure time. This is important given that post diagnosis of the condition people can be very able in the participation of enjoyable activities and achievements that make life worth living (Phinney & Moody, 2011).

Personalised focus on strengths - Existing technology development has addressed the declining cognition that characterises dementia as well as those memories that

have been compromised (Tárraga et al., 2006; Waterworth & Waterworth, 2006). However, an additional focus is required that questions how the person with dementia may benefit from ICT usage in common with the rest of the population and if this can translate in to enjoyable social activity. The intact abilities of the person, what they enjoy and what is done well should be the focus rather than the consistent attention to deficits and this might be achieved through enjoyable ICT based activities. Research is needed to address how the person's hobbies and activities may have altered since receiving a diagnosis and if personalised ICT could positively impact these changes.

3.6 Research aim, objectives and questions

The aim of the research is to explore the potential of existing 'off the shelf' touch screen computer technology in facilitating enjoyable activities with people with dementia, living at home. The research aim is examined through the following objectives:-

1. To identify how people with dementia living in the community currently engage with enjoyable activities.
2. To identify how technology may be appropriated to enable leisure activity with people with dementia.
3. To introduce touch-screen technology to people living with dementia in a creative manner and observe their interactions.
4. To identify and understand the challenges and potential opportunities presented in the use of technology with people living with dementia.

The research objectives gave rise to the following questions to be considered through the programme of research.

Reviewing the literature – chapter 3

What evidence exists concerning people living with dementia and activities enjoyed during leisure time?

To what extent has a diagnosis of dementia altered 'others' perceptions of activities that may be pursued now and in the future?

How is technology currently being appropriated for the purpose of promoting enjoyable activity by people with dementia?

What forms of enjoyable activity can be experienced through technology?

Study 1 – A group setting – chapter 5

How is the technology received by members of a day care centre?

Does the technology enable interaction through enjoyable activities, if so in what ways?

Does familiarity with the technology increase over time, if so in what way?

Study 2 – A one-to-one setting – chapter 6

What factors shape engagement and interaction with the technology?

Does the device present observable challenges and possible gains for the person with dementia and/or their supporter? If so what are they?

Does technology use involve new knowledge and retained learning and if so, in what ways?

Chapter 4: Methodology

4.1 Introduction

This chapter describes the methodological approach of the current research. The philosophical underpinnings of qualitative research are described in section 4.2. Following this, section 4.3 details the methodology unique to this project and is described as a focused, visual ethnography. Section 4.4 highlights the ethical considerations involved when taking a visual ethnographic approach, specifically in dementia research. It will be highlighted throughout this chapter, the importance of being explicit when reporting on methodology, including the use of appropriate methods to answer the research questions, the rationale for using these methods as well as the ethical concerns involved when researching with human participants.

4.2 Epistemology, ontology and qualitative research

The nature and design of the current project required explicit explanations regarding the philosophical underpinnings and methodological decisions that were made. Morgan states that there is a need to *'devote equal attention to studying both the connection between methodology and epistemology and the connection between methodology and methods.....furthermore, we need to use our study of methodology to connect issues in epistemology with issues in research design, rather than separating our thoughts about the nature of knowledge from our efforts to produce it'* (2007 p. 68). It was important to define the relationship between philosophy and methodology for the purposes of this thesis. This is because a tension exists between what Patton (2002) describes as the 'paradigm approach' versus 'methodological appropriateness'. For example, the philosophical underpinnings of a research project can be disregarded and researchers can choose to utilise the same methods irrespective of the questions that need answering. In contrast, the propensity exists to overemphasise theory at the expense of quality research and often the theoretical choices bear little resemblance to the topic under investigation. This chapter will define the philosophical standpoint of the researcher in the relationship with and development of this novel methodology.

4.2.1 Epistemology and ontology

For centuries philosophers including Locke (1690), Hume (1739), Popper (1959) and Kuhn (1970) cited in (Packer, 2012) have debated how best to understand the social

world. Philosophical thinking was historically referred to as 'logical reasoning' and some of these basic concepts of philosophy still influence contemporary social science research, including epistemology and ontology.

Epistemology considers the nature of knowledge, what counts as valid knowledge and how it can be gained. Ontology addresses the nature of the social world, what it consists of, what units it is made up of and how they may relate to each other. Epistemological and ontological assumptions provide explanations of how researchers understand the social world. Researchers have varying beliefs and practices that influence the kind of knowledge they seek and how the evidence collected may be understood. These shared beliefs and practices will influence which paradigm the researcher feels comfortable working within as well as the methodology chosen or developed for the research and the questions to be addressed. In reality, few researchers embark on such a 'top down' approach with epistemological concerns as the starting point to research but certainly a clear understanding of the philosophical underpinnings of a paradigm will add methodological clarity to any project.

Methodology describes the philosophy of reasoning or the particular framework within which research takes place. Justification of a chosen methodology adds credence and plausibility to a piece of research thus influencing the degree to which the findings are accepted, and by whom (Ritchie & Lewis, 2003). Ultimately, different researchers will make use of methodologies in different ways for different projects.

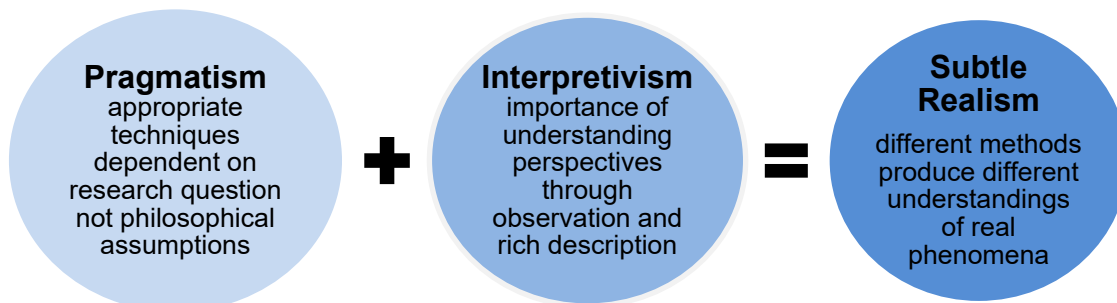
4.2.2 Interpretivism, pragmatism and subtle realism

In broad terms there are two main epistemological stances that a researcher may adopt. Positivism holds that the social world is independent of and unaffected by the researcher and would utilise quantitative methods of deduction to measure relationships of cause and effect. Interpretivism, as an alternative, considers the researcher and the social world to impact on each other utilising qualitative methods that are inductive in order to 'understand' the social world rather than 'explain' it. From within these epistemological stances, researchers would have an ontological view that may vary from '*an external reality exists independent of belief or understanding*' (Realism) to '*reality is only knowable through socially constructed meanings*' (Idealism) (Snape & Spencer cited in Ritchie & Lewis, 2003 p. 16). Other perspectives are situated somewhere between these polarised positions that recognise the need to draw

on a range of resources during the research process. Such epistemological stances are referred to as 'Pragmatic' and take the ontological view referred to as 'subtle realism'. Ritchie & Lewis argue that *'the social world does exist independently of individual subjective understanding, but that it is only accessible to us via the respondents' interpretations, which may then be further interpreted by the researcher'* (2003 p.19). The underpinnings of subtle realism are apparent in organisations that have both long histories of undertaking quantitative research and more recently, qualitative research in an applied policy context, Health Services Research for example.

Not all researchers would acknowledge subscribing to any given paradigm but for the purposes of this thesis, the understanding, at least of certain philosophical assumptions, will contribute to a more comprehensive piece of research. If the researcher makes transparent their philosophical standpoint in the methodologies they adopt, their perspective should then be obvious and consistently reflected in the research questions, research methods, data and reporting. The research reported in this thesis was undertaken from a pragmatic epistemological stance and ontological considerations adopted a subtle realist approach. This is because the researcher's perspective is situated within an applied health context and the phenomenon under investigation is 'real', existing independently of the persons' representations of it, yet understandings are only accessible through individual meanings of diverse experiences' (Hammersley, 1992).

Figure 4.1: Epistemology & Ontology



4.2.3 Qualitative Research

Based on the assumption that knowledge is highly contingent on context, history, culture and experience, qualitative research seeks to produce idiographic accounts by teasing out the particular meanings that people give significance to in particular situations. Interpretation is central to qualitative research and knowledge is gained by asking questions like 'what does it do'? 'How can it be used – by whom, and to what ends'? 'Whose interest does it serve'? 'What does it make possible'? Of paramount importance to qualitative research is the researchers' own ability to be reflexive, to interrogate their own assumptions enabling a justifiable critique when undertaking qualitative research. Therefore, this thesis will be populated by reflexive accounts of the researchers' own experiences, thoughts and feelings.

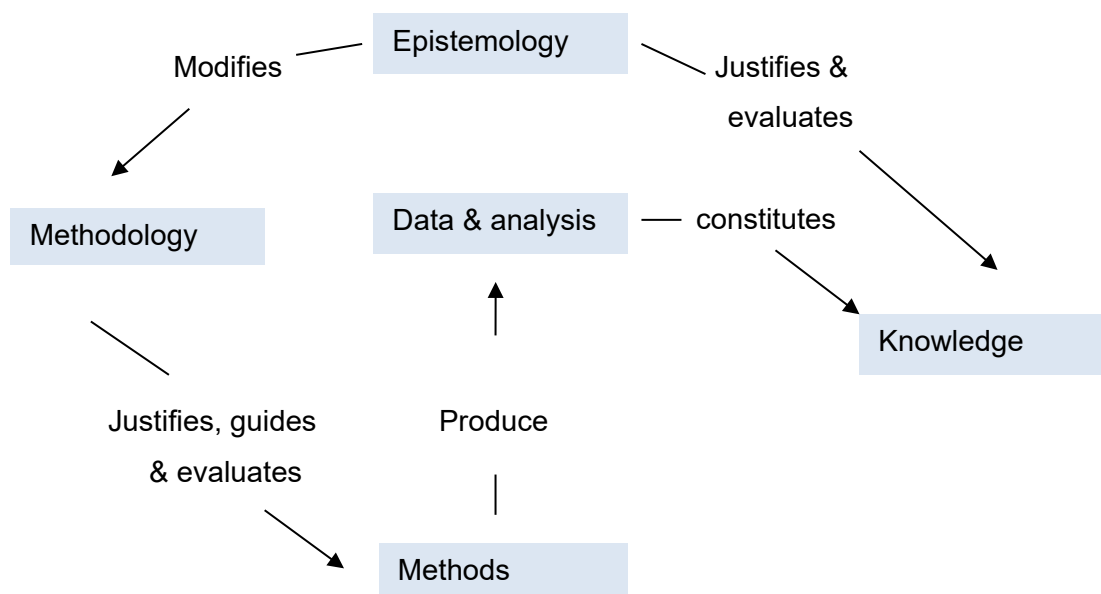
Qualitative research methods describe specific techniques that are utilised in order to gather data relating to the world. When choosing which research methods to use the crucial question that any researcher should ask themselves is '*what is the nature of the information that I need my research to provide*' (Ritchie & Lewis, 2003 p.34)? Research methods are therefore required to be appropriate in order to answer the research questions posed. Thus, qualitative research is characterised by an array of interpretative methods used as tools to understand the phenomena under investigation in a multitude of ways. These include introspection, interviews, observations and case studies. Equally, the data collected differs dramatically dependent on method and can include talk and texts, experiences, unconscious processes, conscious behaviours and social interactions. Data collected is interpreted differently and enables unique insights into the same phenomena being explored yet carried out in imaginative and innovative ways. Although, the knowledge that is gained should be understood as situated and context specific as well as dynamic and changeable rather than static and uniform or applied to all people all of the time.

Qualitative research is appropriate when the phenomenon under investigation is characterised by certain features. These include topics that are not well understood, that are highly emotive, sensitive and deeply embedded in personal experience, interaction and practice as well as the social processes of the participants. The complex and diverse nature of experiences that constitute the condition of dementia requires a strong methodological approach that is theoretically rigorous producing meaningful explanations. Thus, creative and imaginative qualitative research was

required that may promote interactions whilst overcoming possible communication differences in this population.

For the purposes of this thesis, the relationship between epistemology, methodology and method is illustrated diagrammatically in figure 4.2 which states '*methodology justifies method, which produces data and analysis. Knowledge is created from data and analysis. Epistemology modifies methodology and justifies the knowledge produced*' (Carter & Little, 2007, p. 1317).

Figure 4.2: A model for qualitative research adapted from (Carter & Little, 2007)



4.3 A focused, visual ethnography

This project is rooted in the context of applied Health Services Research yet draws on existing concepts and theoretical thinking from additional disciplines including sociology and psychology. This multidisciplinary approach is therefore influenced by theoretical concepts that are interpretative in nature '*and*' pragmatically applicable to real life contexts. Most importantly however, is that this methodology has been adapted and developed specifically to meet the aims of this project. In the context of Health Services Research, the majority of qualitative methods available to researchers have relied on the coherent articulation of users' experiences and views of health; these include interviews and focus groups. The skills required for communicating through writing,

reading and speaking can be compromised in certain groups, older adults with a diagnosis of dementia for example. This increasing population constitute a large proportion of health and social care costs yet they are probably least likely to be consulted regarding their health requirements (Luengo-Fernandez, Leal, and Gray, 2010). Qualitative research methods need to be adopted that consider the spoken word but do not necessarily rely on it as the only form of communication. Non-verbal behaviours are of equal importance when researching with people with dementia thus the development of novel, stimulating and creative research methods are required that can contribute to existing knowledge and increase our understandings of the person and the condition. The methodology adopted in this project was a focused visual ethnography and the following sections provide links between the epistemology, methodology and approaches to data collection and analysis that are pertinent and justified.

4.3.1 Ethnography

Ethnography appears to have many definitions dependent upon the discipline within which it is being utilised and the research questions to be addressed. For the purposes of this study, ethnography was appropriated as an overarching research strategy that could provide in-depth descriptions of everyday action and interaction within a given context. Although the ethnographer will approach a research topic with anticipated issues to investigate, ultimately the approach is an exploratory one (Hammersley & Atkinson, 2007). Key distinctions exist that illustrate why taking an ethnographic approach was appropriate and valuable to this study. Ethnography incorporates a collection of methods or a particular way of doing research that involves researcher participation with the study participants within the context that they are going about their everyday lives rather than under conditions created by the researcher. This may be talking, laughing, questioning or just watching what is going on.

Fieldwork in ethnographic research is epitomised by participant observation that can be described as either covert or overt. Covert participant observation requires the researcher to become a member of the community without the participants' knowledge. Conversely, overt participant observation requires participants to be fully aware of whom and why the researcher is there. There are challenges to both approaches and certainly covert participation observation was rejected for the purposes of this study as unethical and deceitful. Although, it should be acknowledged that there is a risk when

undertaking overt observations that the participants may alter their behaviour if they are aware of the researcher. Nevertheless, overt participant observations enable the researcher to assume an exploratory role whilst maintaining membership of the group. In this role the researcher can begin to learn and understand the actions and interactions as facilitator and participant. The involvement of the researcher both as participant and facilitator was at the core of this study and also a defining feature of an ethnographic approach. A further key distinction is the focus on small scale studies that will enable in-depth exploration in addition to the importance of acknowledging what the researcher brings to any research context. Reflexive writing can detail the complexities that are illuminated when designing and undertaking ethnographic research and specifically, can heighten awareness of the nature and influence of the researcher on the context and participants. Ethnography is therefore defined as a qualitative research process involving ethnographic methods that produce an ethnographic outcome (Hoey, 2014).

4.3.2 Focused ethnography

A further distinction is helpful here between ethnography and focussed ethnography. Historically, ethnographic research has required complete immersion in a remote research context on the other side of the world for months or years at a time. Although this type of practice may still be the case for some, it is no longer an essential characteristic of ethnographic research. Focused Ethnography is a type of sociological ethnography that is particularly but not exclusively adopted in applied research and describes a methodology that may be considered more short term (Knoblauch & Schnettler, 2012). Focused ethnographies are not new and may possibly have been utilised in many research projects without being particularly labelled as such. This method can be characterised by relatively short-term field visits that are typically compensated by the intensive use of audio-visual technologies for data collection and analysis. Focused ethnography is not in opposition to more conventional ethnographic approaches but rather located within different disciplines including engineering, information sciences and organisation studies. Thus, focused ethnography has been considered to have a more practical purpose and has been applied as such (Knoblauch, 2005). It was considered appropriate to methodologically 'label' this research project as a focused ethnography due to the applied nature of the project in addition to the brief engagement of the researcher in the research settings.

4.3.3 The visual turn

Research is following societal trends in the use of the 'visual' in numerous aspects of life, made possible through technological advances. There is a heightened awareness of the possibilities of the 'visual', specifically in academia, that may be explained by various contributing factors. The increased access to reasonably priced technologies that enable such methods to be utilised; the desire of contemporary social researchers to develop innovative and creative ways to disseminate new knowledge; the differing ways that researchers and participants may use technologies to express themselves, using photo-elicitation for example, and the credible influences of science regarding the ways social phenomena may be visually portrayed to the public. These exciting developments have extended the range of techniques available to researchers for the capture, analysis and reporting of visual data, thus opening up new possibilities within academia.

Gaining access to the various ways people make sense of their everyday situations within particular contexts is ultimately a visual endeavour in this project, enabling a deeper understanding of the phenomena being studied. In this sense, visual methods represent a 'window' that provides access to the participants expressed meanings and experiences in ways that traditional audio and field notes may not. Specifically, video-based methods provide a multimodal record through which researchers may systematically explore participants' interactions both verbal and non-verbal. Video-based data collection methods are considered particularly productive when exploring the social organisation and unfolding of interaction coupled with an interest in the multiple modes involved in communication (Jewitt, 2012). Video-based fieldwork has become well established within the social sciences although the collection, analysis and dissemination of visual data in the multidisciplinary field of applied health remain underdeveloped. Nevertheless, video based methods are integral to this project and are utilised during data collection, analysis and dissemination of the research results. This is because *'the flow and pattern of life as it is lived is recorded and retained...to become available for close study and multiple replays....whilst the action can be frozen...and instances separated in time and place easily compared'* (Dant, 2004 p. 41).

4.3.4 Visual ethnography

Combining ethnographic and visual research methods evolved primarily in reaction to the challenges and issues surrounding the representation, interpretation and dissemination of knowledge with the ascent of the digital revolution (Pink, 2001, 2004, 2012). The intention was to unite an ethnographic interest in everyday cultures, life and practices by representing them visually proposing a visual ethnographic methodology. Although visual ethnography remains attentive to 'text' as part of ethnographic practice, it is the notion that culture, life and practices can be 'read' rather than sensed that is challenged (Pink, 2012). Visual ethnography was appropriate for the purposes of this study for a number of reasons but ultimately, this approach permitted the researcher to participate in the event and facilitate engagement with the technology itself without the interference of explicit data collection using field notes. It is vital that we listen to the 'voices' of people with dementia, that they are included in the research process and that the benefits, if any, of their participation can be faithfully represented. Therefore, visual ethnography enabled an inclusive approach to be adopted including and consulting people with dementia whilst recognising the impairments associated with the condition.

A further important factor when taking a visual ethnographic approach is the impact that the condition of dementia can have on verbal communication rendering conventional research methods including audio taped interviews less appropriate or effective. Communicative challenges can have a significant impact on obtaining insight, through verbal reporting, as to an individual's subjective experience. As such, attending to non-verbal communicative behaviour including gestures, body language, facial expression and posture become paramount as non-verbal behaviour cannot be effectively captured using audio recorders or field notes (Rose, 2012). Despite this, attention to non-verbal behaviour remains limited in dementia research. This is a concern and there is a need to acknowledge the significance of non-verbal behaviour as equally important to the spoken word in order to faithfully represent the individual in this particular research context. Visual ethnography is key to this representation as meaning is amplified and supported by visual representation as well as written text.

4.3.5 Visual ethnographic techniques for collecting data

Data collection methods for this study are video-based participant observations in order to unite the researcher and researched through mutual participation in a given context (Pink, 2012). Visual ethnographic techniques for collecting data, specifically the researcher as a 'participating observer' is appropriate because the researcher becomes immersed in the place and with the people and their behaviour rather than being separated from it. For the purposes of this study, these techniques provide access to socially meaningful experiences that may otherwise be difficult to articulate. For example, non-verbal communication will include facial expression, direction of gaze, hand gestures and posture, all or which may provide the researcher with important insights regarding participant experience. Not only does this method form the foundations of ethnographic fieldwork, it is also well established and effective in overcoming communication issues that can be encountered when researching in the field of dementia (Nygård, 2006). Participant observations enable a deeper understanding of the social context and when video recorded, result in rich data that may act as representations providing insight to the ways participants express their own meanings and experiences of the research. Utilising video recorders specifically, can enhance the process of data collection (Margolis and Pauwels, 2011) as these methods allow the researcher to systematically document the behaviours, verbal and non-verbal, of all participants. It was considered that photographic methods producing still images would not allow discreet data collection or enable the researchers' active participation and facilitation and as such would not be appropriate in this case.

Ritchie & Lewis (2003) describe observational data as the 'enactment' of social behaviour rather than the 'recounting' of experience from interviews. Furthermore, Bond & Corner (2001) argue that to focus solely on participants meanings from qualitative interviews has substantial shortcomings as they act only as representations of reality. Focussing on practices through observation was considered essential for this project in collecting complex data that may not be easily articulated by the participant. Thus, video participant observation can be considered a method in its own right that documents the actual 'doing' of activities rather than 'saying', as they are played out in the social context (Pink, 2001). This method can capture data that *'provides a sense of the self and the other that is not easily put into words'* (DeWalt and DeWalt, 2011 p.10), thus an appropriate and effective technique for collecting data in dementia research.

4.3.6 Visual ethnographic techniques for analysing data

The data on its own does not constitute knowledge but rather the approach to data analysis was considered to be a key factor in the conversion of data into new knowledge. Visual ethnographic techniques enable comprehensive data for analysis as the recordings may be repeatedly micro-analysed and subjected to detailed exploration of the phenomenon. This is important as the opportunity to reflect, re-evaluate or even re-live a certain piece of footage is enabled through repeated examination of the video footage. Nevertheless, before embarking on data analysis, an increased understanding was required concerning appropriate techniques that may disentangle the intricacies and complexities from the volume of data collected. To inform analysis it was necessary to return to the literature to review the existing evidence and understand how other visual researchers had accomplished this task.

The findings of the review highlight that published articles reporting primary research including working with images, and the process of collecting, analysing and describing results were noticeable in their absence. Over half of the reviewed studies failed to mention data analysis or were elusive regarding how they used the data to identify the results. Those that did identify specific techniques also contributed to an ongoing debate within visual research regarding appropriate ways to analyse data. Some propose an across-discipline unified methodological framework to analyse visual data and others suggest unique techniques should be developed specifically for certain projects. For example, an 'image-based research methodology' reflects the use of a wide range of visuals including film, video, photographs and cartoons, within a qualitative research context. Image-based research can also involve a wide range of disciplines including sociology, anthropology, education and health studies (Prosser, 1998 p. 25). Furthermore, Pauwels, (2010) proposes an 'Integrated Framework for Visual Social Research' that provides a comprehensive step by step progression to account for the design, implementation and dissemination of research. This framework proposes a methodological approach to visual research that remains discipline specific to visual sociology and visual anthropology. Undeniably, integrated frameworks are required to address certain research questions and it has been argued that without them visual methods can be reinvented over and over again without gaining any 'methodological depth' (Pauwels, 2010). Nevertheless, discipline specific frameworks do not translate sufficiently across disciplines thus failing to account for the multiplicity of research questions that may be addressed using visual methods.

Others suggest that visual research methodologies proposing problematically prescriptive frameworks merely succeed in distancing, objectifying and generalising visual data (Pink, 2001). It is considered that this then comes at the expense of the potential expressivity that is characterised by qualitative research and specifically qualitative visual research. Thus, rather than prescribe a 'how to do visual research' manual, specific methods should be creatively developed within individual projects (Pink 2001 p.4). A clear example is Interpretative Engagement (Drew and Guillemin, 2014) which is a framework for conceptualising the meaning making of visual images that are produced in a research context. The key here is to illustrate that meaning is dependent upon more than just the researcher, but rather the individual/s in the image, the context and those that view the image.

This ongoing debate suggests a dichotomy of extremes as some propose data analysis techniques that may transcend disciplines and others suggest techniques should be unique to the project and discrete from each other, although a continuum of visual analytical methods is a better description. Researchers have situated their research somewhere along this continuum and devised their own 'ad-hoc' solutions to data analysis and reporting that was therefore unique to their project. Some techniques were developed for specific projects and others were adapted from existing methods to address different research questions. The review illustrated that the most commonly described technique used for analysing video-based data was to transcribe talk and action into text. However, for the purposes of this study it was considered that the transcription of rich video into text would be an unsuccessful translation of the data and negatively impact the multifaceted significance of the participant's experience, thereby losing meaning. It was concluded that the analytical technique should be uniquely tailored to the data which in turn would be influenced by differences in the participants, the context, the researcher, the methods and the materials.

4.3.7 Multimodality

The technique of data analysis for this study was influenced by the methodological framework referred to as 'multimodal interactional analysis' (Norris, 2004).

'Multimodality' characterises research data that is not primarily words or numbers. Modes may be audible, visual or contextual but in any social situation they will definitely be multiple. Multimodality as a technique is appropriate for the purposes of this study as traditionally 'talk' has been considered the prominent meaning making

mode of social interaction and everything non-verbal was relegated to context (Norris, 2004). As non-verbal behaviour can be particularly important as a means of communication by the person with dementia the significance of representing multiple modes comes to the fore during analysis. Although not all people with a diagnosis of dementia are challenged when communicating, differences can emerge in the ways people express themselves as the condition progresses thus, an analytical technique was required that may translate these differences effectively. Further, when supported by additional modes including context and researcher reflexivity, knowledge is gained and understanding increases.

The aim was to develop a data analysis technique for the purposes of this study that may increase understandings and descriptions of the text, the images and the social action taking place. The challenge was to decide how the participant's behaviour, in particular the non-verbal dimension, can be represented in the analysis in a way that could do the data justice and without losing meaning. It was decided therefore to incorporate salient images taken from the video data that could describe the gradual unfolding of a specific event that is characterised by multiple modes and when combined with text, transcripts become more meaningful. It was important to represent the data in a way that enabled the audience to connect through a sense of 'being there or being with' the researcher (Jewitt, 2012).

Incorporating images from the video footage alongside transcripts is significant and relevant allowing reinforced meaning and vital insight to the verbal and non-verbal behaviours that would be otherwise dependent on field notes and audio alone. Images may record, reveal, elicit, illustrate, demonstrate or evoke meaning in a far more subtle way than purely text thus transforming the way transcripts may be understood (Felstead, Jewson, & Walters, 2001). An example of a multimodal transcript can be seen in transcript 4.1.


Multimodal transcription required a series of choices that would influence and shape the data analysis in significant ways. Decisions had to be reached concerning what was represented and what was not, and which modes or episodes of social interaction were to be included in the analytic process. *'Such reconstructions are inevitable and essential outcomes of any video analysis, and it is through reconfiguring video data that researchers and their audiences can see the observed interaction in the categories appropriate to their discipline(s) and position themselves in relation to that discipline(s)'* (Bezemer & Mavers, 2011, P.203). This is important as there is ongoing debate

regarding the validity of video data and how it can be characterised depending upon a variation in researcher perspective. These perspectives are: '*video produces a replica of events; video distorts reality; or video is a reflexive research tool*' (Jewitt, 2012 p 9).

Acknowledging the impact of the researcher and the video equipment is an important consideration as the presence of both may be considered to influence the research participants as well as the context. Nevertheless, there is little empirical evidence that video recording research has such reactivity effects (Heath, Hindmarsh & Luff, 2010). The assumption that video data can replicate or distort reality is disregarded by visual ethnographers who focus primarily on how video recordings may be adopted to explore and understand the participants and the research context. In this sense video is utilised as a reflexive tool to preserve data and analysis then enables re-representation from the researchers' perspective so that '*things become visible because of how we see them rather than simply because they are observable*' (Pink, 2006, p 36). Thus, the perspective adopted for this project was to utilise video as a reflexive data collection tool that enabled the analysis of interactions, practices and experiences that were multimodal in nature.

Although the union between multimodality and visual ethnography is novel in dementia research, this combination has been successfully utilised in numerous other qualitative projects including children's learning of new technologies (Dicks, Flewitt, Lancaster, & Pahl, 2011) and an ethnography of corridors in combination with authoring and reading practices (Hurdley & Dicks, 2011).

Transcript 4.1: Example multimodal transcript

Mode 1 – Verbatim transcription	Mode 2 – Description of non-verbal	Mode 3 – Visual representation
<p>Researcher: So this is the strip they wear, this is the manager and this is the logo. Any ideas? Elaine: Oh I know, I know Steven: Sheffield Wednesday!! Elaine: Don't be silly..... Researcher: Ahhh I see why you said that they have the same colour strip don't they? Blue and white Steven: Yes they do Elaine: We watched them last night Steven: Who? Elaine: That.....Come on, who is it...Don't you know? Steven: No Researcher: No....me and you are rubbish at this, Elaine is really good Elaine: Curly C it begins with....Oh you do know it, this is silly Steven: Arsenal?? Researcher: Can you think of another one?.....It begins with C? Steven: Chelsea? Researcher: Brilliant....you got it!!</p>	<p>The researcher gestures to the screen. We wait and look at Steven to see if he is going to have a guess.</p> <p>When Steven guesses incorrectly Elaine laughs Elaine raises her voice and nods her head at the screen.</p> <p>Elaine gives Steven the first letter. Steven proceeds to make another wrong guess. Elaine appears irritated.</p> <p>The researcher and Steven look at each other and smile and Elaine puts her head in her hands and laughs.</p>	

4.4 Ethical considerations when taking a visual ethnographic approach in dementia research

Common misconceptions concerning people with dementias' ability to contribute meaningfully to the research process are increasingly being challenged with many advocating person-centred relationships between research and participants (Dewing, 2002; Harris, 2002; Hellström, Nolan, Nordenfelt, & Lundh, 2007). Although not neglecting the perspectives and opinions of informal carers, clinicians and other professionals working in the field, the importance of first-hand experience from those living with the condition is increasingly being recognised. Promoting public involvement in NHS, public health and social care research is a strategic plan promoted through the Institute for Health Research (NIHR) which states '*public perspectives are integral to the whole research cycle, enriching research and enthusing all those who participate in it*' (NIHR, 2011 p. 2). Dementia does not necessarily hinder the person's ability to report on their subjective experiences (Dupuis et al., 2012), thus an essential prerequisite to ethically sound research requires transparency and a sustained commitment to the research relationship.

Ethical considerations are also heightened when utilising the visual in any research involving human participants as capturing behaviour via video or still cameras could be seen as an intrusion into a person's privacy (Wiles et al., 2008). When certain groups are also considered vulnerable then ethical concerns are elevated to greater levels of importance. Using a visual ethnographic approach can be problematic because recognisable images of the person are produced which make it difficult to guarantee anonymity. Thus issues of confidentiality and anonymity come to the fore requiring sensitive and detailed consent procedures. Any research involving people with dementia also requires heightened sensitivity and close adherence to the guidelines outlined in the The Mental Capacity Act (2005) to ensure each person is treated with dignity and respect.

Regulating the ethical implications involved in social research requires the constant and consistent review of existing and emerging ethical issues. In consequence numerous ethical frameworks have become a popular source of reference for researchers including the ESRC Research Ethics Framework for example (Wiles et al., 2008). As the popularity and incidence of visual methods in particular increases, in accordance with the 'digital age', the corresponding ethical guidelines are becoming more stringent and visually specific. These now include the BSA's Visual Sociology

Group's statement of ethical practice (BSA, 2006) and the International Visual Sociology Association Code of Research Ethics and Guidelines (Papademas, 2009). Given the depth of detail and the possible ethical implications of using the visual in research does this mean that the visual elevates ethics to a new level of importance (Prosser, 2008)? Undoubtedly, concern has been expressed from ethnographers that adhering to rigorous guidelines merely places unnecessary limits upon and detracts from the research project (Murphy & Dingwall, 2007), although this will be dependent on the individual project. Nevertheless, ethically sound research dictates that the methods and processes involved in a project are explicit thus creating comprehensive and transparent results. This in turn should enable increased understanding of the topic under investigation and inform new knowledge. The key ethical considerations for this project are addressed in turn below.

4.4.1 Enhancing communication

Communication with and between people with dementia can be challenging. An ethical way to address any communicative issues is to assume that the person with dementia is similar to all other people in all other respects unless experience suggests otherwise (Killick & Allan, 2001). Techniques to enhance communication are an important consideration when undertaking research with people with dementia. This is because eliciting views, beliefs and experiences can be difficult when short term memory is impaired. Also, the consequences of associated perceptual and sensory difficulties can impair communication. Successful communication with people with dementia is a skill and the work of Killick & Allan (2001) offer some appropriate considerations which have been applied to this project and are detailed below.

Individual differences are apparent across people with or without a diagnosis of dementia. It was considered that if any communication impairments were evident that they would vary greatly between participants and possibly for the same participant at different points in time. Individual differences also require recognition of the varying preferences, capacities and technology capabilities between participants. The aim must be to maintain constant attention and interest despite any communicative challenges, thus empowering the person as an expert of their own condition. In this sense, participants are involved as active collaborators rather than research subjects. It is considered that engaging people with dementia in the research process contributes to the persons self-worth and wellbeing (Sabat, 2003).

Context in general has been considered to have important effects on communication. The aim of this study is to provide each individual with a safe and relaxed environment whereby their participation could be interactive and enjoyable. For study 1 (chapter 5) the day care centre provides the safe and familiar surroundings that may facilitate communication and engagement. For study 2 (chapter 6) participants are provided with a choice of context between a University meeting room and their own home. All participants' in study 2 chose to undertake the research in their own homes which is suggestive of a familiar and safe environment.

Communication challenges may be caused by difficulties in maintaining attention for some people with dementia within certain situations. This can sometimes cause people to lose track of conversations or experience difficulties locating the right word during a conversation. It is essential to never interrupt or finish someone's sentence if gaps in conversation are encountered but rather wait until the word had been located or the conversation changes direction. During studies 1 and 2 the touch-screen computers facilitate enjoyable activity but also act as a supportive prompt if conversation is considered to go off topic or attention wavers. Similarly, the use of 'aid memoirs' can enable prompting if attention is not maintained.

4.4.2 Computer technology

For the purposes of this project it was relevant to address the ethical considerations of introducing computer technology during research with people with dementia. The technology, ethics and dementia guide (Bjorneby, Topo & Holthe, 1999) provides relevant points for consideration and the following points are pertinent.

The technologies utilised are contemporary, popular devices that are used by many in the population on a day-to-day basis (Apple iPad). This ensures that participants are protected from any stigmatising designs or inferences that suggest people with dementia are not capable of interacting with touch-screen computers.

It is essential that participants are assured that the technology does not measure cognition, test memory function or compare one person's abilities with another. The focus is to remain consistently on enjoyable activities and how they may be facilitated by the technology.

The aim of the device is not to replace existing face-to-face social contact. If social contact is facilitated by the technology it will be in addition to the interactions already

shared with the person and their family and friends. Having realistic expectations of the technology was an important consideration. Extra care must be taken to not allude to the prevention or relief of symptoms of dementia but truthfully describe the intervention as potentially enjoyable in the context of leisure and recreation.

The concern regarding exploitation must be considered when introducing individuals who have potentially less knowledge of the internet. Although exploitation was acknowledged and considered a potential issue, technology use was always in the presence of the researcher and the devices did not remain with participants between sessions.

4.4.3 Capacity and consent

The Mental Capacity Act (2005) states that a person must be assumed to have capacity to make informed decisions unless all practical steps to enable that person have been unsuccessful. This Act seeks to empower people when they retain capacity yet protect them if they begin to lose that capacity. Respecting the decisions, dignity, integrity and preferences of persons with dementia relates to the principle of autonomy. Thus obtaining informed consent from people with dementia is an essential part of the principle of autonomy' (Bjorneby, 2004 p.305). The goal was for the person with dementia to provide independent informed and maintained consent with a full understanding of the nature and purpose of the research project and Dewing (2007) offers helpful direction which will be adhered to throughout this research process.

Referred to as the 'process consent model' five key elements are considered for effectively gaining and maintaining consent with people with dementia (Dewing, 2007). **Preparation and background** require the researcher to be transparent with carers (formal and informal), staff and clinicians regarding the recruitment and negotiation of access to the person with dementia. Once gained, an investment in time was required on behalf of the researcher to learn and understand more of the personal histories that may begin the development of effective research relationships. These increased understandings of the person, coupled with the support of those in a caring role can begin to **establish a basis for gaining consent**. Researchers should be skilled in their communication techniques and thoughtful in more practical considerations including accessible consent forms, possibly supported by visual props to aid the process of **initial consent**. Continually assessing the persons' choice to continue with

the research requires **ongoing consent monitoring**. This was achieved through verbal articulation of the participant's ongoing enthusiasm for the research or non-verbally by creating visual prompts to aid recognition. Finally, **feedback and support** was morally essential having built up trusting relationships with people with dementia that will ultimately end (Hellström et al., 2007). The process consent model (Dewing, 2007) was consistently considered throughout this thesis, adherence to which will be explicit in the upcoming chapters detailing study 1 and study 2 of this research.

4.4.4 Confidentiality, anonymity and video recorded data

This study is a visual ethnography thus no alternative method of data collection was offered to participants. Using visual research methods can be problematic because recognisable images of the person are produced which make it difficult to guarantee anonymity. The researcher was clear and reassured participants that the project was concerned with enjoyable activity and touch screen computer technology and images to be used will depict this. The researcher also ensured a commitment to confidentiality by anonymising all transcribed data that was collected using pseudonyms to protect anonymity as far as possible. The information sheets (see appendix II, III & VII) and consent forms (see appendix IV & VIII) were explicit and clearly state that video equipment will be used. In line with the process consent model (Dewing, 2007) participants' were informed before during and after the consent procedure that images from the video recorded sessions will be utilised by the researcher throughout the data analysis stage and subsequent dissemination of the findings to an academic audience. Although using visual methods cannot guarantee anonymity, pseudonyms were used throughout. Providing the person is agreeable to this, has given their consent and is aware of their freedom to withdraw, no ethical concern is established. On completion of the data analysis stage for both studies 1 and 2, the researcher returned to all participants' and those in a supporting role to gain further verbal consent ensuring participants remained happy that their images will be used in the subsequent dissemination of the research. If any participant voiced concern with a particular image the use of alternative images preferred by the individual and those in a supporting role were negotiated.

4.5 Conclusions

This chapter has described visual ethnography as an appropriate methodology in order to explore the possibilities of touch screen computer technology in the promotion of enjoyable activity with people with dementia living in the community. This methodology is required in order to work with people with dementia in an inclusive manner that had rendered existing approaches less suitable. The methodology drew on varying data collection and analytical techniques that were tailored specifically to enhance each participant's involvement in the research. The aim is to utilising various existing techniques in creative ways in order to enhance the meaning as well as doing justice to the richness of visual data. Equally as researchers, we have a responsibility to faithfully represent the complexity of our findings on behalf of those participants who have been committed to the project. In this chapter the importance of methodology has been made explicit, including the use of appropriate methods to answer the research questions, the rationale for using these methods as well as the detailed and sensitive ethical concerns involved when researching with human participants, particularly people living with dementia. The aim was to build on existing knowledge and ultimately enable a more comprehensive methodological grounding in the use of the visual in dementia research.

Chapter 5: Study 1 – Exploring touch-screen computers in a group setting with participants attending a day care facility

5.1 Introduction

Based on the identified gaps in the literature, the aim of study 1 was to focus on enjoyable activities as this has been reported by people with dementia as one of the most frequently unmet needs (Miranda-Castillo et al., 2013). Furthermore, the community day care setting for people living in their own homes was crucial as it is estimated that two thirds of people with dementia live at home (Alzheimer's Society, 2012a). Finally, existing technological interventions have addressed declining cognition and those memories that have been compromised so the focus remained on strengths, maintained skills and activities that were enjoyed and done well. This chapter therefore addresses the following research questions.

How is the technology received by members of a day care centre?

Does the technology enable interaction through enjoyable activities? If so how, for whom and in what circumstances?

Does familiarity with the technology increase over time, if so in what way?

This chapter describes the first of two studies contributing to this thesis and can be described as taking place in a group setting. Following the introduction to the chapter, the methods will be described in section 5.2 and the findings will be presented in section 5.5. The discussion of the findings can be found in section 5.6.

5.1.1 Rationale

The Prime Ministers Challenge on dementia (Department of Health, 2012b) aimed to deliver major improvements in dementia care by 2015 and one area of focus was the creation of dementia friendly communities. Although progress has been made, the PM's challenge has been updated and reports there is still a long way to go (Department of Health, 2015a). Local councils across the country have set up initiatives to implement this policy in order to transform support for people with dementia who live at home. People living with dementia in Sheffield have reported the importance of having supportive groups to involve them in activities that stimulate and enable participation as well as having opportunities to live life as fully as possible (Horner 2013).

Community based day care centres can provide these requirements as well as encouraging wellbeing by providing positive and regular social contact. This is important and the evidence is supportive suggesting that people with dementia who live in their homes but regularly visit a day care centre report having fewer unmet needs when compared with those that do not (Miranda-Castillo, Woods, Galboda, et al., 2010). Although the provision and accessibility of day care centres for people with dementia living in the community vary nationally and regionally, they remain vital in promoting a sense of belonging with others who are experiencing life in similar ways (Hampson, 2009).

Engaging people with dementia in the research process can enhance understandings of the maintained cognitive abilities and the sociality of the person whilst contributing to the persons self-worth and wellbeing (Sabat, 2003a). It is increasingly recognised that providing purpose to the person with dementia may increase feelings of worth and value. This has been achieved by some researchers when they engage people with dementia as active collaborators in the research process (Meiland et al 2007, Sabat, 2001). The suggestion that the participants opinions, thoughts and desires matter and that their participation in the research process will achieve a mutually valued result was an important goal of this research study. Having low expectations of the person with dementia may cause a downward spiral in participation of meaningful activity which in turn could cause further deskilling of the individual and lower expectations (Mountain & Craig, 2012). Study 1 was undertaken in a community based day care centre and one essential aspect was to promote active participation and highlight the importance of each group member's perspective.

5.1.2 Ethics procedure

Study 1 underwent SchARR Research Ethics Review on the 29th October 2012 and the University Chair of Ethics Committee approved the proposal on ethical grounds for the project to proceed on 14th November 2012 (see Appendix I). Ethical considerations are at the height of any research project involving human participants and these concerns are elevated when the participating population are considered as vulnerable. Full and detailed ethical considerations for this project are addressed in the methodology chapter of this thesis (chapter 4).

5.2 Method

5.2.1 Research setting



Darnall Dementia Group (DDG) is a well-established charity organisation that is managed by a registered mental health nurse on secondment from the Sheffield Health and Social Care NHS Foundation Trust (SHSC) and assisted by volunteers and students on nursing and social work placements. The group provides a meeting place three days a week for people with dementia who live at home and have been referred primarily from memory clinics and their names placed on a waiting list until a space becomes available. The waiting list for the day centre is long often resulting in members joining the group in excess of 12 months post-referral. The aims of the group are to provide people with moderate levels of dementia who are living at home in the community with the opportunity to improve wellbeing, develop friendships and maintain existing skills. Attendance also provides carers with respite. Members attend either one or two days a week, supported by a volunteer or staff member on a one-to-one basis within an overall group context.

The group meets in the hall of St Albans Church in Darnall three days a week from 10am until 3pm. Members are collected by the service minibus or brought in by their carers if they prefer. The group accommodates up to ten members per session. Members gather around a large table and are supported primarily on a one-to-one basis by the member of staff or volunteer sitting next to them. All members are at least experiencing moderate levels of cognitive impairment although the capabilities, preferences and participation in activities of each individual are distinct and taken into account. All staff and volunteers are highly aware of the background and inclinations of each member and familiar activities are selected based on the abilities and interests of those attending. New volunteers, including the researcher, are required to familiarise

themselves with details of each group member including background and family history that is recorded when individuals join the group.

Based on observations during the time spent volunteering at the group the researcher considers this group to be welcoming, inclusive and supportive both to the person with the condition and their carer and this is reflected in the atmosphere of the sessions which are informal, interactive and fun. This is a safe environment facilitated by experienced, friendly, knowledgeable staff and committed volunteers who enable group members to be themselves and spend time with friends who are experiencing life in a similar way. This positive environment focuses on the perspectives and experiences of group members thereby encouraging feelings of empowerment, capability and achievement in all activities that are carried out. Maintained strengths are highlighted and members are encouraged to assist in making lunch, peeling the vegetables and setting the table every day that they attend the group. This gives purpose to the day and provides feelings of self-worth to each person in the context of the team at Darnall. It is evident from this group that the research context can impact the quality of participation that the individual experiences. Darnall Dementia Group illustrates the unique way that group members are treated with respect and dignity, without fear of prejudice or intolerance and given the freedom to be themselves. Fulfilling the need for acceptance is one of the most commonly reported requirements in the dementia literature (Lauriks et al., 2007).

5.2.2 Convenience Sample

Researchers have relied on convenience samples when the group of interest already exists or alternatively may be difficult to access. The sample of interest was people experiencing the moderate to later manifestations of dementia living in their own homes. An opportunity was presented to visit Darnall Dementia Group with the aim of gaining an increased understanding of the setting and how the group may fit with the research objectives to be explored. It was concluded that the research would be a good fit for the following reasons; the researcher would be supported effectively by existing staff and volunteers, the research would provide opportunities for group members to try novel activities through their interactions with the technologies and all group members lived at home either with informal support or alone. Having drawn these conclusions, the researcher approached the centre manager with the research idea for her consideration which was met with a high level of enthusiasm.

5.2.3 Selection criteria

The selection criteria were straight forward as the only criterion for participant recruitment was that the person was a member of Darnall Dementia Group. However, this highlighted potential challenges due to the group context and the unique ways that the usual sessions are structured. All group members are supported on a one-to-one basis by staff, students and volunteers who collectively participate in each session by congregating around a large table. There are no opportunities for small group activities as the main aim of the group is to promote friendship and maintain wellbeing in a communal way. Thus if any group member, volunteer, student or staff member declined their involvement then the research could not proceed as members would not have been withdrawn from the context during the research. Equally, had any spouse, family member or informal caregiver declined their loved one's involvement then the research could not have taken place.

5.2.4 Recruitment strategy

Based on the support and extensive experience of the group manager it was considered good ethical practice for the Centre Manager to approach group members and their informal carers at the recruitment stage. This was because the manager had built up relationships based on trust with the members and carers over long periods of time in some cases, which ultimately resulted in the effective recruitment of all group members. Participant and carer information sheets (see appendix II & III) were distributed by the group manager for consideration by potential participants and their informal carers if they had one. Follow-up phone calls by the group manager established that all informal carers were keen for their loved ones to participate. For group members themselves, this agreement was established during a discussion at a regular group session.

5.2.5 Informed Consent

Careful consideration of the 5 elements proposed by the process consent model (Dewing, 2007) was consistent throughout the consent procedure. Preparation for entering the research setting was achieved by volunteering at Darnall Dementia Group prior to the research sessions in order that potential participants, staff, visiting informal

carers and other volunteers may become familiar with the researcher. The researchers' own familiarity with group members was also supplemented by the records of personal histories that enabled some knowledge and understanding of each individual.

Establishing the basis for consent was supported by the clinical manager of the group and information sheets and flyers were distributed before the initial consent took place. Although informal caregivers would not be participating in the research, written consent was sought prior to the research taking place to ensure that they agreed and were happy for their loved ones to be involved. Carer, participant, staff and volunteer consent forms (see appendix IV) also detailed that the sessions would be video recorded and images would be utilised in the dissemination of the findings to an academic audience. Consent was gained for all group members, staff members and volunteers during a usual session at the community group. To aid clarity and provide illustrative information to the initial consent procedure, the technologies were introduced and potential activities demonstrated which enabled participants to make informed choices regarding their participation. It was agreed between the researcher and the group manager that ongoing verbal consent be sought at the beginning of each research session to ensure all participants remained content with their participation. This was achieved through the use of images taken from previous sessions that could illustrate group members' participation with enjoyable activities using the devices. Ongoing verbal consent also enabled a constant awareness of changes in capacity, although it is considered that group members' capacity to continue with the sessions will not diminish over the short duration of the research. Informed consent was gained from everyone involved in the group and all informal carers. No one declined to participate or declined the involvement of the loved ones. On completion of the data analysis stage, the researcher returned to the group with the images intended for the dissemination of the research. This enabled a discussion on the images and verbal consent that all participants' remained happy for their images to be used. If any participant had declined the use of an image, alternative images had been selected for negotiation.

5.2.6 Participants with dementia and those in a supporting role

Twelve participants (table 5.1), nine women and three men, experiencing moderate to later manifestations of dementia provided their informed written consent to take part in the study. All transcribed data uses pseudonyms to protect anonymity as far as possible. Participants were between the ages of seventy and ninety two, living locally within the catchment area of the group enabling community transport for those that required it. Eleven participants had no experience of touch screen computer technology and one participant had used touch screens in his job pre-retirement. It should be noted that since study 1 came to an end, three of the participants have since moved into residential care so no longer attend the group and one lady is now deceased. Nine participants in a supporting role (table 5.2) gave written informed consent including the researcher, paid staff, students and volunteers. The experience of supporting people with dementia was variable from extensive to no experience. Similarly, supporters experience using touch screen computers varied from extensive to none. All the following participant and supporter characteristics have been anonymised as far as possible by using pseudonyms.

Table 5.1: Participant characteristics

Eva	92	Lives alone	Widowed, 4 great-grandchildren, employed at telegraph office as writer of 'telegrams', lives independently, good communication and comprehension, mobility issues. Remains aware of her condition and how it is affecting her life. Diagnosed 4 years.
Shirley	77	Lives alone	Divorcee, supportive family close by. Playful character, factory worker and cleaning jobs. Profoundly deaf and refuses hearing aid. Hearing impairment makes Shirley disengaged at times. Mobility issues, lives independently. Diagnosed 4 years.
Ann	92	Lives alone	Widowed, daughter in Nottingham visits at weekend, 2 sons in New Zealand. Worked in a sweet factory before getting married, lives independently, convinced her mother and husband alive and living with her. Diagnosed 3 years.
Mary	70	At home with son	Widowed, with one son who is disabled. Close to her brother who is her main carer. Recent diagnosis under 12 months ago but deteriorated rapidly, now in full time residential care.
Jessica	89	Lives alone	Never married, no children. Sister is main carer. Worked in steel industry until 65 yrs. old. Lives independently and coping well. Diagnosed around 4 yrs. ago. Now deceased following hospitalisation for a hip injury.
Brenda	78	Lives alone	Widowed, lives independently, very repetitive with certain phrases, symptoms kept quiet by family for a long time. Recent diagnosis under 12 months.
Bob	77	At home with his wife	Married, wife main carer. Used to be a builder and lives in the same house he built. Active, sporty background. Likes to wander from home or from group, diagnosed 2 years ago.
Frank	74	At home with his wife	Married, wife main carer, 2 children and grandchildren, worked in post office until retirement, diagnosed 4 years ago, now quite impaired with communication and comprehension of situations.
Claire	84	Lives alone	Widowed, children live away. Remains aware of the changes that dementia is having which she finds devastating. Diagnosed 3 years ago. Now lives in residential care.
Janet	89	Lives alone	Widowed, husband passed from heart attack 30 yrs. ago. One son visits but lives independently. Diagnosed 2 years, very lonely and group is her lifeline.
Sam	80	Lives alone	Widowed last year, manages well living independently, only just lost driving licence. Has a girlfriend but family not happy accepting. Diagnosed less than 12 months.
Chloe	80	Lives alone	Widowed, daughters visit regularly, manages well although family are pushing for residential care. Diagnosed 3 years.

Table 5.2: Supporter characteristics

Sarah	40's	Researcher, married with 2 children. Psychology background. No experience of supporting people with dementia. Technology experience both work and leisure.
Susan	50's	Clinical group manager for 15 years. Two grown up children. Background in mental health nursing. Extensive dementia experience. No experience of touch screen computers.
Angela	40's	Paid staff for 3 years, married with one young son. Background in social work. 3 years dementia experience. Some touch screen experience from son.
Paul	30's	Paid staff for 2 years, married with 4 children. Initially a volunteer of the group. 3 years dementia experience. No technology experience.
Jane	20's	Student mental health nurse placement for 3 months. Dementia experience through placements. Technology experience using touch screen smart phones.
Craig	40's	Volunteer for past 4 years. Dementia experience from volunteering. Never married, no children. Musical background and no technology experience.
Jean	50's	Volunteer for 6 years, Mother used to be a group member before she passed away. Extensive personal experience of dementia. No technology experience.
Jane	20's	Volunteer, asylum seeker, limited use of English language. No dementia experience and no technology experience.
Tracy	20's	Volunteer, asylum seeker, English as second language. No dementia experience and no technology experience.

5.3 Data collection method

The visual ethnographic technique utilised for data collection was video-based participant observation, full descriptive details of which can be found in chapter 4, section 4.3.5. Data collection was facilitated by the group manager who supported the researcher for the duration of the field work. The researcher attended Darnall Dementia Group as a volunteer, once a week commencing 5th November 2012 to become familiar with the group routine and members as well as providing an opportunity for staff, volunteers and members to become familiar with the researcher. An increased appreciation was required regarding how to stimulate and maintain interest whilst encouraging interaction with the technology before the research sessions commenced. Initially, the researcher's knowledge of group members was supplemented by an existing log of members' information that is available to new volunteers, read in confidence on the premises.

Based on observations of the group during her capacity as a volunteer, the researcher uploaded the touch screen devices with familiar activities already enjoyed by members that appeared to effectively transfer from their traditional form to technology formats. These included dominos, solitaire, photograph albums, reference books and jigsaws. In addition new interactive applications were also uploaded including virtual fish ponds and firework displays and the use of the camera app to enjoy photographs. Some of the applications were chosen because participants were previously observed enjoying these activities in their traditional form i.e. not as a technological application. The keyboard, guitar and drum kit applications were selected because evidence suggests that music can have beneficial, therapeutic effects for people with dementia (Sixsmith & Gibson, 2006). The quantity of applications increased as the researcher became more familiar with the group and individual preferences became apparent. The flexibility of the devices and the plethora of available applications enabled the personalisation of the devices to the voiced preferences of the group. Further, the flexibility of many of the applications enabled levels of difficulty to be adjusted to the person's capabilities. The following applications were utilised during the sessions with the technology.



Drawing box



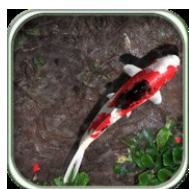
Piano



Jigsaws



Memory Match



Fish Pond



Solitaire



Finger Drums



Solar System



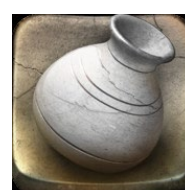
Guitar



Camera



Books



Pottery



Fireworks

At the beginning of each session and prior to group member's arrival the researcher addressed all staff, students and volunteers in a brief training session focussing on the touch screen devices and selected applications. Existing touch screen computer experience was variable as some in a supporting role had extensive experiences utilising such devices on a daily basis whilst others had no experience at all. Although there was some hesitation initially from one or two individuals, overall everyone was positive regarding the new activities and willing to give it a go.

The devices (4 iPads) were placed on the table along with the familiar activities that were usually enjoyed. During initial discussions with the centre manager it was agreed that the best method of introducing the technology would be in small groups of 3 to 4 sitting together yet seated around the communal table. This is the usual way that group members interact with activities and each other thus a familiar part of the group routine. When considered appropriate the iPads were introduced by the researcher, a staff member or a volunteer of the group to members seated in close proximity. The duration

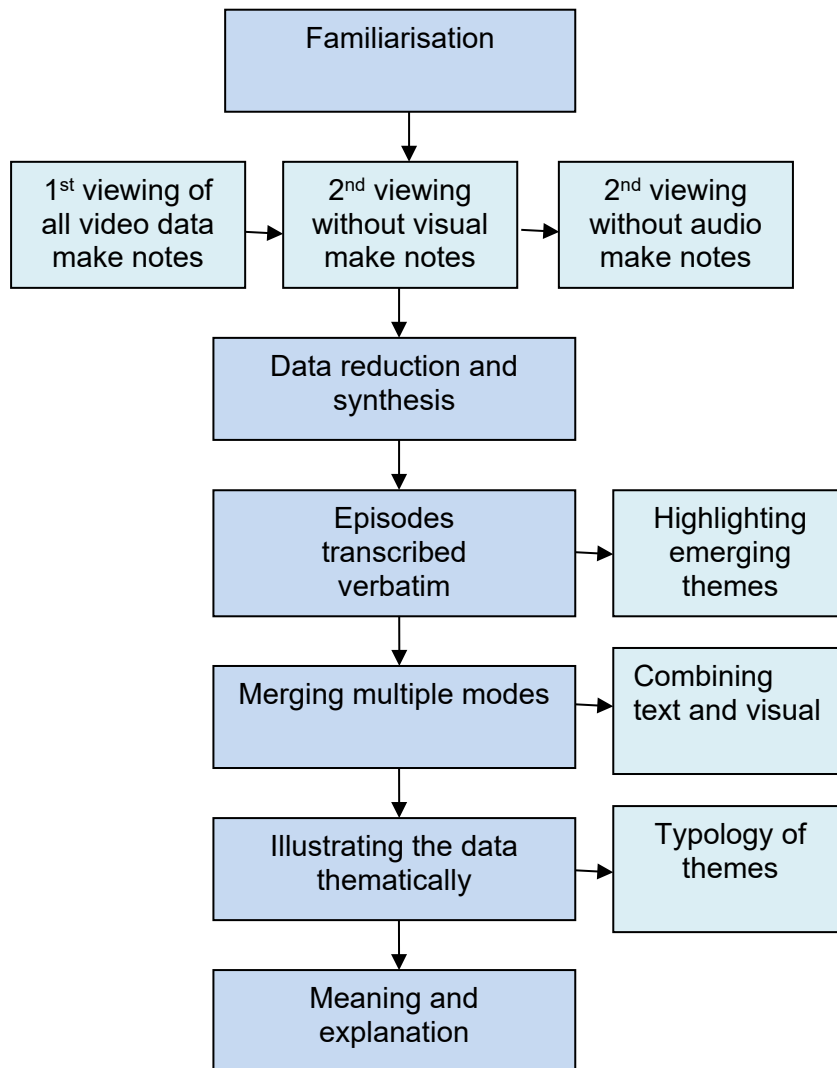
of the research sessions was one hour and always took place before lunchtime. Two discrete video recorders stood on tripods, each positioned at opposite ends of a large table around which the group gathered for each session. Sixteen hours of video footage from two cameras was captured during two, one hour sessions per week over a period of four weeks.

Once group members had departed for the day, the Centre Manager, staff, volunteers and the researcher contributed to a debrief meeting led by the researcher. The debrief provided the opportunity to discuss the session overall and for individuals to express any concerns that had arisen. The debrief sessions did not constitute data for analysis.

5.4 Method of data analysis

Data analysis followed a process of familiarisation, data reduction and synthesis, merging multiple modes, illustrating the data thematically and meaning and explanation all of which are described in turn below.

Figure 5.1: Process of data analysis



5.4.1 Familiarisation

The first step in the process of any qualitative data analysis is a period of familiarisation. For this study it involved familiarisation with the video footage. This initial but thorough review of the data enabled the assessment of the breadth and depth of what had been captured. This assessment highlighted the obvious volume of data but also the complexity of what was going on visually and audibly. The decision was made to undertake a second viewing of the videos with the computer monitor turned off to enable a complete focus on the audible content of the videos rather than the visual content. This proved to be a challenging task as the group setting dictated that the video equipment would record all conversations in range of the microphone which was incorporated into the camera. Nevertheless, during this 2nd viewing notes were made of

audible interactions that were considered by the researcher to be illustrative of possible emerging themes. This process was then repeated with the sound muted on the video recordings in order to attend to all that was visible. It was concluded that viewing videos with no sound heightens what is seen whilst listening to the same video without the visual heightens what is heard.

5.4.2 Data reduction and synthesis

Video based research can lead to overwhelming amounts of rich yet often unmanageable data that can prove complex to manage resulting in overly descriptive and weak analysis (Jewitt, 2012). The notes that were made during the familiarisation stage of analysis illustrated various themes beginning to emerge which consequently enabled the identification of 'episodes' of video data that were selected, synthesised and reduced from the large quantity of data. Reducing the data into episodes, characterised by the themes is appropriate and necessary and enabled the comparison of relevant examples that may identify certain actions and interactions, illustrate similarities, differences and contradictions between and within participants. This required an approach that was able to examine the detailed minutiae of behaviour in the context of an overarching event. Thus, analysis did not focus on the fine detail of behaviour involving every arm movement or blink of an eye. Nor did analysis focus on the whole 60 minutes of each video recorded session. Rather, an active decision was made that could illustrate the emerging themes through episodes that captured significant and meaningful occurrences which consisted of 5-10 minutes of analysed data per hour of video footage.

5.4.3 Episodes highlighting emergent themes

Once the data had been reduced, the episodes that illustrated the emerging themes were transcribed verbatim into charts which created a record of the prominent instances that were identified from the notes made during the familiarisation stage of analysis. Highlighting these prominent instances enabled the gradual emergence of salient themes from the data which are illustrated in the example transcript 5.1. A theme may be described as a thread that runs through the data which are identified as the researcher questions '*What is this about?*' and *thinking interpretively* (Morse, 2008 p 727). The themes that emerged from the data through the various steps in the

process of analysis are illustrated in Figure 5.2 which depicts the typology of themes. Transcript 5.1 is an excerpt of a chart created from one particular session involving Eva, Ann and the researcher in a supporting role.

Transcript 5.1: Highlighting emergent themes


Audible data	Visual data
<p>Eva: I think...for a serious moment...I think the heat from my hairdryer...I think it's that that's made my memory like it is. It might sound daft but I also think that going to the hairdressers every week...I think its effecting my memory...I really do, I know it sounds daft....</p> <p>Researcher: No, it's what you feel.</p> <p>Ann: I think it could be that</p> <p>Eva: Yeah...we didn't realise you know, well you wouldn't would you? I noticed when I went to the hairdressers that they didn't turn it up hot, they kept it quite cool and I wondered, you know, if word had got round and they'd been instructed not to. I'm quite sure in my own mind that it's something to do with that.</p> <p>Eva: So when they ask me what I do next time I come I shan't be able say 'I show people how to knit'.</p> <p>Researcher: No you won't, you'll have to say 'I've been exploring all the different apps in the apple store.</p> <p>Eva: Wait 'till my grandsons come.....err great-grandsons I should say</p> <p>Researcher: I'd be really interested to hear what they say</p> <p>Eva: Who the great-grandson...what about.....?</p> <p>Researcher:you playing on iPads</p>	<p>The camera starts to film and is focussed on two female members of the group, Eva and Ann. The seat between the two members is empty. The pair are seated at a large round table and each have an iPad in front of them. Ann is laughing at something on the screen. Eva is focussed on her screen and navigating around a certain application with her finger. The two members are observed to be interacting independently with the devices. The researcher sits down between Eva and Ann. Ann has stopped interacting with the technology. The researchers' body language shows she has turned away from Ann towards Eva.</p> <p>Ann taps on the table to get the attention of the researcher and Eva. They both look up and all three begin to laugh at something on Ann's device. Eva begins to talk about something she has seen on her screen and the researcher and Ann both listen.</p>

5.4.4 Merging multiple modes

Once each episode had been transcribed verbatim and emergent themes identified, prominent images that could add salient features and increase meaning were then incorporated into the text in order to communicate findings. These multimodal transcriptions incorporating both the visual and the audible illustrated the gradual unfolding of a specific event. The visual image was considered to portray equal meaning to the corresponding text of that image whereas pure 'text' was limiting the meaning of this particular data. The particular images were chosen to draw the attention of the reader, making clear the decisions made thus enabling the reader to

follow the researcher's interpretations. Ultimately, the aim was achieve clarity and transparency in order that the transcripts and interpretations may be accessible to those other than the researcher. The same example given in transcript 5.1 is replicated below in transcript 5.2 to illustrate the merging of multiple modes.

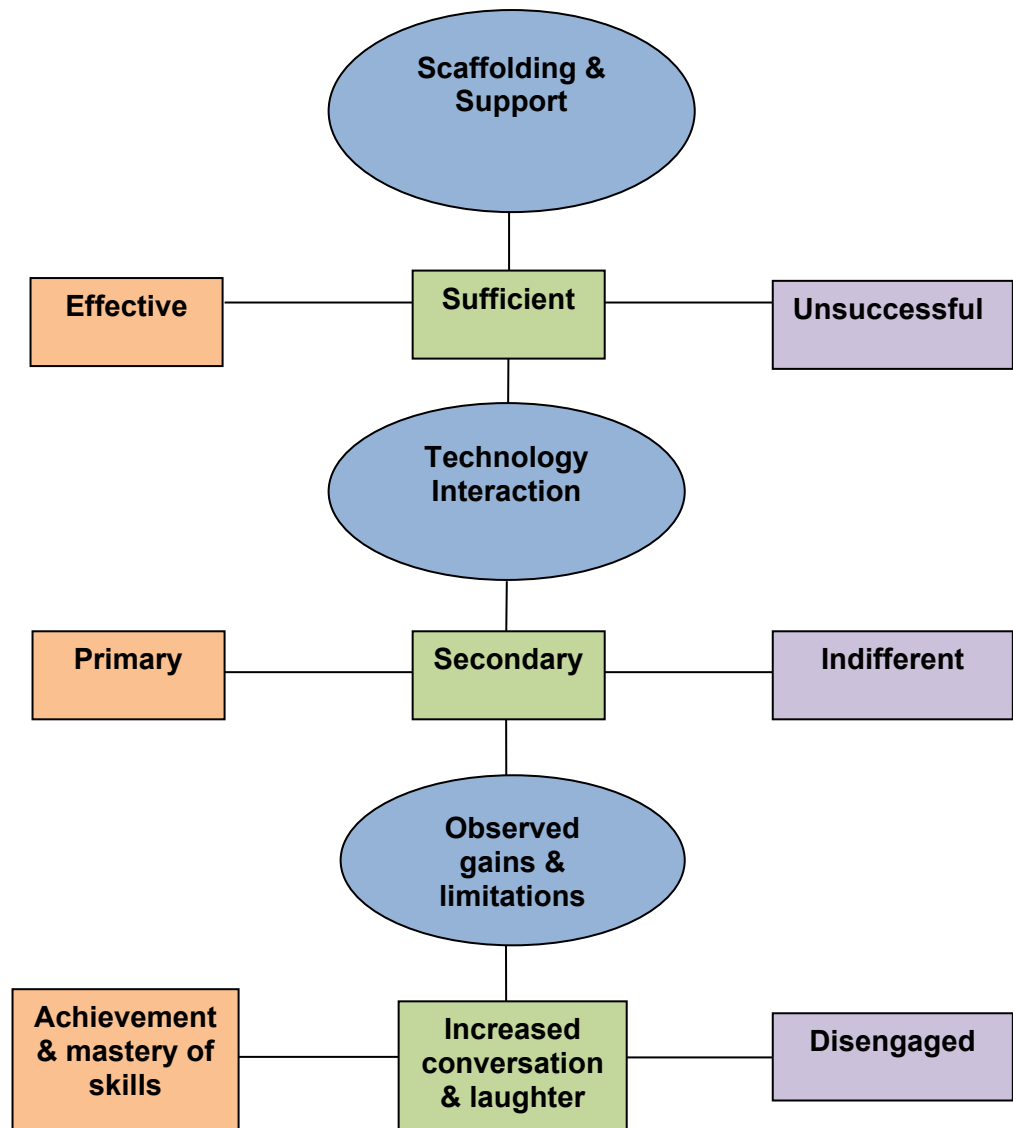
Transcript 5.2: Merging multiple modes

Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Eva: I think...for a serious moment...I think the heat from my hairdryer...I think it's that that's made my memory like it is. It might sound daft but I also think that going to the hairdressers every week...I think its effecting my memory...I really do, I know it sounds daft....</p> <p>Researcher: No, it's what you feel.</p> <p>Ann: I think it could be that</p> <p>Eva: Yeah...we didn't realise you know, well you wouldn't would you? I noticed when I went to the hairdressers that they didn't turn it up hot, they kept it quite cool and I wondered, you know, if word had got round and they'd been instructed not to. I'm quite sure in my own mind that it's something to do with that.</p> <p>Eva: So when they ask me what I do next time I come I shan't be able say 'I show people how to knit'.</p> <p>Researcher: No you won't, you'll have to say 'I've been exploring all the different apps in the apple store.</p> <p>Eva: Wait 'till my grandsons come.....err great-grandsons I should say</p> <p>Researcher: I'd be really interested to hear what they say</p> <p>Eva: Who the great-grandson...what about.....?</p> <p>Researcher:you playing on iPads</p>	<p>The camera starts to film and is focussed on two female members of the group, Eva and Ann. The seat between the two members is empty. The pair are seated at a large round table and each have an iPad in front of them. Ann is laughing at something on the screen. Eva is focussed on her screen and navigating around a certain application with her finger. The two members are observed to be interacting independently with the devices. The researcher sits down between Eva and Ann. Ann has stopped interacting with the technology. The researchers' body language shows she has turned away from Ann towards Eva. Ann taps on the table to get the attention of the researcher and Eva. They both look up and all three begin to laugh at something on Ann's device. Eva begins to talk about something she has seen on her screen and the researcher and Ann both listen.</p>	 <p>The first photograph shows Eva and Ann seated at a table with iPads. The second photograph shows the researcher sitting between them, interacting with the technology. The third photograph shows all three individuals looking up and laughing together.</p>

5.4.5 Illustrating the data thematically

In order to understand how the emergent themes may highlight similarities and differences between participants and across context it was appropriate to illustrate the data thematically. This was undertaken by establishing a typology of themes that were identified through data collected within a group context involving people with dementia attending day care at Darnall Dementia Group. Typologies are an effective way of ordering data into numerous related yet independent themes that have emerged (Ritchie & Lewis, 2003). They are multidimensional and allow the analyst to create and strengthen links between findings thus illustrating patterns and themes that have emerged from the data. In this sense establishing a typology can be likened to coding the data whereby all the relevant dimensions of a theme can be unpicked and then grouped together. For the purposes of this study, establishing typologies was a way of thinking about and illustrating the data thematically which required an iterative process of moving back and forth between the episodes of selected data. The highlighted examples from the multimodal transcripts, developed throughout analysis, were brought together under three overarching themes, scaffolding and support, technology interaction and observed gains and limitations. Each identified theme also consisted of sub-themes as illustrated in figure 5.2.

Figure 5.2: Typology of themes



5.4.6 Meaning and explanation

Building explanations of why the patterns, categories and themes have emerged in the data is the final stage of data analysis. Explanations and understandings are facilitated by the use of sensitising concepts which can give a '*general sense of reference and guidance in approaching empirical instances*' (Blumer, 1969 p 148, cited in Hammersley, 1989). This provides a way of thinking through the data rather than utilising prescriptive concepts as a way of seeing the data. Sensitising concepts drawn from existing sociological and psychological theories will ultimately enable a

multidisciplinary explanation that may be applied to aid understanding of people living with dementia, their interactions with technology and each other in different contexts. Once the data analytic stage was complete, the researcher returned to the group in order to negotiate specific images for inclusion in the research reporting and dissemination. If participants or those in a supporting role considered the proposed images to be unsatisfactory, alternatives were agreed.

5.5 Findings

In the majority of instances participants were receptive to the technology and enjoyed their participation with the activities. However, the interest that the sessions stimulated and the degree of engagement with the technology varied and were observed to be dependent on a range of factors. These factors included the level of cognitive impairment, the type of application and the quality of support available. Not all group members chose to engage with the devices for extended periods of time yet could be observed participating in increased social interaction and conversation enabled by the technology. The themes identified in data analysis are described here as scaffolding and support, technology interaction and observed gains and limitations which will be described in turn enabling a discussion of the findings in relation to the research questions posed in section 5.6.

5.5.1 Scaffolding and support

There were clear differences in participant experience whilst engaging in the research sessions that could be dependent upon the variation of support that the individual was receiving. The influences of those in a supporting role (table 5.2 section 5.2.6) were observed to have the potential to both positively and negatively impact these experiences.

The theme of scaffolding and support is considered to have many meanings depending upon the context within which it is used, for example 'bearing the weight' or 'to keep from falling or failing'. Others theorise the term 'scaffolding' to describe a structure of suitable encouragement and support based on consideration of the individual's capabilities (Vygotsky (1978)). Vygotsky, (1978) proposed that social knowledge can be transformed into individual knowledge through an approach referred to as 'scaffolding',

emphasising individual differences in ability and the potential for learning at that current level of ability if appropriately guided. Drawing on this definition and for the purposes of this study, the theme of scaffolding and support that emerged from the data describes ways 'to encourage and strengthen'. The theme of scaffolding and support identified through data analysis is divided into three types that can reflect differences in the available support which are; effective, sufficient and unsuccessful'.

Effective scaffolding and support was evident from several participants in a supporting role including those with technology experience as well as those with limited experience of working with people with dementia. The researcher, Susan and Jean all displayed effective scaffolding and support and other than their age the characteristics of each broadly differed. The researcher has experience of computers and touch screens in particular yet the knowledge of dementia was mainly academic thus the environment and the condition were relatively new. In contrast, Susan, the group manager, has extensive knowledge of the condition and all group members yet was initially cautious when engaging with the devices due to limited knowledge and experience of ICT in general. Jean has no technology experience yet a wealth of expertise concerning the condition due to being the main informal caregiver to her mother for many years.

This type of scaffolding did not require extensive knowledge of ICT or the condition of dementia in order to be effective during the research sessions. Rather, it was the approach that was taken by some of those in a supporting role that was both personable and enthusiastic. This approach did not take a teacher and student perspective, the effective scaffolders portrayed an equitable partnership that promoted an experience of 'let's try this together'. An example of effective scaffolding can be seen in transcript 5.3.1 which depicts the appropriate delivery and demonstration of new information that is dependent on the individual's interest and capabilities. The researcher and Eva are playing a game of memory match which requires the matching of pairs depicting pictures of animals. Eva is extremely confident in her technology use as she progresses through the increasingly difficult levels of the game. There is a constant dialogue between the pair as they discuss the application and Eva navigates the screen with her finger. Nevertheless, the technology and the applications are unfamiliar to Eva despite her participation in previous sessions.

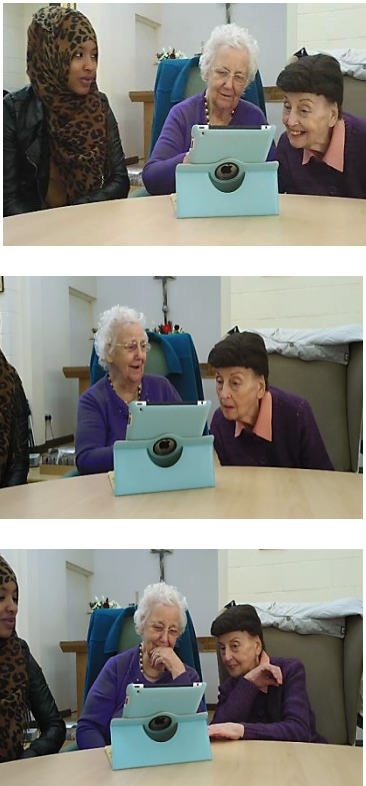
Transcript 5.3.1: Effective scaffolding and support

Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Researcher: Can I show you something?</p> <p>Eva: Of course.</p> <p>Researcher: Thank you...these are...there are pictures behind these...</p> <p>Eva: Mmmm</p> <p>Researcher...and the aim is to find pairs...</p> <p>Eva: okay...</p> <p>Researcher:.....and you just touch the screen</p> <p>Eva: Ahhh and you have to remember.....</p> <p>Researcher...yes.....</p> <p>Eva: That was luck wasn't it...?</p> <p>Researcher: How did you do that?</p> <p>Eva: It was just a bit of luck.</p> <p>Researcher: Try again...that's magic.....do you remember these?</p> <p>Eva: No</p> <p>Researcher: ...have you done this before?</p> <p>Eva: I don't know whether I have or not love...you tell me.</p> <p>Researcher: No?</p> <p>Eva: What am I doing now?</p> <p>Researcher: Same again....</p> <p>Eva: Oh I see....just a minute...can I check these again to remind me?</p> <p>Researcher: yeah, yeah do...that's brilliant</p> <p>Eva: ...and that must be that one...</p> <p>Researcher: Can you slow down a bit? (laughing together)...you're doing them all so quickly I can't keep up...</p> <p>Eva: Am I?</p> <p>Researcher: yes...Although each level is getting harder.</p> <p>Eva: how's that?</p> <p>Researcher: It's very good; I thought you may find in harder...</p> <p>Eva...so I'm not as thick as I thought I was..?</p> <p>Researcher: Not at all....</p>	<p>The beginning of the session shows Eva and the researcher interacting with the device placed in front of them on the table.</p> <p>Eva and the researcher are laughing. Eva is looking at the screen and her expression is joyful. The researcher is looking at Eva and smiling.</p> <p>Eva sits back in her chair with her hands raised in front of her expressively. The researcher has a look of astonishment on her face and they both look directly at one another.</p>	

Sufficient scaffolding and support describes how the presence of support is sufficient to maintain interest and participation with the technology and activities. If input or support from the volunteer is required during any aspect of participation then it is available instantly providing individuals with the confidence and security to maintain

interest in technology use. Transcript 5.3.2 shows Janet and Claire who are interacting with an application on the device that uses a voice recorder, so everything they say is repeated back to them. The pair are talking to the device as if it were a third person in the conversation. Tracy is sitting next to the pair and is in a supporting role.


Transcript 5.3.2: Sufficient scaffolding and support

<p>Mode 1 - Verbatim Transcription</p>	<p>Mode 2 – Description of non-verbal</p>	<p>Mode 3 – Representation of non-verbal</p>
<p>Janet: Hello darling.....hello? Claire: Who are you talking to? Janet: Hello?? What do they call you? Claire: It's asking what they call you? Janet: Janet Claire: Her name's Janet Janet: It just copies what you say doesn't it...I think it's very clever. Claire:...look he's brushing his teeth.....can I borrow them? Janet: What? Claire:.....me teeth I didn't put them in this morning Janet:.....ha ha ha Claire: I don't know what made me do that. Claire: Oh no it's raining on him now Janet: Let's have a look.....hello.....hello Claire: Look that's recording everything Janet: Hello.....hello.....hello...</p>	<p>Janet and Claire lean close towards the device that is placed on the table in front of them. Tracy is sitting next to the pair watching what they are doing.</p> <p>Janet is interacting directly with the device and Claire looks at her smiling. The pair are watching the screen intently whilst leaning close to each other and laughing. Tracy looks on at the interaction taking place.</p>	

The data illustrates that Claire and Janet are supporting each other in terms of enabling engagement with the technology. Tracy is sitting close by but is not part of their conversation or interactions with the technology. The two women engage in a constant dialogue regarding what they are seeing on the screen and enjoying the entertaining activities. For Tracy, English is her second language and she has limited experience of the devices or of the condition of dementia. The presence of the support was observed to be sufficient and communicating this was not reliant on the spoken word. Yet more importantly, it is the interactions between Claire and Janet and their continuous conversation instigated by what they were seeing on the device that appear to provide mutual support to each other.

Unsuccessful scaffolding and support is illustrated in transcript 5.3.3. This type of support reflected limited interest, engagement or conversation with or regarding the devices or each other from the perspective of group members or those in a supporting role. Katie was in a supporting role and had experience of dementia as she was a student mental health nurse on placement at the centre for three months. Katie also had extensive experience of the technologies as owned a similar device for personal use. Frank had experience of touch screens in his job, pre-retirement and Bob had no experience of computers. The influence of the person in a supporting role was observed to negatively impact the experience of technology interaction for Frank and Bob. Of course, it may be that both participants would have chosen not to engage with the technology irrespective of the support available, but sufficient or effective scaffolding may have provided them with more opportunity too. Given the experience of the person in a supporting role in both the condition and the technology, it was unfortunate that engagement and conversation was so limited in this scenario.

Transcript 5.3.3 Unsuccessful scaffolding and support

Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Katie: Do you want to have a go Frank?</p> <p>Frank: Yeah...</p> <p>Katie: Here put your finger on.....and then move it around.</p> <p>Frank: What?</p> <p>Katie: Anything you like. It's nice that isn't it? Do you want to have a go Bob?</p> <p>Bob: Yeah...go on then.</p> <p>Katie: Put a circle in one of these boxes.</p> <p>Bob: Here?</p> <p>Katie: Wherever you want</p>	<p>Katie and Frank are interacting with the technology which is placed on the table in front of them. Bob has turned away from the device and others around him.</p> <p>Katie turns to Bob and Frank immediately looks away. Bob appears to find it challenging to interact with Katie or the device for any length of time.</p> <p>Following brief interactions with the technology and each other, Katie, Frank and Bob appear to disengage and sit quietly.</p>	


Unsuccessful scaffolding was also observed being demonstrated by one of the volunteers of the group. Craig had been a long standing volunteer and he reported that it provides him with something to do. Craig's experience of dementia should be extensive given the length of time he is been volunteering at the group although he had limited computer and no touch-screen computer experience. However, during the sessions there were many examples observed of an expert and novice relationship whereby Craig would take control of the device displaying a definite power imbalance during the interactions. Furthermore, there were instances when the device was manipulated in favour of Craig's own amusement and personal gain and the person with dementia was left to sit quietly. There was a definite negative influence from the person in a supporting role rendering the person with dementia with limited engagement or communication during this particular session.

5.5.2 Technology interaction

Technology interaction in the context of this study does not take account of aspects of safety and security or technologies that compensate for memory impairment. Rather, the theme of 'technology interaction' describes the varying ways that group members relate to the devices, establishing diverse interests and gaining possible benefits using various applications that were facilitated by the same device. However, an activity that one person considers interesting might be considered boring by another person; equally one person may be more serious and competitive whilst another person may prefer to chat and socialise. It was observed that the type and quality of scaffolding support (section 5.5.1) received by group members had an impact on the technology interaction experienced by the individual. Data analysis identified three types of technology interaction; primary, secondary and indifferent.


Primary technology interaction was observed to be a consequence of effective scaffolding, involving thoughtful tactical and competitive strategies using turn taking activities. The main aim of these interactions appeared to be the mastery of particular skills resulting in feelings of achievement when games were won or puzzles were solved. Transcript 5.4.1 illustrates how Jean, Eva and Sam interact directly with the technology and take turns playing a game that gets increasingly more difficult the more levels that are completed. These interactions were competitive and although Eva and Sam are taking turns they were both keen to win.

Transcript 5.4.1: Primary technology interaction

Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Jean: We have to find the letters that make this word.....</p> <p>Sam...Hangman it's called....</p> <p>Jean:yes it is, it's a word game</p> <p>Eva: We used to play this as kids.....and here it is again</p> <p>Jean: So pick a letter.....</p> <p>Sam...Me?</p> <p>Jean: yep.....no it's not that...you try Eva</p> <p>Eva: just guess?</p> <p>Sam: Anyone that I haven't guessed</p> <p>Eva: Oh...OK</p> <p>Sam: My turn...I know this</p> <p>Jean: Ahhh...you got it...Sam won that one</p> <p>Eva: That was quick...blimey. Shall I start another?</p> <p>Sam: Yes</p> <p>Jean: It's you Sam...It's you.....right Eva, you've got to get this one to stop him winning again</p> <p>Eva: Oh...to stop him...</p> <p>Jean: That's it.....</p> <p>Eva: I've won haven't I?</p> <p>Jean: Yeah</p> <p>Sam: Yeah you've won</p>	<p>Eva, Sam and Jean are all interacting together with the device which is placed on the table in front of them.</p> <p>Eva and Sam are taking turns with a game which is supported by Jean. Sam takes his turn whilst Eva looks on.</p> <p>The trio begin another game which Eva promptly wins. They all smile.</p>	

Secondary technology interaction was observed to be a social endeavour and less competitive. Interactions were relaxed and informal and the support in place during these encounters was sufficiently scaffolded and technology interaction appears secondary to social interaction. The main aim of secondary technology use for the participants displaying these interactions was the sociality of the activity rather than competitive opportunities. The device itself or an application on the screen acted as a prompt for a certain conversation or facilitated interesting anecdotes between group members. Secondary technology interaction was observed to be social illustrating increased conversations and laughter whereby group members were interacting with the technology for enjoyments sake. Transcript 5.4.2 illustrates the entertaining conversation that is enjoyed involving Janet and Claire with Paul in a supporting role.

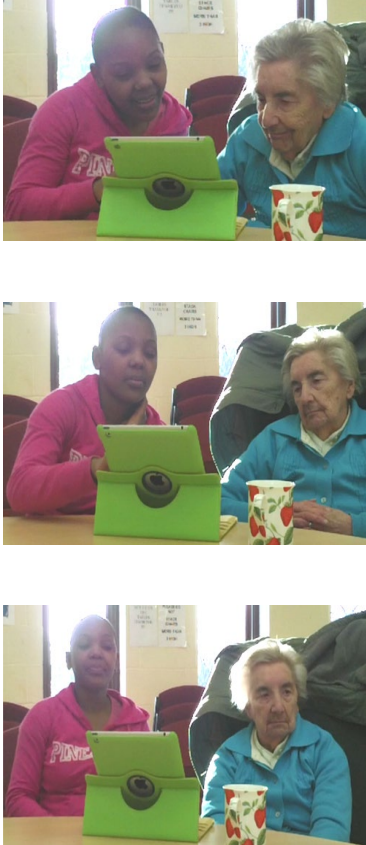
Transcript 5.4.2: Secondary technology interaction

Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Claire: I've left my teeth at the other place. Janet: Have you? Claire: Yeah...I were gettin' ready and they said 'come on yer going to Darnall'....oh and I'll go and wash then, took me teeth out went in the shower then they dashed me out. I got some brand new shoes and they left them an' all...I thought ...thanks! Paul: You're turn madam...try that. Which animal is this, a dodo? Janet: It looks like some kind of dear isn't it? Paul: A dear? Claire: It's a dear little animal...ha ha...innit? A dear little animal...and I haven't got me teeth in... Janet: Why where are they? Claire: They're up there...they come out....the bus is waiting and I says what for? You're going to Darnall and I went Ahhh I haven't got me teeth! Paul: Janet it's your turn now. Choose one of them and match it with another. Claire: Clever clogs Janet: I know</p>	<p>Claire, Janet and Paul are interacting with each other and the device which is placed on the table in front of them.</p> <p>The trio are playing a turn taking game and there is much laughter and joking. A picture on the device instigates a joke by Claire and she pushes Paul on the arm whilst they both laugh.</p> <p>Paul slides the device in front of Janet so she can take her turn. She wins and claps her hands whilst smiling as does Paul. Claire looks at Janet with amusement.</p>	

Indifferent technology interaction describes the reality of technology use as some people have limited or no desire to interact with ICT, irrespective of a diagnosis of dementia. Indifferent technology interaction was considered to be the result of unsuccessful scaffolding and support. Jane is in a supporting role and although she speaks English as a second language, her accent is strong and Anne has difficulty understanding what she is saying. Nevertheless, had an alternative approach to scaffolding been in place it is considered that this may not have been sufficient for Anne to engage with the technology on this particular day. Anne is introduced to the technology and although this is not her first session using the devices she is unfamiliar with it. Anne was observed to be indifferent to the technology or to any interaction during this particular session, displaying a lack of desire and apathy to connect with

Jane in any of the activities. Transcript 5.4.3 depicts Anne and Jane who is in a supporting role interacting with the technology.

Transcript 5.4.3: Indifferent technology interaction

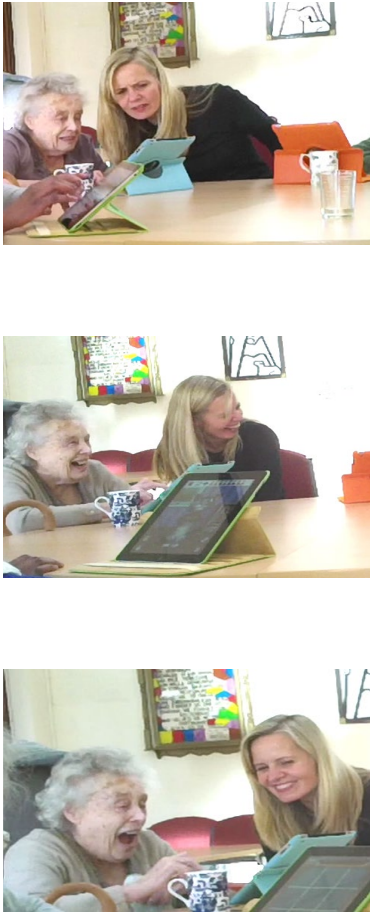
Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Jane: Have you seen these before? They are called iPads. Anne: Pardon? Jane: iPads, they are called iPads. Anne: OK Jane: Each one is a game. This one is a game of cards. Would you like a game of cards? Anne: Pardon? Jane: A game of cards called solitaire. Do you want to play? Anne: No not really Jane: What about tic-tac-toe? I was playing this one with Fiona yesterday. It's like ...if I have three stars here I win...so if I put a star here.....you have to stop me so I can't win. Anne: So If I touch that...? Jane: Yes...so you are using the circles then...? Anne: Pardon? Jane: You have to make them on a single line there..... Anne: I can't really be bothered love.....</p>	<p>The session begins with Anne and Jane in a supporting role and the device placed on the table in front of them. They are both leaning forward in their chairs and looking directly at the screen.</p> <p>Anne sits back in her chair but her gaze remains on the screen. Jane continues to interact with the device on her own.</p> <p>Anne looks away from the device and Jane also sits back in her chair and appears to disengage from the technology and Anne.</p>	

5.5.3 Observed gains and limitations

As the quality of scaffolding (section 5.5.1) was observed to influence the type of technology interaction (5.5.2), similarly the type of interaction was observed to impact the potential gains and limitations for the group member. The emergent theme of observed gains and limitations describes the varying ways in which participants appear to benefit from their interactions with the devices and others around them, or not. Observed gains have been divided into two types, achievement and mastery of skills and increased conversation and laughter. A third type has been labelled disengaged for those interactions that were not maintained. It should not be assumed however, that group members observed to gain a sense of achievement then failed to express

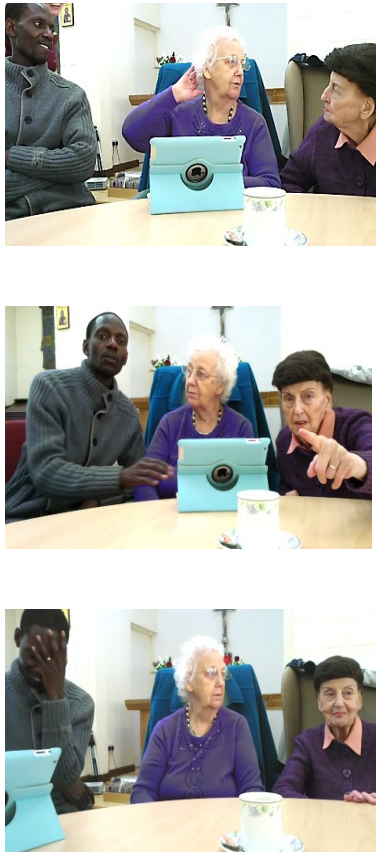
humour during the sessions nor those displaying conversation and laughter failed to achieve or master any particular skill. Rather, these findings illustrate the divergent ways people can experience technology interaction dependent upon the type of scaffolding and support within the same context. The achievement and mastery of skills was observed to be the product of direct technology interaction that had been effectively scaffolded. Transcript 5.5.1 illustrates the interaction between Eva and the researcher who was in a supporting role. Eva is engaged with the technology and is asking questions whilst attempting to understand the rules of the game she is playing. The appropriate encouragement and support resulted in the mastery and achievement of a particular skill enabling Eva's independent interactions to be maintained and her confidence to increase. Eva's delight is clear as she compares her new skill to have replaced the more traditional activities and the prospect of sharing this achievement with her family.

Transcript 5.5.1: Achievement and mastery of skills

Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Eva: This won't do as I tell it. Oh you just bring it down.....</p> <p>Researcher: yeah...that's it</p> <p>Eva:...Ahhh that was it then because I was trying to get the three....</p> <p>Researcher:and they'd gone...yes...yes</p> <p>Eva: So, can you do.....no you can't...I thought that might.....</p> <p>Researcher: You've done the orange ones there without knowing it</p> <p>Eva: When they ask me what I do next time I come I shan't be able say 'I show people how to knit'.</p> <p>Researcher: No you won't, you'll have to say 'I've been exploring all the different apps in the apple store.</p> <p>Eva: Wait 'till my grandsons come.....err great-grandsons I should say</p> <p>Researcher: I'd be really interested to hear what they say</p> <p>Eva: Who the great-grandson...what about.....?</p> <p>Researcher:you playing on iPads</p> <p>Eva: It's a bit better than playing dominos this is...I didn't realise there was anything to them.</p>	<p>The researcher leans across to look at the device Eva is interacting with.</p> <p>The pair look up and laugh at something another group member has said across the table.</p> <p>Eva completes increasingly difficult levels of a game on the device. The look of delight on her face is clear as she gets to the end of another level.</p>	

Increased conversation and laughter was observed on multiple occasions throughout the research sessions and illustrated how the participant's interactions with the technologies and those around them facilitated increased conversation and laughter. This particular observed gain was characteristic of indirect technology interaction that had been sufficiently scaffolded. Participants were observed chatting and humorously conversing with each other around topics that were instigated whilst interacting with the devices in addition to conversations regarding the video equipment on display. Transcript 5.5.2 illustrates the interactions between Claire and Janet whilst Paul is in a supporting role.


Transcript 5.5.2: Increased conversation and laughter

Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Paul: Clever...ok it's your turn now Claire: C'mon lady. Claire: Oohh I'm a lady again.....Greta Garbo that's me... Paul: No.....come on Claire...I want to see your memory working now.... Janet: You have to tap it where its dark, look where it's brown. Claire: Now they tell me...what you talking' about? Paul: ...you choose one of these brown ones...can't you see? You match this with that. Claire: But you've forgot...I'm colour blind ...ha ha ha ha Paul: You're colour blind...?.OK I'll help you. Claire: He just wanted to hold my hand that's all! Janet: What are those? Paul: Those are cameras Janet: Oh are they? Paul: She's trying to record you...How you are...playing the game. Janet: Oh I see Claire: Well thanks for telling me...and I aint got me teeth in!!</p>	<p>Claire and Janet are interacting with the device and Paul is in a supporting role. Claire is doing an impression of a famous movie star and the other two watch in amusement.</p> <p>Janet has spotted the video camera and points straight down the lens. Paul provides an explanation and Janet sits back in her chair and smiles. Claire makes a joke and looks at Janet for a reaction; Paul puts his hands laughing.</p>	

Disengaged is a sub theme of observed gains and limitations that is reflective of those participants who chose not to engage with the technology or others around them on occasion. Not all participants who were considered to disengage did so every time the technology was produced which suggests in some instances that disengagement was

the product of unsuccessful scaffolding and support. Nevertheless, it could also be a consideration that the condition was being experienced differently between sessions, on different days and the individual felt little desire to be engaged with the technology when compared with previous sessions. Alternatively, those who disengaged may not have been particularly interested in the application that was being illustrated. Physical impairments including hearing loss or diminished sight could also impact effective technology interaction. For example, Shirley had severe hearing loss and refused to wear hearing aids which in consequence limited her social interactions within the group. Nevertheless, it was observed that some participants chose not to interact with the technologies irrespective of the support in place and these particular participants displayed limited conversation or laughter during activity sessions with or without the technologies. Transcript 5.5.3 incorporates varying images from different sessions which are all characteristic of periods of disengagement that have previously illustrated unsuccessful scaffolding and indifferent interaction.

Transcript 5.5.3: Disengaged

Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Eva: This won't do as I tell it. Researcher: Won't it....?.There's a blue one flashing there... Eva: Oh you just bring it down..... Researcher: yeah...that's it Eva:...Ahhh that was it then because I was trying to get the three....</p> <p>Katie: Anything you like. It's nice that isn't it? Do you want to have a go Bob? Bob: Yeah...go on then. Katie: Put a circle in one of these boxes. Bob: Here? Katie: Wherever you want</p> <p>Jane: Yes...so you are using the circles then...? Anne: Pardon? Jane: You have to make them on a single line there..... Anne: I can't really be bothered love.....</p>	<p>The researcher leans away from Anne resulting in Anne disengaging from the technology.</p> <p>Katie turns to Bob and Frank immediately looks away. Bob appears to find it challenging to interact with Katie or the device for any length of time.</p> <p>Anne looks away from the device and Jane also sits back in her chair and appears to disengage from the technology and Anne.</p>	  

5.6 Discussion

The findings from this study indicate that touch screen computer technology has the potential to facilitate enjoyable activity with people with dementia when participants are supported appropriately within a group setting. Moreover, this can take place with people that have significant levels of cognitive impairment. However, this study did take place in a day care centre and therefore implications cannot be made regarding possible benefits that might be derived in other settings. It was observed that numerous factors were present that could influence participants' interactions with technology and others within a group context. Influencing factors were described and illustrated in the typology (figure 5.2) as '**scaffolding and support**', '**technology interaction**' and '**observed gains and limitations**' and will now be discussed in turn. The three research questions outlined at the beginning of this chapter will be addressed using various sensitizing concepts that have been identified and drawn from existing theories to aid explanations of the findings.

5.6.1 How is the technology received by members of a day care centre?

The technology was positively received by the majority of participants although numerous differences were observed that may be considered as influential factors. The findings support the fact that individual differences play a significant part in our everyday lives yet a propensity remains in dementia research to consider people with the condition as a homogenous group (Bartlett & Connor, 2007). People living with dementia do not share the same likes, dislikes, capabilities and preferences merely because they share the same condition. It is therefore essential that research acknowledges the aspects of 'self' (Sabat, 2010) and all that is retained. Aspects of 'self' or individual differences can explain the ways that people behave differently in what appear to be similar or the same situations. Thus an understanding is required regarding the ways the person is experiencing the condition at one particular point in time and assumptions should not be made that this is inevitably the way dementia is always experienced.

The typology of themes in figure 5.2 depicts the emergent theme of **technology interaction** which highlights the numerous ways that technology is received by members of a day care centre. Data analysis identified three sub- types of technology interaction; **primary**, **secondary** and **indifferent**. As with any population, there is

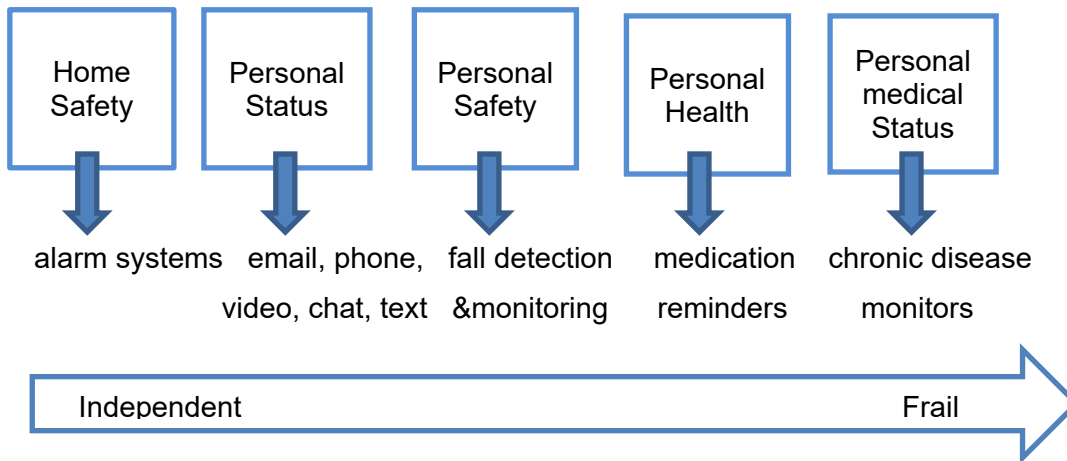
always going to be commonalities found across people with dementia in relation to technology use although it is widely accepted that 'one size does not fit all' (Bjorneby, 2004) which is reflected in the varying sub-themes of technology interaction in this thesis.

Participants involved in this study were considered to be experiencing moderate to later levels of the condition and multiple differences between individuals were observed to impact interactions with the technology and others. Physical impairments including hearing loss and visual challenges were observed to influence communication with others and technology interaction respectively. This is in line with existing evidence that suggest physical co morbidities may have important influences on communication and disorientation as well as hearing loss being an independent predictor of more rapid cognitive decline (Prince et al., 2011). Cognitive impairment including comprehension and attention as well as behavioural manifestations of dementia including apathy and depression were also observed to impact technology interaction. Apathy in particular has been found to be one of the common consequences of dementia (Rea, Carotenuto, Fasanaro, Traini, & Amenta, 2014) which may then lead to a decreased desire to participate in activities in general (Cook et al., 2008). Those exhibiting **indifferent technology interaction** were observed to have apathetic tendencies but this was not the case for all participants. For some, the technology was observed to be **primary** in their interactions during the research sessions and for others it was **secondary**. These findings support current knowledge concerning the progressive nature of the condition and how the varying ways dementia presents pathologically will ultimately impact how the condition is experienced psychologically and behaviourally (Alzheimer's Society, 2012c).

A population based survey of people over the age of 65 found that older adults accounted for only 6% of the total users of ICT in 2010, attributing factors including cost and lack of interest (Ofcom, 2012). Although the majority of participants enjoyed interacting with the technology there was general agreement that these devices would benefit grandchildren or great-grandchildren, an assumption that technology is possibly more suited to a younger generation. This suggests a lack of knowledge and opportunity regarding the possibilities presented by contemporary technologies rather than reluctance to participate in technology use. These findings support the implication that people with dementia lack knowledge of available technologies but they don't lack the desire to interact with them (Nygard & Starkhammar, 2007).

Some evidence suggests that in order to successfully 'age in place' our technology interaction should consist of five dimensions (Orlov, 2011) as illustrated in figure 5.3.

Figure 5.3 Technology related Ageing in Place adapted from Orlov (2011).



There is no indication in figure 5.3 that technologies are being or should be used to facilitate social interaction or enjoyable activity. In addition it appears that the use of email, phone, video and chat is more appropriate for those older adults at the independent end of the ageing spectrum. All the participants in the current study could be located towards the opposite end of the spectrum where it is suggested that technology may be used to monitor chronic diseases (Orlov, 2011). Despite this, findings from the current study suggest that technologies can be harnessed in the facilitation of enjoyable activities with people experiencing moderate to later manifestations of dementia interacting with each other in a group context, although variations in interaction do exist.

Pink (2004) suggests that technology participates in the negotiation of social relationships, almost as if it were a third person. This is interesting as differences were observed in the ways participants interacted with the devices which could be likened to the various ways people interact with others. Thus, touch screen technology acts 'almost' as if it were an additional person during social interaction yet with obvious and different properties which may or may not make it more appealing to interact with than an actual person. For example, participants were observed initiating conversation that had been instigated by the device (transcript 5.3.2) and in contrast participants were observed physically turning away from the device (transcript 5.3.3) as you might if you did not wish to converse with another person.

Nevertheless, not all older adults will have the desire to interact with touch screen computers, irrespective of a diagnosis of dementia. The societal perception of contemporary touch screens technologies is a positive one based on which the younger generations have adopted such devices as part of their everyday lives. Although the perception of 'everybody's using it' does exist, this popularity has not fully extended to the older generations and less so to people living with a diagnosis of dementia. Although, the current findings suggest that some group members were interested and capable of interacting with technologies, few acknowledged that there may be a place for touch-screen computers in their day-to-day life.

5.6.2 Does the technology enable interaction through enjoyable activities? If so how, for whom and in what circumstances?

The emergent theme of **observed gains and limitations** illustrates the divergent ways people with dementia may benefit, or not from their interactions with ICT. For some, interactions with the technology were observed to promote feelings of **achievement** as certain skills were **mastered** whilst others gained opportunities for **increased conversation and laughter**. There were also examples of participants who preferred less interaction with the technology, represented in the sub-theme as **limited observed gain**. These varying ways that participants were observed to gain from technology interaction illustrates how different people are motivated to participate in diverse activities in order to accomplish a certain goal or merely for participations sake (Kielhofner 1995).

The emergent theme of observed gains and limitations also implies varying preferences between those activities that are more cognitive in nature promoting achievement through mastery of a skill and those that are more social facilitating increased conversation and laughter. It could be that participants observed gains were reflective of activities once enjoyed that were characteristic of the person pre-dementia diagnosis. Recent evidence suggests that performance of activities may be heightened if that performance is supported by increased experience of a particular activity (Martin, Clare, Altgassen, Cameron, & Zehnder, 2011). Participation with enjoyable activity may often involve the achievement of personal goals enabling a sense of mastery and accomplishment (Adams et al., 2010) which was observed to be the main gain for some of the participants in this study. For others, the increased conversation and laughter facilitated by the technology was the observed gain. Conversation with

another person is an activity that we all take for granted but that can become increasingly impaired as dementia progresses (Astell et al., 2010). Thus, participation with enjoyable activities enabled new opportunities to interact with technology but also recognises and reflects past preferences and experiences (Genoe, 2010).

This is interesting as it suggests that a person's unique characteristics interact with the context to create a network of ideal conditions (Kielhofner 1995). These conditions influence a person's motivation, what activities that person does and how they perform that activity within a given environment. For example, Eva was observed to gain a sense of achievement through the mastery of increasingly challenging levels of certain applications that reflected her ability and independence with the technologies (transcript 5.5.1). Whereas, Claire was observed participating in increased conversation and laughter facilitated by the technologies gaining increased socially shared interactions with others (transcript 5.5.2).

An important factor during these sessions was to highlight the maintained strengths of participants and those activities that were enjoyed and done well. In order to achieve this ideal environment it was important to identify what application may be appropriate for whom and this was observed to be influenced by the quality of scaffolding provided by those in a supporting role. This is in line with recent evidence that suggests the varying ways activities are enjoyed during leisure time can become increasingly dependent upon the level of support that is available once a diagnosis of dementia has been received (Innes, Page, & Cutler, 2015). The flexibility of the devices enabled enjoyable interactions through a choice of various applications dependent upon the identified preferences and abilities of the individual or small group. Some evidence does suggest that interactive games and puzzles can encourage feelings of achievement and mastery of skills as people immerse themselves in an activity for enjoyment alone (Gee, 2003). In addition, wellbeing, happiness and life satisfaction for older adults in general is associated with participation in informal social activities that are personally meaningful and valued (Adams et al., 2010). This deepens our understanding of how different people accomplish different goals when interacting with the same technologies, within the same context. Thus, providing an environment with opportunities to engage in enjoyable activities that are supported appropriately, the majority of group members were observed to achieve numerous gains. These positive interactions can afford the individual with purpose as well as enabling feelings of worth and meaning in life, proving to society, and themselves that they still have much to give (Sabat, 2003).

5.6.3 Does familiarity with technology increase over time, if so, in what way?

Dementia is a degenerative condition thus it can be assumed that the opportunity for new learning also reduces over time. Published evidence of new learning in the field of dementia is limited although the trajectory of the condition could be considered as '*malleable....where change, adaption and improvement is possible*' (Spector & Orrell, 2010 p.959). Although some of the participants in the current study were managing to maintain independence in their own homes, this will possibly reflect the familiarity, routine and habit of many years prior to receiving a diagnosis of dementia. It is considered that group members were experiencing moderate to later manifestations of the condition thus the possibility of improvement or adaption to memory would be diminished. Nevertheless, familiarity of the technology and mastery of certain applications by particular individuals was observed within sessions. However, this familiarity did not extend between sessions for the majority of people within a group context. Rather, the findings suggest that enjoyment of activities were 'in the moment' or 'in the here and now' and involved limited retained learning.

As a concept, 'living in the moment' has been discussed in the dementia literature in a multitude of contrasting ways. For example some argue that living in the moment encapsulates the way people have 'chosen not to worry about their future but rather strive to appreciate what they have today' (Downs & Bowers, 2008 p. 43). Others have developed technological interventions to promote enjoyable activity that require limited dependence on short term memory. Referred to as 'Living in the Moment', interactive 3D environments populated by on screen prompts can be explored as a joint or independent activity (Alm et al., 2009). Similarly, the findings from this study are described as 'living in the moment' as an attempt to describe the recall or familiarity of the device and applications for group members within sessions. For all group members, the experience of the touch screens and the research sessions was 'in the moment' or 'in the here and now' as no recall or familiarity was observed between each session (transcript 5.4.3). As each session commenced the devices would require reintroduction to the group and ongoing verbal consent from the previous session. For example, at the beginning of one particular session (transcript 5.3.1) Eva was asked if she recalled using the device before and she replied '*I don't know whether I have or not love, you tell me*'.

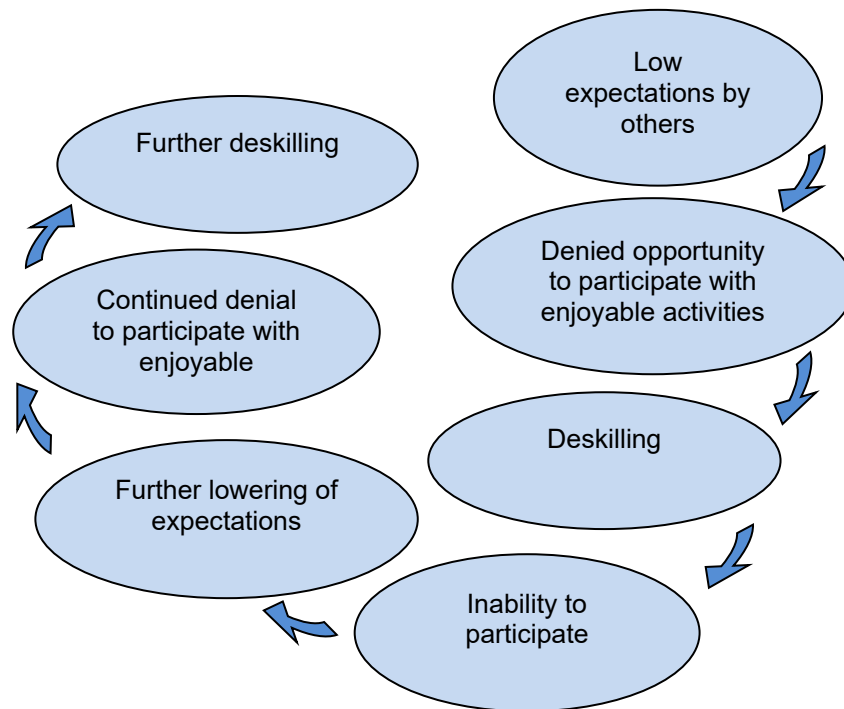
Although the results represent the experiences of group members during their time at the centre; this will not reflect the same person's experiences in other aspects of their

lives away from the centre. Despite there being no evidence of retained learning or familiarity between sessions it is considered that enjoyment of activities was no less meaningful for the person and the group as a whole. The positive experiences that were observed 'in the moment' are considered to have the potential to support function in the person with dementia overcoming some of the obstacles that accompany the impairment (Clare et al., 2013). Nevertheless, it is considered that technology interaction and any potential gains, whether they are mastery and achievement or increased conversation and laughter, are dependent upon the existence and effectiveness of scaffolding and support.

Scaffolding and support was the third emergent theme and consisted of further sub-themes; **effective**, **sufficient** and **unsuccessful**. In the context of this study, scaffolding and support describes effective ways of encouraging participants whilst interacting with the technologies or others. Furthermore, the typology of themes depicted in figure 5.2 illustrates the impact that effective scaffolding and support may have on the ways participants interact with the technology as well as the gains that were observed. This is in contrast to unsuccessful scaffolding and support and the ways this sub-theme may relate to participants indifference to the technology and observed disengagement. The term scaffolding (Vygotsky, 1978) has been used mainly in educational settings as a teaching method that provides the tools to those beings taught as they learn new concepts. The 'scaffolding' is gradually reduced as confidence in the task increases until such time as the behaviour becomes independent and the support may be withdrawn completely. Rather than the pure delivery of information, scaffolding requires the demonstration of information which is a vital factor in the success of the method.

However, further consideration is required when attempting to effectively scaffold interactions with the technology. It is important to never take over a task that may undermine the person's intact capabilities; equally it is important that the person is not left to struggle and fail at a task which could contribute to the further deskilling of the individual. For example, the notion of a self-fulfilling prophecy has been based on traditional societal responses that can exclude people with dementia by offering limited opportunities for this group to engage with enjoyable activities. These limited opportunities result in withdrawal by the person as feelings of competence decrease which consequently magnifies distorted views of dementia and how the individual then responds causing further withdrawal.

Figure 5.4: A self-fulfilling prophecy, adapted from Mountain (2006)



Rather, we need to determine the person's capabilities in relation to any activity being undertaken and support it effectively. In the appropriate moments support should be withdrawn to enable independence in the areas in which the individual feels competent. The essence therefore of effective scaffolding is to work alongside the person whilst remaining aware of their capabilities and retained skills. Opportunities that focus on maintained strengths may then promote feelings of achievement and of self-worth. However, there are two important issues to scaffolding that are relevant here, communication and cognition, both of which can be impaired in people with dementia. This highlights the complexity of the condition as the persons social context, personal reactions to the condition and level of impairment will all impact individual ability to engage and consequently influence the level of support required (Downs & Bowers, 2014).

The findings suggest that limited retained learning of the devices or applications was evident across the research sessions although familiarity within sessions was observed. Although, researchers, professionals and society in general may be too quick when assuming that an inability to recall details of recent events and experiences means that the person has no memory of those events (Sabat 2006). This uncertainty had an impact on the efficacy of the scaffolding as support could not be gradually

withdrawn as confidence increased as theorised by Vygotsky (1978). However, the support and scaffolding in place was observed to be inconsistent in the quality and encouragement demonstrated by staff, volunteers, students and the researcher. It could be that these differences are due to the invested interest that one particular person in a supporting role has in the group. The three members of staff at the centre were particularly constructive in their strategies to provide support during interactions and this could be reflective of their employment and experience within the caring profession and the day care group specifically. Equally, the researcher had an invested interest in providing quality support that may enhance the experiences of the group and consequently provide observable interactions for the research data. One of the volunteers was a long standing member of the group and brought a wealth of knowledge to her supporting role which she did on the basis of 'giving something back' after experiencing dementia within her family. Quality support within this particular group context can therefore be dependent upon the invested interest of those in a supporting role. Conversely, the quality of the support appeared to weaken when those in a supporting role were on secondment to the centre for a limited time or volunteering whilst job seeking, thus no long term investment in the group.

In consequence, not all participants received the same quality of scaffolding as not all those in a supporting role had the invested interest in the group. Equally not all participants would have behaved in the same way had they received the same quality of scaffolding support. It is the joint attention and the social interaction between those in a supporting role and participants that plays a key role and promotes this scaffolding behaviour (Astell et al., 2010). There were clear examples of expert and novice interactions that have also been established in theories of scaffolding behaviour which should be challenged due to the power inequalities that are evoked. Some promote the concept of 'synergistic relationships' whereby recognition of interdependence and reciprocity is paramount thus rendering the dependency of one party on another as invalid (Dupuis et al 2012). These relationships thrive on the strengths of each party and what they can offer whilst valuing each voice equally.

Unfortunately, 'synergistic relationships' are not always a realistic expectation in all dementia care contexts. In this study, not everyone in a supporting role shared the same knowledge and experience of the condition or the technology. Equally, English was the second language for some of those in a supporting role which had an impact on communication in some instances. The majority of participant's had no previous ICT experience instantly placing them in the role of novice and any new knowledge of the

technology or applications that was gained within a session was not retained and carried forward to subsequent sessions. So, although the concept of scaffolding is useful in explaining how certain behaviours may be supportive, this theory did not set out to explain declining cognition and impaired communication that can be characteristic of dementia the condition. Equally, the complexities that are apparent in the ways people experience the condition also extends to the varying ways people may be supported and the scaffolding that is in place. This in turn implies the potential of consistent and effective scaffolding and support and the possibilities this may afford people with dementia in their technology participation.

5.7 Conclusion

It was found that the majority of participants were receptive to technology interaction although the heterogeneity of people with dementia was evident. These differences were found to be both physical and cognitive and were observed to be influential in the ways people with dementia experience the condition and the ways in which enjoyment was derived. The circumstances in which participants interacted with the devices and each other was illustrated through three themes and explored using sensitising concepts drawn from existing models and social theories. The following four key points are pertinent. First, the interactions between those in a supporting role and the participant are required to be scaffolded successfully to encourage optimum enjoyable technology interaction. Second, technology can participate in the negotiation of social relationships, almost as though it were a third person (Pink, 2004). Third, creating an ideal environment requires a focus on maintained strengths and abilities to meet the unique needs and requirements of the individual or group thus providing achievable goals that promote feelings of self-worth. Fourth, the majority of people living with the moderate to later manifestations of dementia in the context of this study are capable of interacting with touch screen computers although acknowledgement is required that enjoyment of activities was 'in the moment'.

5.8 Researcher reflections

Embarking on the first study of this thesis was a huge learning curve, particularly concerning my naivety with the topic of dementia. I had gained some research knowledge previously working with healthy older adults, the experience of which fuelled my passion to pursue further research with this population. Although, I had reviewed the topic of dementia for the 12 months prior to embarking on study 1, my experience of engaging people with dementia was limited. There was trepidation embarking on study 1 however, the unique environment of the research setting provided a place where members are accepted by their peers and those in a supporting role offering a sense of *'we're all in this together'*. The reputation of the group and the clinical manager in post are well known and respected in Sheffield which enabled me the security and support to undertake my project as a novice researcher. Nevertheless, I approached this research context and the participants with some prior knowledge that all new volunteers are required to attend to including routines of the group and participants histories. Although this information was invaluable this meant that as a researcher I did embark on the sessions with some preconception of the context and participants that will have undoubtedly influenced my findings.

It is therefore relevant to acknowledge and reflect on my place as the researcher in particular during the analytical process. This is because I played a fundamental role in the way the data is viewed, how the themes are identified and reflected upon and ultimately interpreted. *'A reflexive reading will locate you as part of the data you have generated ... You will probably see yourself as inevitably and inextricably implicated in the data generation and interpretation processes, and you will therefore seek a reading of data which captures or expresses those relationships'* (Mason, 2002 p 149). I would therefore consider myself as a research tool as the themes and sub themes were characteristic of my own interpretations of the video footage which would inevitably be viewed and interpreted differently by somebody else. My interpretations are subjective and influenced by my own life experiences, thoughts and feelings concerning the participants, the technologies and the research context.

6: Study 2 – Exploring touch-screen computers on a one-to-one basis with participants in their own homes

6.1 Introduction

Based on the identified gaps in the literature, the aim of study 2 was to focus on enjoyable activities as this has been reported by people with dementia as one of the most frequently unmet need (Miranda-Castillo et al., 2013). As with study 1, involving people living in their own homes was essential as it is estimated that two thirds of people with dementia live at home and remain in need of post-diagnostic psychosocial support (Alzheimer's Society, 2014b). The majority of existing evidence that has been undertaken in peoples own homes has focused on Activities of Daily Living (ADL's) (Graff et al., 2008) or dyadic interventions providing education and health resources (Reamy, Kim, Zarit & Whitlatch, 2011) thus rendering the topic of enjoyable activities as under researched in this particular context. Furthermore, numerous existing technological interventions applied to people living at home have addressed declining cognition and those memories that have been compromised by supporting daily functioning generally using memory aids (Meiland et al., 2014; Rosenberg & Nygard, 2011). Thus the focus of this study remained on strengths, maintained skills and activities that were enjoyed and done well. Following on from the findings of study 1, exploration of all that is retained post diagnosis was also considered worthy of further investigation. This chapter therefore addresses the following research questions.

Does technology use involve new knowledge and retained learning, if so, in what ways?

Does the device present observable challenges and possible gains, if so what are they?

What factors shape engagement and interaction with the technology?

Section 6.1.1 provides a rationale for undertaking study 2 and section 6.1.2 acknowledges the ethical procedure undertaken, full details of which can be found in the Methodology chapter of this thesis (chapter 4). In section 6.2 the methods are described followed by data collection and analysis methods in sections 6.3 and 6.4 respectively. The findings are described in section 6.5 and take a within-case and cross-case approach to illustrate similarities and difference between participants. The chapter concludes with a discussion of the findings in section 6.6.

6.1.1 Rationale

Findings from study 1 showed how touch-screen technology can promote enjoyable activity with people experiencing moderate to later levels of dementia within a group context. Familiarity with the technology and activities was observed within sessions but not between sessions. Further, individual interest could be variable depending upon each participant although it was observed that engagement was facilitated when supported or scaffolded effectively. It was concluded that enjoyment of activities was 'in the moment' and memories of the touch screens and applications used were not carried forward to subsequent sessions. Based on these findings, study 2 recruited people with a more recent diagnosis, thus possibly, but not categorically, experiencing milder consequences of the condition. Participants lived in the community and the sessions were carried out on a one-to-one basis in the persons own home with the researcher. One of the aims was to create opportunities that exploit retained skills thereby promoting possible new learning through personalised technology use when supported effectively by the same researcher. Encouraging such behaviours may enable and empower the person in the present as well as the future as they adapt to their changing circumstances.

To achieve this it was necessary to identify the unmet needs of people living with dementia through interventions that might be able to address personalised interests and requirements. Through the use of touch-screen computer technology, the focus of study 2 is on promoting enjoyable activities that may emulate past and/or present hobbies and interests. Personalisation of the technologies enables the emphasis to be maintained on all that is enjoyed and done well rather than highlighting those memories that have been compromised. This in turn allows exploration of the potential for new learning providing opportunities that may be enjoyed in the future by the dyad or independently.

6.1.2 Ethics procedure

The project for study 2 underwent NHS Ethical Review on the 28th November 2013 and the NRES committee Yorkshire & Humber gave a favourable opinion for the project to precede on 4th December 2013 (see Appendix V). Ethical considerations are a prime consideration to any research project involving human participants and these concerns are elevated when the participating population are considered to be vulnerable. Full

and detailed ethical considerations for this project are addressed in the Methodology chapter of this thesis (chapter 4).

6.2 Method

6.2.1 Research setting

During the recruitment stage of study 2, all participants were offered the choice of location for their participation including a meeting from at the University or in their own homes. All participants chose to participate in their own homes. Descriptions of each research setting can be found in section 6.4.1 of the within-case process of data analysis.

6.2.2 Purposive sample

Sampling in qualitative research is frequently purposive in nature, with a 'purpose' in mind, as opposed to the random selection of participants as are common in larger scale statistical studies. Purposive sampling describes a method of selecting participants who characterise a particular phenomenon; in this case a diagnosis of dementia. Thus, critical thinking and decisions are required in order to seek out populations that are more likely to characterise the processes being studied (Silverman, 2013). Purposive sampling is a deliberate effort to recruit participants based on their ability to contribute information that will reflect the research questions to be addressed. Thus the purposive sample population for study 2 was based on people attending Sheffield Memory Services for a follow up appointment having received a diagnosis of dementia within the last 12 months. For the purposes of this exploratory study, this population was considered to provide an inclusive sample of those people who had received a recent diagnosis of dementia from a heterogeneous sample to represent diversity in gender, age, ethnicity, location, socio-economic status, education, living independently or with informal care, secondary long-term conditions and computer experience.

6.2.3 Selection criteria

The selection criteria were prioritised to enable a sample that will allow exploration of the research topic in depth based on the aims of study 2 and the practical limitations of the study scenario and these were:-

1. Individuals who score over 21 on a Mini Mental State Exam (MMSE) are clinically considered to be experiencing milder manifestations of the condition (NICE, 2011). Thus, those scoring below this level were considered to be representative of study 1 and people experiencing moderate or later levels of cognitive impairment.
2. Individuals who maintain the capacity to provide independent informed consent thus eradicating the need for consultee involvement. This was considered relevant criteria based on the subsequent interactions with technology and the researcher that the project would necessitate.
3. Individuals living in their own home, independently or with a spouse or informal carer. This criterion was prioritised based on the aim of the research which identified this population as under researched with increasingly reported unmet needs.
4. Individuals that had sufficient visual competencies were required as it was considered that a visual impairment would negatively impact the technology use required for the research.
5. Adequate use of the English language was required in order for potential participants to communicate sufficiently with the researcher during the project.

Effective purposive sampling relies on the skill of those in a recruiting role who may identify specific participants based on prior knowledge and expertise in the topic area. For the purposes of this study, a dementia research nurse assigned to Sheffield Memory Services was approached in order to discuss the possibility of her involvement in the recruitment process. This particular professional had extensive clinical and research experience as well as advanced knowledge of those people attending follow up appointments from their medical records and prior clinical appointments. Furthermore, a past professional relationship built on trust was already established

between the research nurse and those attending the clinic and this was considered a vital component to achieving an effective recruitment strategy.

6.2.4 Recruitment strategy

Participants were recruited through the Sheffield Health and Social Care (SHSC), NHS Foundation Trust, Memory Services. The Clinical Director approved the site for recruitment purposes and accepted that the information sheets and flyers (see appendix VI & VII) to distribute to potential participants were appropriate for this purpose. The participant information sheets and flyers illustrating the study were distributed to the research nurse who had agreed to recruit participants for the study. As indicated, participants were selected based on the criteria detailed in section 6.2.3 and the existing knowledge and expertise of the research nurse. The research nurse approached potential participants who were attending a follow up appointment 6-12 months after receiving a diagnosis of dementia. The project was explained and potential participants were provided with an information sheet and study flyer to take away for further consideration. The research nurse followed up those individuals who were given information sheets 2-3 days later with a phone call to gauge interest in the research. All the potential participants that were approached expressed their interest at being involved in the research and no one declined their involvement. Due to this interest the researcher requested that the research nurse suspend recruitment after 5 days as the quantity of interested potential participants had reached the maximum capacity for the study. The research nurse passed on the details to the researcher of those individuals that expressed an interest in their involvement in the study. In this sense participants involved in the study can be considered as self-selecting. The researcher then made contact with potential participants who were offered an initial, informal meeting to discuss the research and their potential participation further. This provided the individual and their chosen supporter, if they had one, the opportunity to meet the researcher, ask any questions and gain clarification of details of participation that they may have. It was made clear at this stage that the research would involve video recording of all sessions; this was an indispensable part of the project and non-negotiable. This initial meeting provided the individual with all the information required to make an informed decision whether the research was something they felt inclined to be involved in. Individuals were also offered the choice of where the meeting should take place either in their own home or in a meeting room at the University of Sheffield.

Eighteen potential participants agreed to an informal meeting to find out more about the research. All potential participants chose to undertake the informal meeting in their own home. Two potential participants declined further involvement due to visual impairment. This was distressing as the individual and his spouse were very keen to participate but the person with dementia was unable to see the screen. Sixteen potential participants were offered a period of reflection to discuss their possible participation in private with their chosen supporter if they had one or with another significant family member/friend. A follow up phone call was then scheduled by the researcher after 48 hours to discuss the decision reached. A further meeting was then arranged with those individuals who expressed a wish to proceed with the research in order to gain written informed consent.

6.2.5 Informed consent

Gaining consent was informed by the process consent model (Dewing, 2007) and the 5 key elements of the model were adhered to. The researcher obtained informed consent from all individuals and their supporters if they had one through prior arrangement at the participant's venue of choice. The touch-screen devices were available for illustrative purposes during this meeting to aid clarity and understanding to the consent procedure. This meeting also provided potential participants with further opportunity to ask questions as well as beginning to establish a familiar and trusting research relationship between all parties. The intended use of video recording the research required consent and the logistics of equipment use was also established during this meeting in preparation for video recording at subsequent sessions. As each session commenced, the researcher provided a summary of the previous session and brief overview of the current session. The researcher confirmed with the participants that they are happy to continue which was considered essential as a process of ongoing consent monitoring throughout the research process. On completion of the data analysis stage the researcher returned to each individual and supporter with images depicting their participation for dissemination. This enabled the negotiation of images if the person was unhappy with images the researcher had chosen but also an opportunity for feedback and support as proposed by the process consent model (Dewing, 2007). This is important and consideration needs to be given to participants when building research relationships that will ultimately end.

6.2.6 Participants with dementia and those in a supporting role

The person with dementia, their preferences, opinions and experiences were the major focus of this research. Ultimately, the intervention would be personalised to the person with dementia with their informal carer acting as enabler or supporter of the activity. In this sense the person with dementia was the Primary Participant. The initial aim was to recruit individuals who could participate as part of a dyad although it became clear during recruitment that not all people living with dementia in the community have access to informal support. Thus some individuals were recruited as part of a dyad and others participated on their own.

Dyadic participation constitutes a caregiver and a care receiver. Spouses are the predominant care providers for people with dementia (Braun et al., 2009) but the main support could also come from a son/daughter, family friend or neighbour. Dyadic participation in research can illustrate the importance of the relationship as well as enabling two perspectives on the topic. This in turn can provide a more detailed and comprehensive understanding of what might be the most appropriate intervention. Recent evidence from a meta-analysis suggests that psychosocial interventions that have been tailored to the dyad are effective in two distinct ways. First, by reducing the psychological symptoms of the condition for the person with dementia and second, by reducing the supporters' burden and stress (Brodaty and Arasaratnam, 2012). More specifically, Searson et al (2008) argue that activities enjoyed by the dyad together are significantly related with wellbeing for both parties.

Nevertheless, the needs of the person and the supporter do not always correspond and their perceptions and experiences of dementia will not always be consistent with one another (Beard et al., 2012). For example, when asked, family carers highlight the need for enhanced safety and security in the home yet the person with dementia is more inclined to place emphasis on the need for enjoyable, meaningful activity (Topo, 2008). This intensifies the necessity to identify a balance between the needs and requirements of the individual and their chosen supporter without compromising the relationship between the two (Mountain & Craig, 2012). If this balance is not met there is a danger that the needs and requirements of the person with a diagnosis may be overlooked in favour of the family carer rendering the individual powerless and sidelined (Mountain & Craig, 2012). This damage to the persons self-esteem can have important consequences to social relationships, new learning and overall wellbeing (Kitwood, 1997) which may lead to assumptions regarding decreased interest and

ability to participate effectively in society. However, there is increasing evidence to suggest that people with a recent diagnosis can be as fully aware as their family caregiver of their diagnosis and its immediate and future impact (Whitlatch, Judge, Zarit, & Femia, 2006).

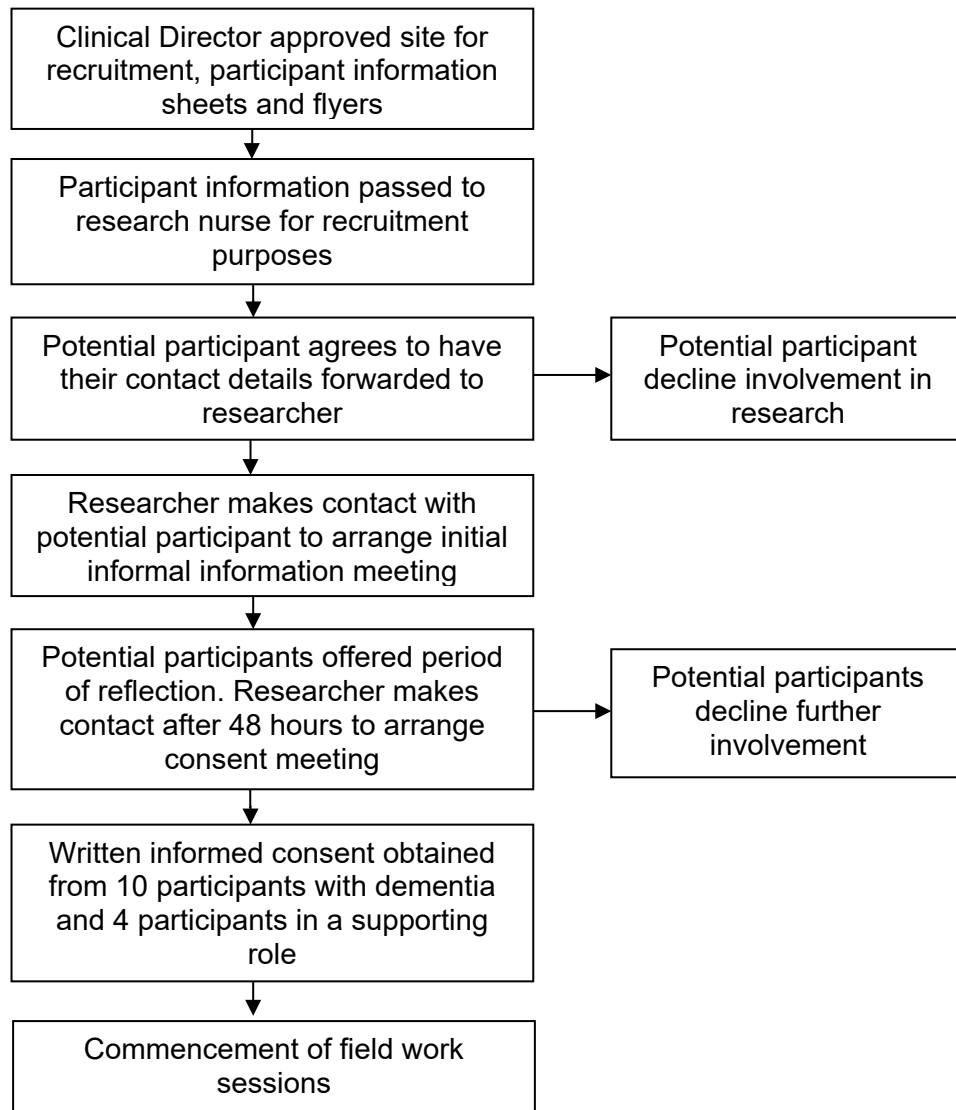
Solo participation The initial aim to recruit individuals who could participate as part of a dyad was premature for two reasons. First, the person with a diagnosis may have a spouse but choose to participate independently. Second, it is estimated that in the UK nearly 150,000 people with dementia live independently without regular informal support (Alzheimer's Society, 2012b). People with dementia that live on their own have been found to have significantly more unmet needs than those that live with informal support (Miranda-Castillo et al., 2013). Thus, it was essential to not exclude people who expressed an interest to participate because they could not participate as a dyad.

Sixteen participants consented to take part in the research, ten had a diagnosis of dementia received approximately within the last 12 months, and six were in a supporting role. All transcribed data used pseudonyms to protect anonymity as far as possible. Of the ten participants with dementia, six participated on their own. A further two participants in a supporting role withdrew after consent providing an opportunity for respite during the sessions from their supporting role. One individual participating on her own (Kathleen) withdrew before session 2 although data collected up to that point has been included as agreed with the participant at the withdrawal stage. Five solo participating individuals and four dyads (each dyad involving the spouse) were involved for the duration of data collection, a total of 13 participants overall. All the following participant and supporter characteristics have been anonymised as far as possible by using pseudonyms.

Table 6.1 Participant characteristics

Name	Age	Participation	Characteristics
Kathleen	88	Solo	Lives alone in sheltered accommodation. One son and grandchildren visit regularly at weekends
Jean	89	Solo	Lives alone, widowed over 20 years. Two daughters and two sons, one son visits every weekend
Jack	73	Dyadic	Lives with his wife Carole, married for over 50 years. Jack also living with reduced mobility and impaired speech as consequences of a stroke
Colin	80	Dyadic	Lives with his wife Jane, married for over 50 years. Three children and grandchildren live locally and visit regularly
Rose	84	Solo	Lives with her husband Geoff, married for over 40 years. No family members live locally although Rose attends her local church regularly
Charles	86	Solo	Lives alone, widowed 15 years ago. Two sons and a daughter visit regularly and Charles has formal care twice a day
Mary	80	Solo	Lives with her husband. Two daughters and grandchildren visit regularly. Also living with emphysema and Parkinson's disease.
George	85	Solo	Lives alone widowed 15 years ago. Son, grandchildren and great-children live away but daughter visits as regularly as work permits. Formal care three times a day
Steven	79	Dyadic	Lives with his wife Elaine, married for over 50 years. Two sons and grandchildren visit regularly
Christine	78	Dyadic	Lives with her husband Michael, married for 50 years. Four children and grandchildren visit regularly. Michael uses a wheelchair as the consequence of a stroke

Figure 6.1 Participant recruitment and consent process



6.3 Data collection methods

As with study 1, the visual ethnographic technique utilised for data collection was video-based participant observation, full descriptive details of which can be found in chapter 4, section 4.3.5. For study 2 and prior to undertaking the participant observations, in-depth interviews were carried out with all participants and those in a supporting role. Each interview lasted up to one hour during week one of participation and the four subsequent technology sessions take place weekly thereafter.

6.3.1 In-depth interviews

The in-depth interviews enabled a discussion with participants on their own terms as well as enabling the research relationship to develop and strengthen. The primary focus of the in-depth interviews was to gain knowledge and understanding of the person, their individual needs and requirements and their past, present and possible future hobbies and interests in order to personalise the devices accordingly. These in-depth understandings were key to the effective personalisation of the devices thus ensuring interactive subsequent participant observation sessions to meet individual needs and requirements. However, the understandings gained from the in-depth interviews also enabled relevant narratives that are appropriate when utilising a within-case approach to data analysis (section 6.4.1).

The researcher had developed a topic guide (see appendix IX) to ensure comprehensive coverage of the topic but this was necessarily flexible and not rigid or determined. The questions and topics that were covered through the interview varied depending upon the participant as well as their past and present life experiences. In this sense, the in-depth interviews were not interrogative but more exploratory in nature. Although extensive field notes were not taken as each interview was video recorded, key points were noted throughout to enable the researcher and participants to reflect on what had been said. These key points were also available to act as an 'aid memoir' for the participant if there were challenges recalling what had been discussed. The use of '*aid memoirs*' have been considered appropriate when researching with people with dementia as a way to enhance communication (Killick & Allan, 2001). To finalise each interview a process of validation took place. The researcher verbally summarised the findings of the interview which had been noted throughout. A small quantity of key requirements and preferences were identified and agreed with each individual during this period of validation. Key points included 'daughter lives in Australia', 'loves doing crosswords', 'talking about the war makes him sad'. This process of validation ensured that a comprehensive understanding and interpretation of the persons expressed wishes, needs and requirements had been achieved in the interview. Each interview lasted approximately one hour.

6.3.2 Topic Guide

As mentioned above, the topic guide (see appendix IX) was flexible and acted as a tool to assist with the consistency of topic areas covered across all interviews. In-depth interview questions are required to be '*sufficiently general to cover a wide range of experiences yet narrow enough to elicit and elaborate the participants specific experiences*' (Charmaz, 2006 p.29). The guide was structured into four sections consisting of: -

Opening – this section begins by establishing a **rappport** whilst making introductions and confirming the research institution. The **purpose** of the research is then reiterated including the possible benefits of participation providing **motivation** for individuals. A **timeline** is then provided to ensure participants remain content with interview length and finally a **transition** sentence which leads on to the main body of the interview.

Middle – provides the core of the interview and explores each participant's activities and hobbies once enjoyed, no longer enjoyed and reasons for this. Current hobbies and interests are also explored as well the individual or dyads' past ICT use (if any) and the possibilities that new or resumed technology use may offer. **A transition** sentence leads onto the validation summary.

Validation summary – was an essential component of the topic guide as it enables the researcher and participant to reflect on the topics discussed as well as acting as an 'aid memoir' to confirm all relevant points had been noted. The researcher verbally summarised the information gathered from the interview which had been noted throughout. A small quantity of key requirements and preferences were identified and agreed with each individual during this period of validation. This process ensured that a comprehensive understanding of the persons expressed wishes, needs and requirements had been achieved in the interview.

Closing – the final section brings the interview to a close whilst offering participants the opportunity to ask additional questions. The researcher also confirms that contact details are available should further questions arise before the next session.

6.3.3 Personalisation of the devices

Information gathered from the in-depth interviews informed and established how the tablet devices may be personalised to meet the wishes, needs and requirements of the person with dementia and their supporter if they had one. Participants were not required to be present at this stage. Careful consideration was required in order to delineate between the needs and requirements of the individual and those of their chosen supporter if they had one. Key applications were uploaded on to each device dependent upon the individual's preferences as established during the interviews. Caution was taken to not inundate participants with too many choices on each device as it was considered that applications could be continually added as the session's progressed if the participant so required. The choice of applications was based on preferences identified through the interviews, examples including Skype, photographs, books, puzzles, recipes, social media, music, You Tube and exploring the Internet.

6.3.4 Video-based participant observation

Video-based participant observation enabled the capture and retention of participant's interactions with each other, if participating as a dyad, the technology and the researcher. This method also enabled the researcher to participate in the event and facilitate engagement with the technology without being occupied taking explicit and extensive field notes.

Once each device had been personalised (see section 6.3.3), the researcher returned to each participant as previously arranged and carried out one session a week over four weeks exploring the technology together. The device did not remain with participants between sessions. Rather, the device was re-introduced at the beginning of each weekly session in order to explore the possibility of new learning or retained skill and familiarity with the technology that had occurred. It was anticipated that some individuals may be well practised interacting with touch screen technology and have use of their own tablet device although information from the in-depth interviews indicated this was not the case.

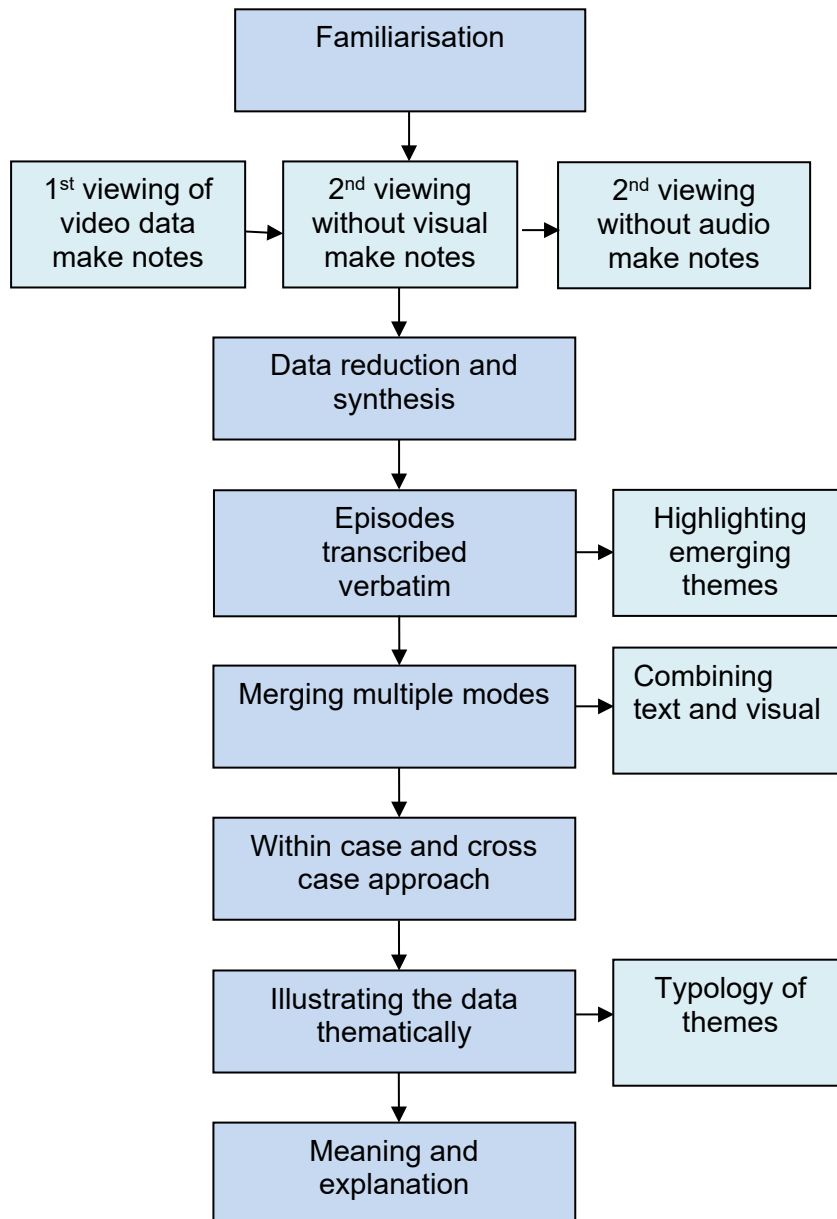
On arrival at each participants home, the researcher set the video equipment in place depending upon where the individual considered their participation to be most comfortable. This could be sitting at the dining room table or in their usual chair in the

lounge. As each session commenced, the researcher provided a verbal summary of the previous session and brief overview of what would be explored in the current session. The researcher continuously checked that the participants were happy to continue. Each of the four sessions were video recorded and involved the person with dementia, their chosen supporter if they had one, the researcher and the technology all interacting together. The sessions were interactive and informal consisting of conversation, laughter and quieter moments that were illustrative of naturally occurring behaviours. The focus during the sessions of participant observation had shifted from discussions concerning what participants 'think' about technology and enjoyable activity during the interviews towards what they physically 'do' with the technology during the activity sessions. Each session of video recorded participant observation lasted approximately one hour, once a week for four weeks.

6.4 Method of data analysis

The process of data analysis followed that of study 1 (chapter 5 sections 5.4.1 – 5.4.6) and involved the stages of familiarisation, data reduction and synthesis, episodes highlighting emerging themes, merging multiple modes, illustrating the data thematically and meaning and explanation. However, the process of data analysis differed from the group context in study 1 by exploring meaning and discussing explanations using a within-case and cross-case approach to the process of data analysis for study 2. Data analysis identified the potential gains and challenges presented in the use of personalised touch screen technology with people living with a recent diagnosis of dementia. Data analysis also enabled the production of in-depth descriptions and explanations of the differing ways that participants used the technology to interact. Once the data analytic stage was complete, the researcher returned to participants in order to negotiate specific images for inclusion in the research reporting and dissemination. If participants considered the proposed images to be unsatisfactory, alternatives were agreed.

Figure 6.2: Process of data analysis



6.4.1 A within-case approach to the process of data analysis

Assumptions remain which suggest that people living with dementia are a homogenous group thus diversity can be side-lined during data analysis. *'By factoring in race, ethnicity, class and gender the picture of life with dementia that emerges is bound to be more nuanced and complex'* (Hulko, 2009 p. 141). Further differences have become apparent during this project between the ways that people with dementia experience the condition and many factors may be of influence irrespective of the level of cognitive impairment. These differences may depend on the existence of consistent support, or indeed the quality of the relationship if there is one, secondary long-term conditions including stroke, diabetes and arthritis and additional psychological symptoms including depression, apathy and anxiety.

The strength of utilising a within-case approach to the process of data analysis is that each individual case can define the complex assortment of experiences that occur within each distinct context. To a great extent the data will illuminate experiences unique to that individual that will be essential in gaining a comprehensive understanding of that person and what their participation means for them. Equally, experiences may emerge that highlight important commonalities across participants yet within the context of a common phenomenon, in this case dementia and technology use.

The distinction between and the process involved when using a within-case and cross-case approach is important. If a particular experience is revealed from within one case but is then consistently identified across cases it enables the analyst to develop that particular reoccurring experience as a theme. Identified themes that are common within and cross-cases may then have wider implications and the potential to be applicable externally to the research group. Findings will address the question *'Do these findings make sense beyond this specific case'* (Miles and Huberman, 1994 p. 173)?

6.5 Findings

6.5.1 Within-case approach

The findings in section 6.5 take a within-case and cross-case approach to data analysis. Section 6.5.1 describes in detail each participants characteristics, context, in-depth interview and subsequent sessions of participant observation. The descriptive and explanatory text is punctuated with images taken from the data analytical process to aid clarity and understanding, as highlighted in the methodology chapter of this thesis (chapter 4). Section 6.5.2 takes a cross-case approach which brings together the obvious and the discrete similarities and differences observed into a thematic structure in section 6.5.3.

Participant 1 Kathleen (88)



Kathleen is an 88 year old woman who never married and lives on her own in the north of Sheffield where she grew up. Kathleen is friendly and welcoming and enjoys being sociable and chatting with likeminded people. Initial contact at the beginning of the research project was with Kathleen's son who made appointments on behalf of his mother. Kathleen appeared happy with her involvement in the research and is generally physically fit although is struggling with deafness in both ears. Kathleen's participation was solo although she chose to withdraw before session 2 as she felt the research was beginning to encroach on her social life.

The setting

Kathleen lives on her own within a sheltered housing development in a suburb of Sheffield. Kathleen's living accommodation is a one bedroom apartment with a separate lounge and kitchen. It is secure with warden presence 24 hours a day and in an area of Sheffield that Kathleen knows well. This particular accommodation is for adults over the age of 60 and is categorised as sheltered/retirement accommodation which was purpose built in the 1970's. Within the sheltered accommodation, regular social activities are organised by the tenants themselves along with outside help, each facilitated by the warden. These include bingo and coffee mornings as well as arts and crafts. In addition, small gardens surround the building and Kathleen and her friends enjoy brief walks here in the warmer months. It is a consideration that to live successfully in sheltered accommodation would possibly depend on the sociality of the person which could be very individual. For Kathleen, this kind of housing works well as she is a sociable person and involved in the daily activities that are organised. She reports having many friends within the building enabling regular social contact and for Kathleen, an increased sense of wellbeing.

The Interview

Kathleen said that she had no previous computer experience and limited hobbies and interests, past or present that she could recall. When Kathleen is in on her own she likes to watch the television but when asked she said that she doesn't like reading newspapers, books or doing puzzles or crosswords. Kathleen was able to describe her daily life and speaks on the phone most days to arrange activities with friends in the building or to arrange for her son and grandchildren coming to visit at the weekends. Kathleen has lived in the area all her life and spends some time describing her childhood. She has a love of animals, especially dogs and the family grew up with various pets. Kathleen worked in the steel industry for many years but is unable or unwilling to describe the numerous other jobs she held. Kathleen feels close to her only son who visits with one or more of Kathleen's grandchildren most weekends. Based on the details from the interview the applications that might prove enjoyable were limited. However, Kathleen was happy to be guided and try various different activities based on the researcher's suggestions. The applications that were enjoyed in session 1 were as follows:-



Potter's Wheel




Drawing Box




YouTube

Session 1 description


Kathleen appeared intrigued, interested and engaged with the technology during the session. Beginning with the Potter's Wheel, Kathleen immediately interacts with the device once the researcher illustrated how to do it. It appears Kathleen has quite a flair for art and she remains engaged until she is happy with the product on the screen.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: it's clever isn't it?</p> <p>Kathleen: yeah</p> <p>Researcher: why don't you have a little go?</p> <p>Kathleen: yeah....</p> <p>Researcher: I'll hold it and just put your finger on the screen and move it up and down. Well done, look at that!</p> <p>Kathleen: look at that....well, you'd never believe it would you?</p> <p>Researcher: have another go</p> <p>Kathleen: Oohh...isn't that lovely</p> <p>Researcher: that's very artistic Kathleen...</p>	<p>Mode 2 – Description of non-verbal</p> <p>Kathleen watches what the researcher is doing. Kathleen takes the computer from the researcher and begins to interact with the potter's wheel app. The look of enjoyment on her face is instant</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Noticing Kathleen's obvious enjoyment of creative applications it was suggested that we move onto the drawing box. This application enables the user to draw and paint using a variety of different colours, materials and tools. Kathleen drew an excellent picture of a dog, then a horse.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: what about drawing, did you do much drawing at school?</p> <p>Kathleen: ooh yeah I like to draw and paint, I think it relaxes you really</p> <p>Researcher: What do you think your friends would say if they saw you using this computer?</p> <p>Kathleen: 'ooh I can't do that' they'd say</p> <p>Researcher: Well you can</p> <p>Kathleen: It's marvellous; it's easy I suppose you've got to see it to believe it.</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher laughs with Kathleen as they talk about what 'others' might think of Kathleen's ability to use the technology</p>	<p>Mode 3 – Representation of non-verbal</p> 
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As the session moves on Kathleen begins to lose interest in the technology and the conversation starts to drift. The researcher attempts to bring the topic back to the technology by asking Kathleen her thoughts on it.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: look at that, it's brilliant Kathleen: it's alright isn't it, it's something different this, you know, you're using your own hands Researcher: do you think it looks like a computer? Kathleen: I don't know Researcher: sometimes people get put off using computers, you know, they can look quite complicated Kathleen: that's right yes...this doesn't, it's easy</p>	<p>Mode 2 – Description of non-verbal</p> <p>Kathleen looks very thoughtful as she contemplates the touch screen computers</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Moving onto YouTube the researcher decides to search for an activity that requires less interaction from Kathleen as she was becoming less engaged the longer the session went on. Although Kathleen enjoyed singing along during a song she had chosen to listen to the session came to a close quite abruptly as Kathleen was keen to go out and meet her friends.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: Have we done do you think? Have you had enough for today? What times your coffee? Are you meeting Maude? Kathleen: I phone her you know, then go down and meet her, we sometimes have a drink. Researcher: you two are good friends aren't you? Kathleen: oh we are</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher notices that Kathleen is getting restless. As Kathleen looks at her watch the researcher decides to bring the session to a close.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Session 2 - On arriving at Kathleen's home for session 2, Kathleen informed the researcher that she did not want to be involved in the research anymore. The researcher asked whether she should inform Kathleen's son of her decision but Kathleen declined and said she would speak to him herself. This was unexpected given the moments of enjoyable engagement during session 1 but understandable due to the social activities and daily commitments with friends, Kathleen felt that she had little remaining time to dedicate to the research. Although this was not a success story as far as the research is concerned, Kathleen's circumstances are unique in this project

and she is a great advocate for the possibilities of a continuing social life as an older adult if provided with effective circumstances.

Overview of Kathleen's participation

As session 1 progressed Kathleen began to recall activities that she used to enjoy and did well at school that had not come to light in the interview. In this sense the activities enjoyed in session 1 were prompting memories that had not been thought about possibly for some time. This was encouraging but the opportunity to explore further activities in subsequent sessions was not possible due to Kathleen's early withdrawal from the research. Kathleen had no prior computer experience and when asked if she thought the device looked like a computer she had no experience to draw from and to compare it with. This is consistent with findings from a review comparing older adults attitudes and beliefs towards computers (Broady, Chan, & Caputi, 2010). Results suggest that negative self-belief and stereotypical views of older adults computer use in general deter people from learning new skills as they are not commensurate with their existing skills and knowledge. Certainly, opportunities to learn new skills including ICT usage can be limited but the desire to participate would be a pre-requisite, and this was not apparent for Kathleen.

It could then be questioned why Kathleen chose to participate in the current research if she had limited desire to learn more about computers. However, Kathleen's participation in the research project was volunteered by her son and not Kathleen herself, although they had both attended the appointment at Memory Services where recruitment had taken place. This illustrates that the priorities and perspectives of the person with dementia and those in a caring role are not always in accordance with one another (Miranda-Castillo et al., 2013). Yet, Kathleen represents a third of people living at home on their own without fulltime informal support and there has been limited attention in the literature given to the support of enjoyable activity for this demographic. The evidence that does exist mainly focuses on the dyadic relationship between the carer and cared for and the impact a dementia diagnosis has had (Braun et al., 2009; Hulko, 2009; Morgan & March, 1992). Although Kathleen agreed with her son at the time, he was not present for the subsequent consent meeting, interview or the first technology session. It may be that Kathleen assumed her son would be attending all further research meetings which would provide her with opportunities to see more of him. Alternatively, Kathleen may have not fully understood the commitment the

research would have on her social time or maybe she just became bored in session 1 which could also explain Kathleen's reluctance to continue with her participation.

Overall, it is considered that Kathleen's achievement was limited with regard to her participation in the research. She talks enthusiastically about her friends in the building and how much time she spends with them leaving limited time for anything else. Kathleen gives no indication of being socially isolated and no inclination to engage with ICT in the future. This result may not be positive in terms of this project but Kathleen's circumstances are encouraging and suit her and her lifestyle.

Participant 2 – Jean (89)



Jean is an 89 year old woman who was widowed over 20 years ago. She lives on her own in the north of Sheffield on a purpose built estate consisting of single story dwellings. When asked, Jean will usually say that she is not feeling too well today but very quickly brightens up when interacting with the researcher and the technology. Jean has suffered with facial paralysis since the age of 18 and requires quarterly injections at the hospital to counter this.

Jean's son accompanied her to the appointment at Memory Services where recruitment took place but since then Jean's involvement in all aspects of the research has been independent. On arrival at her house, Jean is always waiting in the window to welcome the researcher with the kettle boiling and tea being made. Jean looks forward to these sessions and says so at every opportunity, she also reports feeling lonely and bored with her own company. Jean reports missing her late husband every day for the last twenty years although one of Jean's son's goes to visit every Sunday she still feels socially isolated. There are a few stories that Jean repeats over the 6 week duration of the research and varying versions of particular scenarios get expressed, some more elaborate than others.

The setting

The property is all on one level and includes one bedroom, bathroom, kitchen and lounge. Jean keeps her house clean and tidy and takes pride in the way she looks. Jean has a favourite chair and always sits in the same place during each session. From this seat she can see outside through the glazed doors and is able to see the television. The house and Jean are both warm and welcoming.

The Interview

Jean is a very amiable person who loves a chat over a cup of tea. Some of her stories can be repetitive and vary in the level of elaborateness each time they are heard. She appears so happy to have some company and this is reflected in how much she talks and how frequently her conversations jump topic. Jean reports that a whole week may go by before she talks to someone again. In consequence, the interview regularly strays off topic as Jean reminisces and the conversation needs guiding back and focussing on several occasions. The interview highlighted that Jean had no previous computer experience but was willing to attempt the research anyway. Jean has few hobbies and interests except reading books, watching the television and occasionally listening to the radio. When she was younger she used to enter dance competitions and reports that she travelled the world with her husband competing.

Jean has two sons and two daughters and once they were born she describes there being little time for anything else. Jean was a nurse for twelve years and worked at Bassett's sweet factory in Sheffield for fifteen years. There are no local social groups that Jean is part of but she describes enjoying a twenty mile round bus trip into town when the weather is nice. Based on Jeans interview the applications that may prove enjoyable are limited. However, Jean was happy to be guided and try various different activities based on the researcher's suggestions. The applications that Jean enjoyed over the four sessions were as follows:



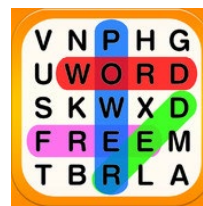
Pottery



Piano



Jigsaw



Word Search



YouTube



Bird Song



Pocket Pond




Drawing Box




Memory Match

Session 1 description

In the first session Jean enjoyed watching short videos on YouTube of professional ballroom dancers in competitions. Although Jean was enjoying watching the videos this was quite a passive activity and the researcher asked if Jean would mind being shown something else.

Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Jean: Oh it's marvellous isn't it? I shall be at this all day. Goodness me, you wouldn't think a square object would do all these things like that.</p>	<p>Jean points to the device whilst laughing with the researcher and watching ballroom dancing videos on YouTube.</p>	


The app was changed to the Pottery application which Jean instantly engaged with. This suggests that Jean is happier when actively engaging with an activity rather than passively watching a video on YouTube. She loved the way she could be creative and design the pot to her own liking.

Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Researcher: It's great isn't it? Oh look at you!! That's brilliant, very fancy. Jean: Oh I shall never be off that Researcher: You've taken to that really well. Have you used one of these before then? Jean: No, no, I haven't.....I feel like a youngster.... Researcher: Ahhh...that's good isn't it?</p>	<p>Jean independently interacts with the technology with no prompting. She is painting a pot that she has made in the colours of her choice. Jean shakes her head in disbelief and continues to interact with the computer whilst laughing.</p>	


Session 1 was characterised by quite a few lengthy conversations instigated by Jean on the occasions she became disengaged from the technology. Getting back on track took some cajoling but ultimately Jean was happy to have another go each time. Jean also enjoyed the drawing box app in session 1.

Session 2 description


Jean reports feeling unwell and has been up in the night so the researcher needed to check that she was happy for the session to go ahead. She was and Jean recovered enough to enjoy herself as the session went along. Beginning with the pottery application, Jean recognised the pot she had designed the week before and had no difficulty interacting again.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: Did I show you the pottery last time...the potter's wheel? Shall I show you that? Jean: Yes, yes please.....Ahhh that's what we did last time. Researcher: Yes, you remember. Jean: I do</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher indicates a wheel turning with her finger.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Jean describes her disappointment at the end of session 1 when she discovered that the touch-screen computer had not been left with her to use between sessions as she reports feeling quite able to use it independently.


<p>Mode 1 - Verbatim Transcription</p> <p>Jean: I've thought about it, you know and when you'd left last time I made myself another cup of tea, sat down and I thought 'where is it?' Researcher: Ahhh that's a shame and do you think if it was here you would have had another go on your own? Jean: Yes yes I would, it would be nice that, really interesting.</p>	<p>Mode 2 – Description of non-verbal</p> <p>Jean nods her head repeatedly and smiles as she talks to the researcher</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Jean also enjoyed the piano app and was thrilled when she remembered some notes from the past when she had played the piano as a young girl

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: What else shall we have a look at? Are you musical Jean?</p> <p>Jean: It's lovely, I did play piano years and years ago but I've forgotten how now....one or two notes are coming back to me, eventually you know.</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher selects the virtual keyboard and Jean immediately presses the keys. The look of surprise on her face on hearing the notes playing is wonderful</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Session 3 description

Session 3 began with an app that the researcher had come across whilst searching potential activities for a different participant. Jean had regularly talked about how she enjoyed feeding the birds and this particular application might appeal in identifying some of the types she sees on a daily basis. The bird song app is a catalogue of pictures, facts and figures as well as the related bird song.

<p>Mode 1 - Verbatim Transcription</p> <p>Jean: oh yes, I feed them every morning before I have my own breakfast. In fact there is one little bird that taps on the window if I'm late feeding them.</p> <p>Researcher: What type of bird is it?</p> <p>Jean: A robin.....lovely isn't it? If I had one of those I'd be listening all day</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher selects robin on the bird song app and the bird begins to sing. Jean appears overjoyed.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Jean really enjoyed this app and the look of delight was apparent in many images taken from session 3. However, the researcher then changed the app to a word search and this resulted in Jean disengaging.


Jean describes how the injections she needs make her eyes water which consequently impairs her vision and as a result she is finding it challenge to search for the words.

Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Researcher: We need to find it in a straight line, not all separate</p> <p>Jean: What am I looking for now?</p> <p>Researcher: The same word 'tour'</p> <p>Jean: T...o...u...r</p> <p>Jean: I'm having a bit of trouble with my eye, I've had ermm.....what do you call it?</p> <p>Researcher: The injection?</p> <p>Jean: That's it, I'm not in pain it just effects it when I'm reading</p>	<p>Jean proceeds to tap each letter of the word rather than finding the whole word hidden</p> <p>After a few failed attempts at finding different words Jean sits back in her chair and the session comes to an end.</p>	


Jean did not engage with the concept of the word search and could not grasp the idea of putting a line through a word using your finger as if it were a pencil. Jean appears to enjoy apps that are more creative than cognitive.

Session 4 description

Session 4 begins with the memory match game, which requires the player to find matching pairs in a collection of cards facing down on the screen. There appears to be a lot less conversation in session 4 when compared with session 3.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: That's it! Well done! You're really good at that.</p> <p>Jean: I am aren't I?</p> <p>Researcher: You are</p> <p>Jean: They're very interesting though aren't they?</p>	<p>Mode 2 – Description of non-verbal</p> <p>Jean instantly engages with the technology when the game starts. Jean taps on the first card then the second. Jean appears thrilled with herself and proceeds to finish that level of the game</p>	<p>Mode 3 – Representation of non-verbal</p> 
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There is less conversation because Jean is completely engrossed with the memory match game and gets a great sense of achievement from progressing through the many levels. The researcher spent the majority of this session observing Jean and the way she manages to complete a game and navigate her way to the next level. It is unlikely that Jean was remembering where each card was but rather her success was based on luck and persistence. This was a really enjoyable session.

<p>Mode 1 - Verbatim Transcription</p> <p>Jean: I'm going to start at the bottom corner this time.</p> <p>Researcher: Is this your tactics?</p> <p>Jean: I've always liked anything like this, you know.</p> <p>Researcher: Well it keeps the brain active doesn't it and that's a good thing. Have you enjoyed it today Jean?</p> <p>Jean: Oohh I have, I really do look forward to you coming</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher claps Jean's achievement and she looks so happy</p> <p>Jean shakes her head laughing</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Overview of Jean's participation

Jean had no previous experience of computers but found the touch screens to be accessible to her if provided with the opportunity and if sufficiently supported. Yet, understanding is limited regarding the use of ICT by people with dementia and some suggest it is inadequate knowledge rather than fear of utilising new technologies (Nygard & Starkhammar, 2007). There were many observed examples of the joy and sense of achievement in Jean's conversation and expressions that illustrated how effectively she had engaged with the technology and used the research sessions to her ultimate gain. Similarly to Kathleen, Jean's interaction with various activities prompted memories of hobbies and interests she had enjoyed as a girl that had not been recalled in the interview. Jean was observed to enjoy applications that were more creative and visual in nature rather than applications that draw on cognitive abilities including word searches and puzzles. However, it is considered that technology use was secondary to the regular social contact that Jean achieved on a weekly basis through her participation in the research. Jean had been very vocal throughout the sessions regarding how lonely she feels and the difference it makes having some company and how much it means to her. Loneliness is an environmental factor that has also been associated with cognitive decline and Alzheimer's disease whereas the maintenance of social networks has been associated with less cognitive decline in older adults (Holwerda et al., 2014; Pitkala, Routasalo, Kautiainen, & Tilvis, 2009). At the end of session four the researcher explained that she would return to Jean in the summer to share some of the images from her participation. Jean was thrilled with this prospect as she said it gave her something to look forward to.

Jean's need for social contact greatly influenced the lengthy conversations that took place that were not directly focussed on the research. The constant dialogue throughout most sessions felt like she had been saving up everything she had to say for the one hour a week when the research took place. These conversations could sometimes be repetitive and often contradictory. For example, Jean mentions on occasion that she goes out every day for a walk then on other occasions she says she hasn't been outside the door since the last research session. On other occasions, Jean reported that she loves reading novels yet numerous times over the research sessions she describes how she is no longer able to read the text due to problems with her vision.

Although it may appear that Jean is fabricating stories it is considered that these are not deliberate or meant to be misleading and she may not be aware that these memories are erroneous. Rather, these contradictory stories may be a way of replacing the gaps in memory that Jean is experiencing. One possible explanation is the concept of confabulations. A confabulation describes a story, phrase or recount of a scenario that is strange or inconsistent with actual events. There is evidence to suggest these particular types of cognitive disturbance are apparent for some people, post diagnosis of Alzheimer's Disease (Cooper et al 2006).

Participant 3 – Jack (73) and Carole



Jack is a 73 year old man who has been married to his wife Carole for over 50 years. Jack suffered a stroke in 2010 and although he had a diagnosis of Mild Cognitive Impairment (MCI) prior to the stroke, there has been a gradual decline in his memory since. He presently has a diagnosis of probable Alzheimer's disease. Jack has limited speech as a result of the stroke and has difficulties walking which is also due to the pain caused by arthritis. He rarely leaves the house but when he does it is always with his wife and he requires a wheelchair. Carole does not drive and although she is physically very able she is unable to get Jack on a bus or push the wheelchair for any length of time. Carole and Jack rely on family members to get them out or as a treat every few months they will get a taxi to a large shopping centre a few miles away. Jack relies totally on Carole for all activities of daily living and they participated as a dyad throughout the research.

The setting

Jack and Carole live in a semi-detached house on the outskirts of Sheffield. A stair lift has been fitted to enable Jack to move between floors of the building although he requires assistance getting in and out of it. Jack sits in an adapted chair that leans forward when Carole helps him stand up. The sessions all take place quite formally at the dining room table and Jack regularly gets uncomfortable when he sits for prolonged periods of time. Jack rarely speaks and displays limited expression although Carole is very welcoming and chatty and the researcher always enjoys a coffee during the session.

The Interview

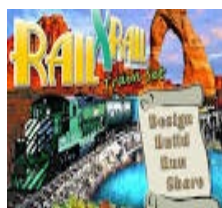
Jack has a speech impairment as a consequence of the stroke and consequently spoke very little during the interview and Carole did most of the talking and answered most of the questions. The researcher consistently directed questions to Jack but he would turn to his wife to answer. Before his stroke and the onset of Alzheimer's disease, Jack was actively involved in computers as a hobby but Carole reports that his memory impairment has taken this away from him and he struggles to come to terms with what he can no longer do. Nevertheless, Jack remains able to use his laptop for basic activities including solitaire but not for any ICT based activities involving the internet. Carole describes Jack's love of model trains and the numerous boxes of track in the attic that have now been forgotten. Carole describes how Jack taught himself to play the keyboard and it now sits in the corner with a blanket over it, he has not been near it in 4 years. He enjoys jazz music and they have been to a local pub to see one of their favourite bands play. Based on the discussions during the interview the following apps were used across the four sessions.



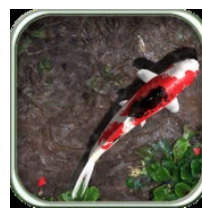
Solitaire



YouTube



Model Train



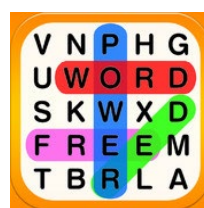
Pocket Pond



Piano



Memory Match




Word Search


Session 1 description

The session began with the familiar card game called solitaire as Jack and Carole report often sitting with their laptops in the evening playing solitaire in front of the television. When Jack had come to the end of possible moves on his first game the app gave the user no way of knowing if any more possible moves could be made. Hints or tips could be helpful in this situation to prompt the person to the next move. The

researcher makes a note to search for alternative solitaire apps that provide more direction during the game. Jack does require prompting to move forward in the game.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: Do you want to have a go at solitaire Jack? Jack: Yeah OK Researcher: Do you play solitaire Carole? Carole: Yeah I do, I was playing last night in fact</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher searches on Jacks computer for the relevant app whilst Carole searches for solitaire on her computer and they both begin the card game</p>	<p>Mode 3– Representation of non-verbal</p> 
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The researcher changes the app to a piano because during the interview Carole reported that Jack used to be quite good on a keyboard. Although Jack has a go this does not hold his interest for very long and the researcher decides to go onto YouTube and listen to a local jazz band that Jack likes. It is difficult to say whether Jack enjoys listening to this on the computer as his expression does not change. Rather he closes his eyes and rests his chin on his hands.


<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: Do you have a particular band or singer that you enjoy listening to Jack? Jack: Brennan..... Researcher: Sorry? Carole: He like this jazz band that we go and see, Dave Brennan, it's not like on the telly or anything, they play in the local pub sometimes</p>	<p>Mode 2 – Description of non-verbal</p> <p>The music begins to play and Jack closes his eyes and rests his chin in his hands</p>	<p>Mode 3– Representation of non-verbal</p> 
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Jack then disengages from the technology, Carole and the researcher. In an attempt to engage Jack again the researcher selects the model train app but unfortunately Jack does not reengage, he remains with his eyes shut suggesting he has had enough. When searching and uploading model train apps to the computer for Jack, caution was needed as many were very childlike. Ironically the application that was chosen was too complicated for the researcher or participant to interact with. The final app of the session is the Pocket Pond which was selected as it is a passive activity requiring


limited input from the user. Rather, the app is very visual as well as having numerous sounds to interact with which Jack seemed to enjoy briefly but his attention was limited and he quickly became disengaged.

Session 2 description

This session began with solitaire again but Jack appears less engaged today than he was in the first session. Carole is very chatty and interested in the device in general and wants to know all she can about them.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: Do you remember having a go at solitaire on this computer last week Jack?</p> <p>Jack: yep</p> <p>Carole: You never know sometimes he says he remembers but he doesn't.</p>	<p>Mode 2 – Description of non-verbal</p> <p>Jack is disinterested and has limited engagement with the technology today</p>	<p>Mode 3– Representation of non-verbal</p> 
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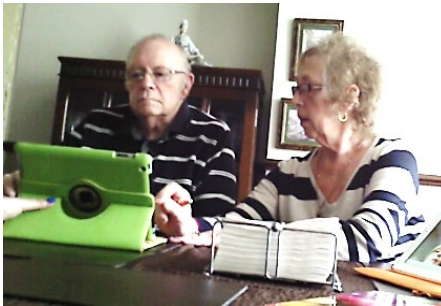
The solitaire game has been changed for a more intuitive version of the game in the hope that Jack will pick up on the prompts provided as he interacts. Jack does engage to an extent but spends most of the session with his eyes closed. After 30 minutes Carole asks Jack if he is OK and has he had enough, he has and the session comes to an end.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: Do you want to have a go at something different Jack?</p> <p>Jack: No</p> <p>Carole: Are you alright?</p> <p>Jack: Yep</p> <p>Carole: Have you had enough for today?</p>	<p>Mode 2 – Description of non-verbal</p> <p>Jack close his eyes Carole places her hand on Jacks arm The session comes to an end shortly after</p>	<p>Mode 3– Representation of non-verbal</p> 
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Session 3 description

The researcher asks Jack what he would like to have a go with at the beginning of session 3. Jack decides independently to begin the session with solitaire, this game is

familiar to him and he seems happy to spend his time playing it. Carole, in contrast has many questions regarding the technology and thinks of different things to explore on the device during each session. Although Carole occasionally checks that Jack is still interacting with the device, she is busy with her own computer. Jack does not maintain attention with the device for any length of time so the researcher changes the application to the card matching game in an attempt to engage some interest.


<p>Mode 1 - Verbatim Transcription</p> <p>Carole: No you can't move it back up Jack, you have to wait now 'till it comes back again.....no no no it's a red one, it can't go there.....will that go anywhere? Jack: There? Carole: Yeah go on then.....that Queen can go there.....do you remember what you're meant to be doing? Jack: Yep</p>	<p>Mode 2 – Description of non-verbal</p> <p>Jack is struggling to focus and solitaire is generally quite familiar to him. Carole is trying to help but ends up doing 'for' Jack rather than enabling Jack to do himself.</p>	<p>Mode 3– Representation of non-verbal</p> 
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The card matching game appears to engage Jack again and Carole spends a couple of minutes explaining to Jack what he is meant to be doing. It is interesting that throughout all the sessions Jack's expression rarely changes. The researcher attempts to take a step back in this session and hopefully let Carole support Jack and actually the card matching game seems quite suitable and Jack requires limited support.

<p>Mode 1 - Verbatim Transcription</p> <p>Carole: Did you enjoy that? Jack...Jack...open your eyes, open your eyes....you can't see with your eyes shut.....press next.....there's nine now...right try again now. It does actually get your memory working doesn't it? Researcher: Yes I think so Carole: Do you like doing that Jack or not? Jack: yep</p>	<p>Mode 2 – Description of non-verbal</p> <p>Carole leans across and explains to Jack how the card matching game works. Jack keeps closing his eyes.</p>	<p>Mode 3– Representation of non-verbal</p> 
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Session 4 description

The final session begins with solitaire which is always Jack's choice. Carole is supporting Jack but on occasion physically lifts his hand and uses it to touch the screen to demonstrate where to tap. Jack plays solitaire for some time and asked if he would like to try the card matching game again he agrees recalling exactly what to do from the previous session. Jack spends the second half of the session engaging with the matching pair's game. He is very independent in his technology use with these two games and chooses not to engage with any other apps.

Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3– Representation of non-verbal
<p>Carole: Tap that, then that ...then that....you see? You've got a space so put your King down there...in fact you've got two spaces....put that jack on there</p> <p>Jack: Here?</p> <p>Carole: that's right....no no no you've got to alternate colours</p> <p>Researcher: Do you want to have a go at the card matching game again Jack? You may remember it from last week?</p> <p>Jack: Yes</p>	<p>Carole physically moves Jack's finger across the screen to demonstrate what she is trying to say</p> <p>Jack remains engaged with the card matching game until the end of the session</p>	

Overview of Jack and Carole's participation

It was quite clear throughout the research session that Carole was the main beneficiary of the sessions with the technology. On completion of the research Carole purchased two touch-screen computers to replace their existing laptops as she considered the devices more intuitive for herself and Jack to interact with. For Carole, the research sessions were an opportunity to discover more about contemporary ICT's with the end goal being to replace their existing technologies. Although Carole feels isolated and cannot get out much due to Jack's wheelchair use, the social contact was valuable yet secondary to Carole's interest in learning about the new technologies. Jack, in contrast appears to have less desire to learn new things and limited wish to socially connect which highlights how the cognitive losses characteristic of dementia often lead to a loss of autonomy and decreased interest in social activity (Graff et al., 2008). Rather, Jack would prefer to remain with what is familiar to him even though these activities may

require modification as cognition declines (Menne, et al 2012), he maintains attention for longer periods of time when interacting with activities including solitaire and the memory match game.

A clear indication of Jack's disengagement is the length of time he spends with his eyes closed and he would regularly stay like this until Carole told him to open them. There is rarely any emotion expressed on Jack's face either when he achieves something during a game or watching a music video that is possibly evoking past memories. Although what appears as disengagement may also be a consequence of the stroke that Jack is dealing with. It is clear that Carole now undertakes the majority of activities that Jack used to do for himself as she explains it is quicker than showing him how to do it for himself which extends to all the daily activities in the home. This could be illustrative of a malignant social psychology which can occur when tasks are carried out for the person even though they may be done independently, if not with the care and attention previously known (Kitwood, 1997). It has been argued that such behaviours, albeit not intentional, often result in apathy, depression and 'learned helplessness' (Sabat, 2001). Jack's participation was passive except for the occasions when he was interacting with a familiar application like solitaire. Carole's participation, in contrast, was pro-active as she had definite goals to achieve from each session and used her time with the technology to her benefit and gain.

One of the observed consequences of the condition for Jack is his loss of motivation and desire to be involved with anything that it is not familiar resulting in apathy and disengagement. Yet Jack and Carole are coping with much more than the effects of dementia as the stroke has rendered Jack with limited speech and mobility. Physically, for Jack and Carole, it appears that the results of the stroke are most debilitating yet psychologically the effects of dementia have rendered Jack feeling apathetic and unmotivated. It is estimated that 72% of people with dementia are also living with other co-morbid conditions which are considered to increase the complexity of an already complex condition (Alzheimer's Society, 2014b). In combination, the effects of these long term conditions have had overwhelming consequences on the social lives of Jack and Carole.

Participant 4 – Colin (80) and Jane



Colin is an 80 year old man who has been married to his wife Jane for over 50 years. Colin and Jane participated as a dyad throughout the research. They live on the outskirts of Sheffield in a purpose built single storey dwelling. Colin has difficulty walking but has a mobility scooter and routinely goes to the local shops, doctors and library independently. Jane is less mobile due to severe back problems and consequently spends the majority of her time indoors. The couple have three grown up children and grandchildren that all live locally and as a family they are very close. Jane regularly has the family for Sunday lunch, an occasion that they both welcome and look forward to. All the research meetings take place on the same day and time every week and on arrival, the researcher often meets Colin coming up the road on his scooter having been to collect the morning paper. Colin and Jane are warm, welcoming people who enjoy company and socialising but feel isolated from opportunities and activities that may promote this as they get older.

The Context

Colin and Jane's home, like them, is warm and welcoming. The video recorded sessions are carried out quite formally in the small dining room which used to be a second bedroom, each sat at the table. Jane always makes tea and we enjoy our drinks whilst interacting with the technology.

The Interview

The interview with Colin and Jane was focused on the needs and requirements of the dyad and they both had maximum input into how the devices may be personalised to meet their wishes. They mention some local social groups that include rambling and boules but neither feel physically able to participate anymore. They used to enjoy the outdoors and often took the girl guides and scout groups out for the day. The couple attend church every Sunday and have found some comfort in difficult times through worship. Colin and Jane rely on each other for company and whatever activities they do, they do together. Jane has no computer experience at all and Colin has some very basic skills from using desk top computers at work before he retired. During the interview Colin focused very much on his love of music and produced a list of famous singer songwriters that he would like to listen to. He used to play the keyboard but considers now that his memory will let him down when attempting to remember the required chords. He also included his love of brass bands, bird watching and reading crime novels. Jane preferred activities that involved cake decorating, knitting or sewing as well as enjoying puzzle books. She misses dancing whenever they go to family parties because she is just not physically able anymore. They both explain that all the activities they used to enjoy have not been replaced by anything else as they have got older, leaving them bored and socially isolated. A selection of apps was agreed upon but it was also decided that the choices may evolve over the course of the research and additional apps could be added at a later stage if required.



YouTube



Pocket Pond



Drawing



Pottery



Piano



Google Earth



Drums




Bird Song




Cake Decorating

Session 1 description


The first session was very much about trying everything. Colin was so eager to get started it was great to see his enthusiasm.

<p>Mode 1 - Verbatim Transcription</p> <p>Colin: Are we going to get to touch that then and have a go with it? Researcher: Of course!!! Hopefully that's what these sessions are all about.</p>	<p>Mode 2 – Description of non-verbal</p> <p>Colin gestures towards the device and appears very keen to get started.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Colin had never used a touch screen before but there was no hesitation in trying it for the first time which took a few attempts to master the sensitive screen. Colin was so keen to have a go that he incorrectly pressed an icon marked with a musical symbol because we had been talking about music videos.


<p>Mode 1 - Verbatim Transcription</p> <p>Colin: I'm going to do it myself if I can. Researcher: Of course you can but I just need to show you how....we're not going to use that one, we're going to try using YouTube</p>	<p>Mode 2 – Description of non-verbal</p> <p>Colin reaches toward the device to press the music icon The researcher gestures to the app Colin was wanting to press</p>	<p>Mode 3 – Representation of non-verbal</p> 
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After watching many videos on You Tube the researcher asked if Colin would like to have a go on the virtual keyboard. Again, he was very enthusiastic at the prospect of engaging in any activities suggested to him.


Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Colin: I used to play the keyboard, that's it over there.</p> <p>Researcher: Yes, I remember you saying last week</p> <p>Jane: He was getting quite good.....that is until the Alzheimer's took over</p> <p>Colin: I keep saying I'll try again but it's remembering the chords....I can't</p>	<p>Colin has a go on the keyboard as Jane and the researcher watch. He is completely engrossed with the activity.</p>	

Session 2 description

Session two was much more focussed than session 1 and there were instances when Colin and Jane preferred to use their own devices enjoying different apps. Colin loves to chat and there were numerous examples when Jane would remind him, good naturedly, that the researcher only had an hour and not all day to listen to his stories.


Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Researcher: Now I found one, I found a bird watching app as you spoke about enjoying that in the interview. Jane, I found an app about cake decorating would you like to have a look at that one?</p> <p>Jane: Yes OK</p>	<p>Both Colin and Jane are interacting independently with different devices using different apps. The researcher is assisting Jane as Colin manages to navigate his screen independently.</p>	

The dyad are independent in their choices of what to explore in this session and both opt for contrasting activities. During the session the researcher and Jane begin to discuss wedding cakes as Jane's interest in the app stems from her enjoyment of cake decorating.


<p>Mode 1 - Verbatim Transcription</p> <p>Jane: Well I've always enjoyed cake decorating and often made them for special occasions for family or friends, you know.</p> <p>Researcher: Do you not do that anymore?</p> <p>Jane: No not any more.</p>	<p>Mode 2 – Description of non-verbal</p> <p>Jane and the researcher are having a conversation whilst Colin is engrossed with the device.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Session 3 description

Colin and Jane had a specific goal for session 3 and that was to revisit the Norfolk coastline where they had many holidays when the children were small. They are revisiting the area in June with one of their sons and are keen to search for places to visit and things to do. They inform the researcher that after the last session they sat down and decided between themselves that this is what they would like to do in session 3. Their imagination and commitment to the research is impressive and they are taking every opportunity that is given to them.


<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: Now, you two are always full of ideas about what you would like to do during these sessions. This is great and at the end of last week's session you were talking about the Norfolk Coast?</p> <p>Jane: I'm not sure if it's actually Norfolk or....wait a minute, let me get me bearings, that's it there, it's a little village near Newport</p>	<p>Mode 2 – Description of non-verbal</p> <p>Jane closes her eyes to concentrate for a moment Colin selects the correct app and types in Sandringham. Jane points to an area on the screen</p>	<p>Mode 3 – Representation of non-verbal</p> 
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During session 3 Colin appears more content to chat than interact with the technology whereas Jane is very focused on the technology. Jane has happily dominated this session searching the Norfolk coastline on Google Earth. She is very clear what she is looking for and seems content for Colin to take a back seat.


<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: So what do you do nowadays, where do you like to go? Colin: I just do as I'm told Jane: Wales, Scotland mainly, not down south. Colin: We used to like Torquay but... Jane: there are too many stag and hen parties, you know...</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher and Colin laugh at this comment and both look at Jane for her reaction. Jane answers the question ignoring Colin's comment but she is smiling.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Session 4 description

Colin and Jane have found a brochure of the campsite they are visiting in the summer and having searched using Google Earth last week they are now keen to search the internet for specific places to visit during their trip. They are both independent with the technology and quite able and sure of what they want to achieve through this research session.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: So, let's look at this website..... Jane: Oohh parks and gardens.... Researcher: Select that one then and let's have a look through Jane: Oh it's near Helsby, we've been there haven't we Colin? Colin: Many times...</p>	<p>Mode 2 – Description of non-verbal</p> <p>The couple are watching a video of the campsite and surrounding areas and lean in close to see the screen</p>	<p>Mode 3 – Representation of non-verbal</p> 
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All of session four is focused on searching the internet and Colin and Jane make notes of all the places they intend to visit when they go on holiday in June.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: Doesn't that look lovely?</p> <p>Jane: Yes, yeah, Applesburgh, we've been through there many times...</p> <p>Colin: We have</p>	<p>Mode 2 – Description of non-verbal</p> <p>Colin and Jane are writing notes of all the places of interest they are finding using the internet.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Overview of Colin and Jane's participation

Colin and Jane participated as a dyad throughout the research which reflects the way they reported living their lives on a daily basis. They are both friendly and warm and Colin's enthusiasm for conversation and laughter was infectious, there was no indication that he felt apathetic or depressed during the sessions. Jane is slightly more reserved and in control which maybe either the role she has adopted since Colin's diagnosis or possibly the role she has always played. Their participation was observed to be pro-active as they spent their time actively searching the internet for topics that were interesting to them. Interacting with gaming applications did not suit either participant; they were far more focussed on gathering information and making good use of their access to a computer. In this sense, Colin and Jane's pro-active interaction with the technology and applications is purposeful and they both report having specific goals they want to achieve through the research sessions. Between each session Colin and Jane had come up with varying ideas of how they would like to use the time with the technology which created interesting and interactive sessions for everyone involved.

Although both Colin and Jane report feeling increasingly socially isolated they attribute their situation to older age in general rather than a consequence of Colin's condition. In fact, Colin is the more physically able to get out and about, with the use of his mobility scooter, than Jane as she suffers with chronic back pain. The couple appear supportive of each other and report coping well and being accepting of their changing circumstances. This acceptance may be due to the consistent support and contact they receive from their family which also provides Colin and Jane with a continued purpose as parents and grandparents. The couple describe doing everything together and this supported activity can also sustain meaning for both parties (Phinney, 2006) and

produce benefits for people with dementia and their family members (Clare et al., 2013). The couple appear to advocate 'living well with dementia' and retain the desire to stay socially connected if the opportunity arises.

Participant 5 – Rose (84) and Geoff



Rose is an 84 year old woman who lives with her husband Geoff in the east of Sheffield in the same terraced house they have lived in for over 40 years. Rose is a positive, warm individual and when asked she will tell you that she is happy with her life and every day is a good day. Rose is sociable and loves to chat; in contrast Geoff is quiet and thoughtful and only speaks to answer a question. Rose struggles with her hearing and her sight; she has no hearing aid but will use a magnifying glass to do her puzzles or read the paper. Rose is physically able enough to attend daily prayer meetings at the local church but feels more secure when Geoff accompanies her on trips into town as she fears falling when on her own. Rose and Geoff grew up in Jamaica but moved to Britain in the 1960's. Geoff has two grown up sons and one granddaughter from his first marriage who all live in the south of England. Rose and Geoff have no family members that live locally to them. Rose describes her condition as manageable and is sure that the medication prescribed to her has improved her memory.

The Context

The property is full of pictures, ornaments and mementos from the extensive travelling that Geoff does. The television is generally on when the researcher arrives and due to Roses' hearing impairment the volume can sometimes be quite high. Geoff does not sit and watch the television; he prefers being in the garden or undertaking jobs in the house. Rose and the researcher sit next to each other on a settee in the dining room for all the visits.

The Interview

Although Geoff participated in the initial in-depth interview he chose not to continue with the subsequent sessions, using the time that Rose was occupied with the researcher to do other jobs. Rose explains that she gets out and about most days although all her activities are focused around the church. One day there is an exercise class, another day there is a singing club or maybe crochet and sewing classes or prayer meetings and then she attends traditional services at the weekends. Rose also befriends newcomers to the church who may be new to the congregation or area. When Rose is not at church she may go into town on the bus and walk around the shops but only if Geoff accompanies her. When Rose is at home she enjoys watching the television, completing word search puzzles and reading the paper. Geoff does not share Roses' commitment to the church and is more physically active preferring to go out walking, rambling and often travelling abroad on his own. Geoff still travels extensively and he is interested in visiting new places and learning of a particular country's history. Rose feels physically unable to travel abroad anymore and stays with family in London when Geoff goes travelling. She explains that she no longer feels able to visit her beloved Jamaica and although she loves England she misses her family and friends back home. No shared activities were spoken of and when asked Rose admits that even when she was physically more able, she did not join Geoff in the majority of his activities. Geoff enjoys regularly tending the small garden as well as swimming on a weekly basis. Neither Rose nor Geoff has any experience of computers and both say that they actively avoid the touch screens in supermarkets, train stations, banks and libraries. Based on the discussions during the interview the following applications were considered appropriate to begin the sessions:-



Word Search



Google Earth



YouTube




Memory Match


Session 1 description

On arrival for session 1 Geoff informs the researcher that he is not going to take part in the session but rather use the opportunity whilst Rose is occupied to get some jobs done around the house. The first session begins with a word search and Rose instantly understands how this familiar activity is being represented on the computer. It becomes

clear very quickly how practised Rose is at this activity. The touch screen is new to her but it only takes a minute for her to realise she needs to use her finger as if it were a pen. However, Rose has some difficulty being exact with her touch on the screen as she suffers from arthritis in her fingers. The researcher provides her with a stylus to use which Rose finds easier than her finger.


<p>Mode 1 - Verbatim Transcription</p> <p>Rose: What word am I looking for? Researcher: Well, you see here there is a list of words to find.... Rose: Ahhh....I've found the first one Researcher: Already? Gosh that was quick</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher demonstrates what she means on the screen whilst Rose watches then copies what the researcher has done. Rose sits back and laughs.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Once the first game is finished Rose decided that she did not want to do any more. The researcher attempts to keep Rose engaged by locating her beloved Jamaica on Google Earth before she loses interest. The remainder of the session is spent chatting about Roses' childhood growing up in Jamaica.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: Do you want to do another one? Rose: Oohh I don't know, I don't want to mess about too much...I'm sorry Researcher: No that's fine, I want you to be happy....let me show you something then.....you don't have to do anything</p>	<p>Mode 2 – Description of non-verbal</p> <p>Rose removes her glasses and sits back, appearing to disengage from the screen. The researcher selects Google Earth on the device and begins to search for Jamaica.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Session 2 description

Rose has a present for the researcher when she arrives for session 2, it is a fan that she had brought back from Egypt which she wanted the researcher to have. The gesture was so thoughtful and it was clear a connection had been made in the last session. Rose says that she had been looking forward to the researcher coming back since the last visit. Rose then turns the television off and says that she does not need it anymore now that the researcher has arrived. The session begins with a word search but it becomes clear that Rose would much rather carry on chatting.


<p>Mode 1 - Verbatim Transcription</p> <p>Rose: Oh I can't find it....where are you.....I can't see you.....I think I'm going to cry....</p> <p>Researcher: There's no rush you know, you're not being timed....it's not a race</p> <p>Rose: Oh I've found it...I've found it</p>	<p>Mode 2 – Description of non-verbal</p> <p>Rose is frantically searching for the word on the screen she appears to get agitated during the word search game.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Session 3 description

We begin session 3 by listening and watching Bob Marley on YouTube, who is Roses' favourite singer. She watches intently and laughs a little when she recognises a lyric and begins to sing along.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: Who's your favourite singer?</p> <p>Rose: I like reggae really so I suppose Bob Marley.</p> <p>Researcher: Shall we have a look at one of his concerts?</p> <p>Rose: Ok</p> <p>Researcher: Do you remember this one?</p> <p>Rose: Yep...no woman no cry</p>	<p>Mode 2 – Description of non-verbal</p> <p>Rose and the researcher watch the screen and Rose begins singing along with the lyrics.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Without warning Rose gets upset and the researcher gives her a hug and asks if she is ok. Rose is not keen to elaborate but the researcher assumes that the song lyrics may mean something to her or brought back a poignant memory. The video is forgotten very quickly as the researcher turns the volume down and Rose begins to chat again. The application is switched to the card matching game and Rose laughs out load every time she gets a pair. There are no tactics involved here just guesswork but playing the game makes Rose and the researcher smile.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: I'm trying to find pairs that match....you have a go Rose: I don't remember where they were Researcher: It really doesn't matter....just tap on any one and we'll do it together.....that's a scorpion Rose: A scorpion yes..... Researcher: Now where's the other one.....there it is.....I thought you said you weren't any good at this? Rose: Got one.... Researcher: That is a very good tactic</p>	<p>Mode 2 – Description of non-verbal</p> <p>Rose starts to chat and takes her glasses off. The researcher changes the app to the card matching game. Rose puts her glasses back on. She is watching the researcher playing the first game. Rose laughs and begins to tap on every card hoping to find a pair.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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After a while Rose stops and announces that she cannot be bothered anymore, she has a brief conversation before the session comes to an end.

Session 4 description

The researcher asks Rose to turn the volume down on the television because it is too loud and a discussion ensues that sometimes noise from the television can feel like company. It is difficult to motivate Rose today and the researcher gets the impression that Rose does not really want to interact with the technology. The researcher does not want to influence Rose into participating in an activity that she does not want to do so gives Rose the choice of app. Rose decides to have one game of the matching pairs.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: That's amazing Rose: I think I remember where they are Researcher: I think you do, every time...that's really, really good Rose: Do you want me to do another one? Researcher: Only if you want to Rose: No Researcher: That's fine...that's fine</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher selects the card matching game and Rose immediately manages to navigate the screen. After one game Rose takes off her glasses and disengages.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Rose is very able when navigating between the levels and realises when more cards are introduced that the level is getting more difficult. Nevertheless, Rose is quick to disengage when she has completed one level of the game.

Overview of Roses' participation

It was clear that Roses' participation involved limited interest in the technology and had more to do with the regular company that the research sessions enabled. Realistically, had Geoff continued his participation after the interview, the applications that they could have enjoyed together were restricted due to their contrasting interests. Rather, Geoff and Rose may have participated using different devices and applications in line with their reported preferences. Rose is more inclined to participate in cognitive word searching applications as she reports this type of activity as familiar and one that she enjoys. It is unclear whether Geoff withdrew his participation satisfied that Rose would be capable interacting with the researcher on her own or maybe he realised during the interview that the research had limited personal gain offering an opportunity for respite.

Even though Rose and Geoff have each other, assumptions should not be made that spousal relationships fulfil the much needed social contact that both parties may crave. Although evidence from a recent systematic review suggests that psychosocial interventions tailored to the dyad will ultimately be more effective (Van't Leven et al., 2013). Other evidence suggests that spousal dyads who find themselves 'working together' will ultimately characterise the perfect scenario when living with a dementia diagnosis (Keady & Nolan, 2003). Yet realistically, this will not always be the case for couples living with dementia and some may be characteristic of just 'working', the importance of which should not be downplayed (Beard et al., 2012). Rose reported on numerous occasions that the television was her company which supports the existing evidence that suggests more than half of older adults in the UK consider the TV as the main form of company (Age UK, 2014). Although Rose reports how much she looked forward to the researcher's visits, the church is her main source of social activity. There is no indication that Roses' diagnosis has a negative impact on the activities once enjoyed by the dyad, rather it appeared that Rose and Geoff had rarely participated in hobbies together.

There was a definite sense that Roses' technology use was merely to benefit the researcher, which is endearing, but a constant lack of desire to engage with the device throughout the research was observed. Rose's yearning to chat indicates that she

looked forward and gains a lot from the increased social contact that the sessions were providing and this far outweighed her interest in the possibilities that the technology interaction had to offer.

Participant 6 – Charles (86)



Charles is an 86 year old man who lives on his own in the family home he once shared with his wife, two sons and one daughter. Charles' home is a large detached Victorian stone fronted house towards the north of the city. He has lived there for 51 years and is very attached to the property and the memories it holds.

Charles' daughter was present for the consent checking stage but all of Charles' subsequent participation was independent. Charles' wife passed in 1998 and he talks about missing her every day. His children are adults with families of their own. The initial contact was with Charles' daughter who arranged the appointment to check consent and for the in-depth interview. After this Charles organised each of the sessions independently and made a note in his diary. Charles was anxious at the first meeting and asked his daughter to be present, unsure of the research and what was expected of him. After this initial introduction Charles appeared more confident and from this point all of Charles' participation was independent. Charles has formal care visiting twice a day as well as his meals delivered three times a day. He describes his life being made into a timetable whereby family members and formal carers are each allocated their own slot to visit or attend to him. He never leaves the house on his own and rarely with a family member. This is because Charles suffers from dizzy spells and anxiety attacks and he is nervous of being away from home and having an episode that may lead to a fall. Charles wears an alarm around his wrist in case of emergency which he says gives him the security of someone being close by. Paradoxically, Charles always mentions that the wristband has to be taken off in the shower and questions what would happen to him if he fell whilst having a shower.

Charles reports being an intelligent man who retired from a long and successful career in Engineering. He is well travelled, articulate and has many interesting topics available for discussion. He explains that his mind continues to question everything around him despite his failing memory although Charles feels isolated he considers there to be limited stimulation for him these days. Some of Charles' topics of conversation are repetitive and he finds it a challenge to recall what has already been said during and between sessions. To keep himself busy and as a way of remembering, Charles employs a constant logging of information in a note book. This can range from the times the various street lights come on and go off in a day to the guests on a certain lunch time chat show. Charles explains that he is bored and lonely and this routine of logging information gives him something to do. When asked, Charles will say that he does not always feel safe and secure in his home, he stays alert to possible intruders and always keeps his walking stick close by. Charles has a brother who lives a few miles away whom he has not seen in years. This is because his brother is the main carer for his wife who has Alzheimer's disease. Charles does not acknowledge that he himself also has a diagnosis of the condition.

The Context

The house is warm, welcoming and comfortable. Charles loves his garden but feels physically unable to tend it himself these days. He sits in his chair by the window overlooking the back garden where he can see his birdfeeder but recent storms have blown this over and Charles gets distressed that he is physically unable to attend to this job. The walls of Charles home are covered in family photographs enabling Charles the memories of all the good times which he says have now passed. Charles' granddaughters have also created a life story book for him that he regularly looks through and shared with the researcher on the first visit. There are post it notes in varying locations around the house to remind Charles that he is not to stand up too quickly as he suffers from dizzy spells.

The Interview

Charles explains that he always used to have a very well balanced life including children, hobbies and social activities but he feels age, not the diagnosis, have taken this from him. However, he feels that if his wife had still been with him then life would be enjoyable again. Charles already had a good idea how he would like the sessions to proceed and had many ideas of how the technology may be useful to him. He reports having some experience of computers from work before he retired but also had

his own desk top computer at home that he used for basic word processing until a few years ago. Charles' main activity every day is watching television although he does have shelves full of books he chooses not to read anymore and he dislikes crosswords and other types of puzzles. His favourite television programs include football, news, wildlife and travel programs although he also has an interest in astronomy. Charles also enjoys listening to the local radio station every day. He is an avid football fan and has supported his local team since his own father used to take him to matches from the age of five. Charles enjoyed rambling and pot-holing as a younger man as well as being a scout leader for the local group. Numerous possibilities were identified during the interview that Charles was keen to interact with, these included:-



Ancestry



Flight Tracker



Football Quiz



Astronomy




Bird song




Coin collector

Session 1 description


Session one begins with a brief introduction to the device and the many applications that can be uploaded. Charles is interested and engaged and is already coming up with new ideas to be explored in the next session.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: So this one is satellite navigation and I use it to get here each time. Charles: Ahhh well that's interesting because you know what I would love to do? I would love to track aeroplanes Researcher: Ahhh you mean their flight paths? Charles: mmm. I'd like to know where he's come from and where he's going to Researcher: Ahhh interesting</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher shows Charles the satellite navigation app on the device.</p> <p>Charles points to the sky and explains his interest in flight paths. The researcher makes a note to search for a flight path app for the next session.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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The session continues exploring Charles' handwritten family tree that he is interested in expanding upon using the device. After spending the majority of the session inputting information into this application the researcher changes the application to the football quiz. Neither the researcher or Charles are any good at this quiz and Charles decides that this is because the quiz is based on European teams and not his local team which he has more knowledge on.


<p>Mode 1 - Verbatim Transcription</p> <p>Charles: Head of the family at 24 and worked for the Master Cutler Researcher: So who was Frederick Collins married to then? Charles: Sally North I think her name was, hang on..... Researcher: yes, there it is.</p>	<p>Mode 2 – Description of non-verbal</p> <p>Charles inputs the information onto the device independently from the handwritten family tree on the table.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Charles disengages from the technology and takes the conversation away from the family tree for a while.


Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Charles: So do you like your job then? Researcher: I love my job, this is the best bit getting out and about and meeting people. Charles: Well I know what that feels like...being on your own. Researcher: yes, you do don't you, some people just aren't meant to be on their own Charles: Well my research is logging what times those lights come and off.....that's no life is it? Researcher: Well, no not when your brain is so active</p>	<p>Charles changes the topic of conversation and disengages from the technology.</p> <p>Charles points out the front window towards the nearest streetlight</p>	

Session 2 description

On arriving for session 2, Charles explains that he had been having a tidy up in the week and found a container that had fallen down the back of the furniture. The container was full of very old coins and Charles was keen to look them up on the device if possible and find out more information. The researcher downloaded a suitable application and began to explore the coin collection with Charles. Charles was interested and alongside the researcher, discovered the origin of a few of the coins until Charles sat back in his chair and appeared to disengage.


<p>Mode 1 - Verbatim Transcription</p> <p>Charles: I have no idea where these came from, I must have been given them some years ago</p> <p>Researcher: You don't think you collected them then?</p> <p>Charles: No I don't think so.....what's this one then, I can't even see a date on it, it's that old</p> <p>Researcher: Ahhh, this one says India, let's start there shall we?</p>	<p>Mode 2 – Description of non-verbal</p> <p>The device has been uploaded with a coin collector's index in order to identify some of Charles' collection. The researcher and Charles begin to search the app for Indian coins</p>	<p>Mode 3 – Representation of non-verbal</p> 
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In an attempt to engage Charles with the technology again, the researcher moved on to the bird watching application to address Charles' reported love of wildlife. Charles is impressed with this app and describes his love of bird watching when he was a younger man. The researcher suggests that the application offers people with opportunities to engage with wildlife virtually if they feel they can longer physically engage with such activities and Charles acknowledges this as his current situation.


<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: Were you ever interested in.....</p> <p>Charles...birds.....</p> <p>Researcher: Yep</p> <p>Charles: oh yes very much, there's one that's distinctive for me and that's a magpie, my other interest is blackbirds</p> <p>Researcher: Good, let's have a look</p> <p>Charles: this is amazing, really interesting</p> <p>Researcher: well it means people who don't get out and about anymore can still engage with wildlife</p> <p>Charles: People like me....</p>	<p>Mode 2 – Description of non-verbal</p> <p>Charles' clock chimes every 15 minutes with a different bird call each time.</p> <p>The researcher uploads the bird watching app and selects the information on blackbirds</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Session 3 description

Session 3 begins with a tour of all the photos displayed in Charles' dining room. He enjoys reminiscing and is very proud of his family and all their achievements. After some time the researcher directs the conversation towards the technology. Charles decides to have a look at the astronomy app, a past hobby which he described in his interview. Exploring the different levels on the app fascinates Charles; he has considerable knowledge of the solar system and is very impressed at the way it is displayed on the screen before him.


<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: can you see that OK? Charles: Yes fine.....that is fantastic isn't it, I can't believe what they can do nowadays Researcher: So all this here in the dark is the other side of the world.....it's good isn't it? Charles: fantastic</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher selects the astronomy app and Charles begins to interact with it independently.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Charles manages to direct the conversation away from the technology again and begins to discuss some of the pictures that are facing him on his wall.


<p>Mode 1 - Verbatim Transcription</p> <p>Charles: You know that picture don't you? Researcher: I do know that yes, it's Shepherds Wheel Charles: That's right... you told me its empty isn't it....? Researcher: Well I think it's a museum...nobody lives there Charles: Do you have to pay to go in there then? Researcher: No I think it's free Charles: I must get Fiona to take me down there Researcher: I think you'd enjoy it, it has all the old grindstones there and a working water wheel...</p>	<p>Mode 2 – Description of non-verbal</p> <p>Charles points to an oil painting he has on the wall. He is recalling a conversation we had at the last session.</p> <p>The researcher turns to Charles and gestures a wheel like motion with her hand.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Session 4 description

On arrival for the final session Charles is keen to sit in a different room and have a chat rather than interact with the technology. He suggests we have a chat first then move through to the usual room where the camera will be set up. When the video recorded session begins, Charles is going back over the handwritten family tree that was transferred onto the computer during session 1. The researcher attempts to introduce the technology again and Charles asks if the researcher is familiar with the documents he has on his ancestors. The researcher has seen these documents every week since the research began but this has slipped Charles' mind. He seems keen to skip the technology interaction today and prefers to carry on chatting. However, Charles becomes engaged with the technology when he recognises the solar system app from the week before.

<p>Mode 1 - Verbatim Transcription</p> <p>Charles: That was the planets we were looking at last time Researcher: Yes it was do you want to have another look? Charles: Yes OK Researcher: You recall all of this don't you? Charles: Yes I do, its short-term memory I have a problem with.</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher begins to scroll through the apps and Charles recognises the astronomy one. Charles has no problem remembering the application that he enjoyed interacting with last time</p>	<p>Mode 3 – Representation of non-verbal</p> 
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However the application fails to hold his attention for extended periods of time today. Charles points to the video recorder in the corner of the room. He had forgotten that the session was being recorded.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: Do you keep forgetting it's there? Charles: I do... Researcher: Me too..... Charles: Is it recording my voice as well? Researcher: It is, does that bother you? Charles: No Researcher: OK</p>	<p>Mode 2 – Description of non-verbal</p> <p>Charles notices the video camera in the corner of the room. He smiles and points at the camera.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Overview of Charles' participation

Charles expresses himself as an intelligent man with an inquisitive brain and reports the need to find strategies inside the home for keeping his mind active. This has extended to the constant logging of information from street lights switching on to the time and content of television programmes that have been viewed. Evidence suggests that adopting these kind of strategies act in a compensatory way in an attempt to adapt areas that are becoming cognitively weaker (Mowszowski, Batchelor, & Naismith, 2010). However, interventions that are designed to cognitively rehabilitate people living with a recent diagnosis of dementia are considered ineffective although no negative effects of such interventions have been observed (Clare & Woods, 2008). Nevertheless, Charles seeks some comfort in his strategies and is open to new opportunities and ways of keeping his brain active and feels these activities compensate for his lack of physical activity.

Charles appears to be a proud man and rarely acknowledges that he has a diagnosis of Alzheimer's disease. He reports feeling desperately lonely and isolated from the outside world but attributes these feelings to his physical condition and his fear of falling. This increasing isolation is having a negative impact on Charles' confidence and given the opportunity to socially engage outside the home would now be declined in his opinion. Although Charles describes feeling lonely and isolated, he uses these descriptions interchangeably. Existing evidence suggests that they are two different concepts as it is possible to be socially isolated and not lonely and vice versa (Age UK, 2014). Nevertheless, persistent loneliness can have profound impacts on physical and mental health as well as quality of life and people with a high degree of loneliness are twice as likely to develop Alzheimer's as people with a low degree of loneliness (Holt-Lunstad, Smith, & Layton, 2010). Charles relies on formal and informal care yet he feels that he is the product of a rota system which he finds constantly diminishes his confidence and self-esteem.

Charles is confident in his technology use and was pro-active in his choice of topics and applications to explore. This extended to applications that fulfilled a purpose with an end goal rather than activities for enjoyments sake. However, for Charles, it was the regular weekly social contact enabled by the research that he looked forward to over the technology use and often Charles would disengage from an activity in favour of engaging the researcher in lengthy conversations about his family and reminiscing of the way life used to be.

Participant 7 – Mary (80)



Mary is an 80 year old woman who lives with her husband in a purpose built single story dwelling towards the north of Sheffield. Mary has a diagnosis of emphysema and requires a constant supply of oxygen administered through a tank in her lounge. In addition to dementia, Mary also has a diagnosis of Parkinson's disease and considers both of these conditions as secondary to the emphysema.

Mary considers the Parkinson's more debilitating as the symptoms deter her going out in public yet dementia for Mary has no physical symptoms. She explains that her daughter seems more worried about the dementia whereas Mary appears unconcerned. Mary is friendly and sociable with a sharp sense of humour. She is very self-aware and has a good knowledge of what is happening to her and why. She has a tendency to use a lot of 'sayings' when she talks that are not necessarily common to Sheffield but which are certainly used more by the older adult. These include 'if you don't laugh you'll cry', 'there's no pockets in shrouds', and 'I've come from the school of hard knocks'.

Between each visit Mary appears to recall everything we've talked about the session before and she rarely repeats herself. However, most debilitating for Mary is her physical inability to get outside and enjoy her garden. Her greatest fear is falling and although she has a crutch she complains that the rubber end slips on the decking leading to her garden. When she moved to the property 10 years previously she says she was physically much fitter. Getting out was not an issue then as Mary had a car and was physically much more able. However, Mary describes her greatest challenge to be social isolation for two reasons. First the emphysema stops her walking more than a few steps and second, the dementia diagnosis has meant her driving licence

has been taken away. Mary describes a decline in confidence overall due to her inability to get out and interact with others.

The Context

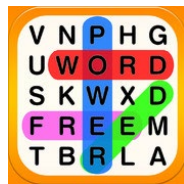
Mary's home is warm and welcoming. She is an early riser so the sessions always take place in the morning whilst her husband is still in bed which Mary explains gives her some 'peace and quiet'. Mary has a small dog who she says is her best friend and provides her with companionship and company. The lounge is full of photos of Mary's grandchildren and she speaks of their achievements with pride. There is an oxygen tank, walking frame and wheelchair in the lounge, which are all visual indicators of Mary's long term health conditions.

The Interview

Mary has no knowledge of computers as she was never required to use them at work. She has difficulty identifying particular activities from the past as her time was spent working and bringing up her children. Currently, puzzles are a favourite of Mary's if she comes across one in the paper or magazine she will save it for later. Mary describes her love of reading until a few years ago but she reports that the dementia causes a lack of concentration and she often finds herself reading the same sentence over and over again. Mary talks about holidays abroad when her family were young, back in the day when Benidorm was a 'quaint fishing village'. Mary worked for many years in the Sheffield branch of John Lewis in the soft furnishings workroom. She was a very talented seamstress and curtain maker but her 'shaky hands' do not allow her to continue with activities like this anymore. Mary is content to try anything on the computer and leaves it up to the researcher to select a range of applications for session one.



Bird Song



Word Search




Memory Match




Google

Session 1 description

The first session begins with a conversation about birds and exploring the bird song app. The bird songs are so realistic that Mary looks around the room for the bird, this makes both Mary and the researcher laugh when she realises the noise is coming from the device.


<p>Mode 1 - Verbatim Transcription</p> <p>Mary:.....but of all the birds I used to feed that was the only one that became a friend Researcher: See what you think to this Mary:.....aww I was looking for the bird then Researcher: it sounds real doesn't it? Mary: Oohh it's lovely....</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher selects the call of the Robin and the sound comes from the device. Mary looks around the room for the bird. Mary looks at the researcher and they both start to laugh. The robin continues to sing.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Mary enjoys chatting and very soon the conversation moves off topic and away from the device. The researcher attempts to engage Mary with the device again by selecting the word search app. Mary is independent in her technology use and very able in completing a word search. As the session continues the conversation covers various topics which we enjoy talking about whilst completing the word search together.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: Have you seen one of these before?...a word search Mary: Yes, yes, in fact I've saved my magazine over there as it's got one on the back page Researcher: How does it look, can you see the letters OK? Mary: Yes that's fine... Researcher: So you're a word search fan are you? Mary: Not particularly but it keeps the grey matter working Researcher: I think that's great, exercise for the brain is important Mary: Well, I feel like I'm doing something</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher selects the word search app in an attempt to steer the session back to the device. Mary points to a magazine on a chair across the room Mary studies the screen and nods her head also in answer to the question Mary points to her head referring to her brain.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Session 2 description

Following a lengthy conversation on arrival, the researcher attempts to introduce the technology to Mary again. She has no problem recalling what she did last session and very quickly familiarises herself with the device again. Mary's hands shake quite a lot unless she sits on them which she often does. The researcher offers Mary the stylus which seems to help contact with the screen.


Mode 1 - Verbatim Transcription	Mode 2 – Description of non-verbal	Mode 3 – Representation of non-verbal
<p>Researcher: Did I show you that last week?</p> <p>Mary: Yes you did...you use it to sort of dab on the screen</p> <p>Researcher: That's it, well done. So if you press select there, then play and we'll have a go at level three. This is like a matching pairs game so tap on any.....good.....then find it's pair</p> <p>Mary: Laughing</p> <p>Researcher: I gather you're finding this too easy? (laughing)</p> <p>Mary: A bit....(laughing)</p>	<p>The researcher holds up the stylus when asking Mary the question. The researcher hands the device to Mary who takes it and independently follows the instructions the researcher is offering Mary completes the next three levels. Mary continues to complete varying levels whilst keeping a conversation going with the researcher.</p>	

We begin with a card matching game but it quickly becomes clear that this is far too simple for Mary. The speed in which she completes the levels makes us both laugh and the researcher begins to wonder if Mary is trying to get this exercise out of the way so that the earlier conversation can be resumed. Mary continues completing levels in the memory game whilst holding a constant conversation with the researcher. The conversation does not include the technology but rather Mary steers the discussion towards whatever she chooses.


Session 3 description

During this session we sit in the kitchen as Mary's husband is having his hair cut in the lounge. Mary is cross that he has chosen to book this appointment for this morning when usually he 'refuses' to get up until lunchtime. There is limited space in the kitchen

for us both to sit and engage with the technology and this is not an ideal condition for the session.

<p>Mode 1 - Verbatim Transcription</p> <p>Mary: Of all the days.....I'm annoyed, he should be sat in here having his hair cut. Researcher: It doesn't matter Mary: Any other day he wouldn't roll out of bed until lunchtime</p>	<p>Mode 2 – Description of non-verbal</p> <p>The session takes place in the kitchen but there is limited space for the video equipment and technology. Mary is cross with her husband and her anger is expressed on her face.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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We begin with the card matching game again and Mary is completely familiar with the technology and the app, requiring little input from the researcher. After a while the application is switched to solitaire and Mary recalls playing the game as a child with traditional playing cards. Mary finds this more challenging but understands the rules and the instructions given by the researcher. Mary's mood also improves as the session progresses.

<p>Mode 1 - Verbatim Transcription</p> <p>Mary: mmm, I think I'm getting mixed up here Researcher: I think you're doing great.....Did you ever play solitaire, the card game when you were growing up? Mary: Yes, and the board game solitaire</p>	<p>Mode 2 – Description of non-verbal</p> <p>Mary has a game of solitaire on the device. There is a constant dialogue between Mary and the researcher. Mary begins to enjoy herself.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Session 4 description

The final session takes place back in the lounge where there is more room. The researcher asks Mary what she would like to do and Mary decides that she would like to look at some pictures on the internet of her old place of work. Working was a big part

of Mary's life for decades and she has many stories to tell, ultimately prompted by the pictures explored on the device.

<p>Mode 1 - Verbatim Transcription</p> <p>Researcher: So where's this in comparison to where it is now? I can't think where Coles Corner was?</p> <p>Mary: Do you know where the cathedral is?</p> <p>Researcher: Yeah</p> <p>Mary: Well that's the Cathedral there, traffic used to go up there, passed Marks & Spencer's</p> <p>Researcher: Ahhh</p> <p>Mary: If you went this way, that's Church Street</p> <p>Researcher: Ahhh I get you</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher points at the screen and asks Mary a question. Mary points to the picture on the screen in front of her describing her answer for the researcher.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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The majority of this session is spent reminiscing about Mary's place of work and coincidentally, the researcher also worked there for 10 years both recalling many staff members that were known in common.

<p>Mode 1 - Verbatim Transcription</p> <p>Mary: We walked out of Coles' and started walking down the High Street and one of them says....Mummy, Mummy look what she's got.....two big red candles</p> <p>Researcher: Oh no...never....(laughing)</p> <p>Mary: So I said 'where've you got 'em from' and she says 'she got 'em from in that shop', and she'd walked out of the shop with these two massive candles and she couldn't even get her fingers round them.</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher loads some images of Mary's old place of work onto the device. The first image reminds Mary of a story which she recalls with much hilarity.</p> <p>Mary mimes holding two large candles.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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Overview of Mary's participation

There are numerous occasions throughout the sessions involving Mary that are so entertaining. Mary is a comedian and not in a silly way. She appears intelligent and very quick witted which can make her humour quite edgy at times. Mary enjoys having an audience and the researcher enjoyed every session involving Mary and her stories. It was considered that Mary has a real need to socially interact with the outside world and this project is fulfilling that need at this moment in time. Many topics are covered during the sessions including Mary's marriage, the war, and family as well her childhood and growing up. Mary acknowledges her conditions in a pragmatic way and it is not evident that she feels less confident when interacting with people. At present, the dementia is merely an irritant that has limited Mary's abilities to continue reading novels. However, the emphysema and the Parkinson's disease are the debilitating conditions that physically limit Mary both in her ability to get out of the house and the stigma she feels is associated with the conditions. This supports existing figures that suggest 72% of people with dementia are also living with other co-morbid conditions (Alzheimer's Society, 2014b).

Mary's spousal relationship offers limited companionship and in her opinion it is her pet dog that remains her closest friend. The research sessions provided vital social contact for a short period of time enabling Mary to interact with another person and explore all the experiences she has had, past and present. Mary faced no challenges when interacting with the devices, although this was secondary to the increased social interaction, the technology could be considered a facilitator to these encounters or a catalyst to conversation (Cutler et al., 2014) enabling topics of interest to be explored and discussed.

Participant 8 – George (85)



George is an 85 year old man who lives on his own in the south west of Sheffield in a ground floor 2 bedroom flat. George has been a widow for over 15 years, his two children visit when they can. All contact during the field work was made directly with George although he does have a hearing impairment which consequently makes telephone calls problematic. George waits at the window for the researcher's arrival at the start of each session.

George has formal carers three times a day and aside from this there is limited other regular social contact. He also has problems walking and feels physically unable to get out independently. George states that he is lonely and bored as well as missing his son, grandchildren and great-grandchildren who live in various parts of the country. George has a daughter who lives in Sheffield and she visits whenever she can, work commitments permitting. There are some extended silences in George's conversation where he is attempting to reconnect to what he was saying previously. He describes this as a brain problem and gets irritated when it happens. George is always quick to admit when struggling to articulate something and although this infuriates him he will wait patiently a minute to see if the required word would come forward. If not he would apologise and move on. George appears as an educated, well-spoken individual who is constantly reading magazines or newspapers. George explains that he has numerous subscriptions to many magazines that get delivered to his home either weekly or monthly.

The Context

The property is comfortable and compact; one wall holds a bookcase packed with books and photo albums. There is a large straight backed chair where George spends the majority of his day sitting watching television and a small dining table where he sits

to eat his meals. There is a large rack of CD's next to the television although George explains that he can no longer remember how to use the CD player. One of the properties bedrooms has a large Hornby train set that takes up most of the room but George rarely uses that these days. There is a notice on the lounge door that has been handwritten by his daughter, it says 'If I forget where I am and what I am doing then call Margaret on this number -----'

The Interview

George is excited about the research but equally important to him in his opinion is having made a new friend. He is confident and enthusiastic regarding the topics he would like to cover during the four sessions. The first topic is his army career, of which he spent 12 years as a young man based in Libya, Palestine, Israel and Cairo as well as home service in Windsor, England. We discussed friends that he had made in the army and the researcher was curious whether he may have stayed in touch with anyone from those days. George said that it was not that kind of grouping and nobody stayed in touch with army comrades who came from all over the country. He explains that his battalion only lost one service man in an ambush whilst taking an interpreter home. On George's return to civilian life he met his future wife and had two children, an experience he describes as 'pleasant'.

George's main hobby that has spanned the decades is his interest in archaeology. He describes having been on a 'dig' and also subscribes to a monthly magazine depicting the topic. Music has always been important to George and he enjoyed going to concerts of classical musicians, in addition he was a member of a bridge club for many years. George describes these activities as giving meaning to his life and how that meaning has gone because he feels unable to participate socially anymore. He explains that he is physically unable to get out of the flat and no longer drives but in addition to the physical aspects he can no longer remember the rules of bridge, for example. George still enjoys music but feels that he has become 'idle in his old age' and rarely plays any of his CD collection anymore. He speaks of family holidays in Filey when the children were small and renting a flat on the sea front for two weeks at a time. Once a week the local church organise a lunch meeting for some of the local older adults in the area. George feels fortunate as the community bus picks him up and drops him home afterwards. He describes an incident last week where he had gone for a lie down, forgetting that the bus was due, and when he woke up he thought it was 11 o'clock at night but actually it was 11 o'clock in the morning.

George has had no past computer experience at home or at work. He has never used a touch screen in a supermarket, library or bank but considers his participation in the research as a great opportunity to have a go. The applications considered relevant were:-



Google Earth



Google



Archaeology



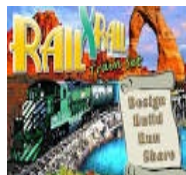
Astrology



Word Search




Blue Block




Model Train

Session 1 description

The first comment George makes at the beginning of session 1 is how the interview from the week before has stirred so many memories for him. He says this is a good thing and these were topics that he had not thought about for many years. The session begins with Google Earth as the researcher is keen to show George the army barracks he was based at in Windsor. For all of the sessions involved in study 2, 3G network coverage was required in order to search on the internet and YouTube for the topics that most interested participants. The devices had a sim card installed enabling 3G network coverage in places that had no Wi-Fi connectivity. Unfortunately, on the particular road that George lives, network coverage was limited and did not allow enough data for searching and downloading information. This problem was not discovered until the first session as the devices were not used for Wi-Fi during the interviews. George was disappointed and blamed the problems with today's technologies. The researcher attempted to explain that it was connectivity problems in that particular area rather than a fault with the technology.

<p>Mode 1 – Verbatim transcription</p> <p>Researcher: I was keen to show you Victoria Barracks on Google Earth. Now Google Earth is a live feed from a satellite so the images should be in real time. George: Ahhh Researcher: So I thought we could have a look and you could show me what you recognise. George: Brilliant.....Come on; don't make a liar of her..... It's being awkward</p>	<p>Mode 2 – Description of non-verbal</p> <p>George taps the screen bringing up Google Earth. The device fails to connect to 3G. George speaks directly to the technology George sighs. After several minutes trying to connect to 3G the researcher moves on.</p>	<p>Mode 3 – Representation of non-verbal</p> 
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George was disappointed, he is blaming the technology for not being able to access the information he would like. The researcher decided to move on to the Archaeology app as this did not require internet access and the second half of this session was spent reading and discussing topics of interest from this particular application.


<p>Mode 1 – Verbatim transcription</p> <p>Researcher: Instead why don't we have a look at this archaeology app I downloaded and we can search for information on the million year old footprint? George: A what? Researcher: footprint, the million year old footprint George: oooooh great</p>	<p>Mode 2 – Description of non-verbal</p> <p>The interest on George's face is instant and he leans forward in his chair closer to the screen. George looks amazed at the video on the screen</p>	<p>Mode 3 – Representation of non-verbal</p> 
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The researcher assured George that by the next session a solution will have been found to get 3G coverage and search for the information he was so eager to know. This assurance was premature and George's expectations were raised before the researcher had fully explored the connectivity problems.


Session 2 description

The area in which Charles lives, in particular the steep road he lives on has had an impact on the coverage available on the 3G tablet devices. On further discussions with the Wi-Fi provider, it was discovered that Sheffield and the area in particular where

George lives is notoriously bad for receiving 3G connectivity. The solution was for the researcher to search and download information onto the device specific to George's interests in between session thus available during the following session. Session 2 began with the astrology app and the globe was explored looking at the different placement of countries and archaeological digs that were of interest to George. This prompted a lengthy conversation from George about two holidays he had spent in Australia.

<p>Mode 1 – Verbatim transcription</p> <p>George: I enjoyed our trip to a million years BC you know last time</p> <p>Researcher: Yes I did too George I just wish we could have got more information for you. Don't worry though because I've got lots of ideas and interesting things to show you that I've been searching for this week.</p> <p>George: Oh good, I really have been looking forward to it.</p>	<p>Mode 2 – Description of non-verbal</p> <p>George looks directly at the researcher as he talks with the technology open in front of them.</p> <p>George's enjoyment of the session so far is explicit on his face.</p>	<p>Mode 3 – Visual representation</p> 
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Based on George's interest in model railways the session then proceeded to an application that enables the user to construct their own model of a virtual railway.


<p>Mode 1 – Verbatim transcription</p> <p>George: I've been collecting the track for years now, a piece comes in the post every week</p> <p>Research: You really do have a passion for trains don't you?</p> <p>George: Oh I do and do you know it stems from being evacuated in the war.</p>	<p>Mode 2 – Description of non-verbal</p> <p>George leans closer to see the screen, he is very focussed. The researcher points to the screen.</p>	<p>Mode 3 – Visual representation</p> 
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Having spent some time interacting with this app, George appears to disengage. It is possible that this activity has failed to translate appropriately as an application on the device as it can get tedious and childlike which fails to retain George's attention.


Towards the end of the session George asks if we can search the internet for information on Tripoli. It is a challenge for George to understand the connectivity limitations in his area which is to be expected given his inexperience with contemporary technologies. He attempts to rationalise the situation by considering that the government might be blocking our attempts to get the information we require. There is a definite disappointment from George and the researcher feels that his expectations have been raised and neither the technology nor the research have delivered.

Session 3 description

The first question George asks the researcher at the beginning of session 3 is whether or not she has managed to solve the connectivity problems on the device yet. In an attempt for the sessions not to continually disappoint George the researcher came prepared to session three with numerous additional articles and videos on the topics he is interested in already downloaded onto the device. The session begins with a video of the unearthing of the million year old footprints. George was transfixed and wanted to watch the video a second time straight after the first. It really feels like he is thirsty for knowledge and would much prefer to learn about new things than play games or do puzzles on the device.


Mode 1 – Verbatim transcription	Mode 2 – Description of non-verbal	Mode 3 – Visual representation
<p>Researcher: Now look at this and tell me what you think.</p> <p>George: May we see that again? I think it's fascinating</p> <p>Researcher: Of course</p> <p>George: Fantastic isn't it?</p> <p>Researcher: Well that's a little bit of information for that busy brain of yours.</p>	<p>Both watch the ten minute video in silence.</p> <p>The researcher sets the video back to the beginning</p> <p>George is engaged and animated.</p>	

After watching the video twice the researcher shows George some images that had been previously downloaded depicting his regiment at Victoria Barracks, Windsor. The various uniforms and what they mean are discussed as well as the jobs that George had been involved in during this time. George appeared to enjoy this session far more than the previous one.

<p>Mode 1 – Verbatim transcription</p> <p>Researcher: OK, yeah. Oh look here is a more up to date picture and look they've converted the Barracks into apartments and townhouses</p> <p>George: Gosh what a shame, I wouldn't recognise the place now.</p> <p>Researcher: So this must be the cricket pavilion that you mentioned</p> <p>George: Yes could be</p>	<p>Mode 2 – Description of non-verbal</p> <p>The pair lean close to the device and attempt to work out exactly where George resided when he was in the army.</p>	<p>Mode 3 – Visual representation</p> 
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Session 4 description

For the final session the researcher attempts to unite George's love of history and culture with Blue Block, a Chinese puzzle that relies on tactic, patience as well as trial and error. George immediately engages with the puzzle and although difficult, George appears to enjoy the challenge. There was limited conversation whilst interacting with the puzzle and the majority of the dialogue was spoken by the researcher. When the puzzle was finally complete there was a great deal of satisfaction from the task, it had not been easy but with much perseverance it was completed. It was agreed that there was a definite sense of achievement in such an endeavour but when asked George decided he did not want another game. George does not ask again about the connectivity problems with the device.

<p>Mode 1 – Verbatim transcription</p> <p>George: How about that then?</p> <p>Researcher: YES!!</p> <p>George: See what you can do with a bit of joint co-operation.</p> <p>Researcher: It's very frustrating that game</p> <p>George: No I didn't think so</p> <p>Researcher: I think you have more patience than me</p>	<p>Mode 2 – Description of non-verbal</p> <p>George and the researcher are attempting to complete the Chinese puzzle Blue Block. On completion the pair share a look of delight and achievement</p>	<p>Mode 3 – Visual representation</p> 
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Overview of George's participation

George's participation could be considered as pro-active and he was observed to maintain a desire for new knowledge and opportunities to learn. It is unrealistic to assume that George may have knowledge of the connectivity challenges despite the figures which suggest older adults are the fastest growing group of internet users (Ofcom, 2012). Yet, understanding is limited regarding the use of ICT by people with dementia possibly due to a range of barriers including memory impairment, lack of confidence, or support and technical challenges (Mitseva et al., 2010). George expressed increasing disappointment with this situation as the sessions went on and in consequence by session 4, appeared resigned to the limitations of the technology. This particular barrier to technology use was frustrating as out of all the participants in the study, George was possibly the most pro-active and interested in searching the internet for information that was important to him. Although, it would not be realistic to expect an 85 year old person to be familiar with such devices, especially given the fact that George had no ICT experience pre-retirement. It is a challenge to understand how the connectivity challenges may be overcome in the future if George ever decided he needed a home computer. The researcher attempted to compensate by downloading alternative information pre-session which George enjoyed but these activities did not allow for the active participation that George appeared to crave, whilst interacting with puzzles and games appeared to be beneath George's thirst for new knowledge.

Promoting realistic expectations of the technology is an important ethical consideration and one that was adhered to throughout the research project. However, the emphasis was not to allude to the prevention or relief of symptoms but truthfully describe the intervention using the technology as potentially enjoyable in the context of leisure and recreation. Understanding participant's expectations of this research project was crucial as a way of exploring what they hoped to gain from their involvement. It is proposed that the degree of discrepancy between expectations and experiences determines satisfaction, thus satisfaction is obtained when perceived inputs and outputs are balanced (Bowling et al., 2012). For George, his experience of the research did not meet his expectations and it had not occurred to the researcher that expectations could be raised and not met due to connectivity challenges with the technology. For George, the research sessions proved to be disappointing and by the final session he appeared resigned to the limitations of the technology.

Participant 9 – Steven (79) and Elaine



Steven is a 79 year old man who participated in the research alongside his wife Elaine. The couple have been married for over fifty years and have two sons, three grandchildren and one great-grandchild. The couple live on the outskirts of Sheffield, towards the north of the city in a two bedroomed bungalow. One son lives close by and often visits his parents on the way home from work.

Elaine is chatty and outgoing whereas Steven is quieter and generally only speaks when spoken to although they both have a great sense of humour. Elaine does comment that since Steven was diagnosed she has had to assume the role of two people and as well as her usual tasks she now has to pay the bills and look after the household finances which was never her job in the past. It was also observed that Steven appears to be using certain strategies to compensate for his memory impairment. For example, the researcher may ask where they have been on the coach with the social group and Steven would answer 'all over the place' and not be able to recall a previous destination. Another example would sound like this:-

Researcher: What is your favourite island in the Canaries?

Steven: What's yours?

Researcher: Mine is Gran Canaria

Steven: Same as me

Elaine drives and takes them both out now and again to the shops but never in the dark. Elaine explains that the winter months are worse as the days feel so long when

they are stuck indoors. Other than the television, she explains there is little to keep them occupied.

The Context

The house and the couple are warm, welcoming and friendly. The house is situated at the bottom of a large hill which the couple now have difficulty walking up due to mobility problems. They drive everywhere they go which becomes problematic due to accessibility in bad weather conditions rendering them socially isolated in the winter months. The interview and the four sessions all take place quite formally at the dining room table. Steven is always waiting at the window for the researcher to arrive and equally waves her off on her departure.

The Interview

Elaine makes a comment early on in the interview regarding her irritation at people speaking over Steven and taking no notice of what he says. There are occasions when Steven is asked a question and Elaine will answer it for him. This was a difficult situation as there is a real need to acknowledge everything Steven has to say whilst respecting how Elaine deals with everyday life. Steven needs reminding that the session is being filmed and he keeps pointing at the camera asking what it is. Steven also uses a couple of mild swear words during the interview which upsets Elaine. The researcher reassures them both that there is no reason to worry and the video of the interview is will only be seen by her, Steven mutters that he is always wrong.

Stevens' passion is football and he played semi-professionally before he was called up for national service in the RAF. Up until retirement, Steven was an accountant and played football or coached teams as a hobby in his free time. The couple still enjoy their holidays abroad to the Canaries and have also been on a few cruises in recent years. They are both members of an over 50's group which meets locally and they also join in on the annual coach trips to various locations across Britain. When asked Steven says he likes doing crosswords but Elaine tells him to stop telling fibs and that he had not done a crossword in years. She continues that he has never read a book in his life although they both enjoy watching sports on the TV.

Steven did not retire until he was 70 years old and had a computer on his desk for twenty years before that. Elaine explains that over a period of time Steven has lost all desire to maintain past activities including computer use and does very little these days

except stare out the window. He can be persuaded to do a crossword as long as it is with Elaine and not independently. Based on the discussion during the interview, the applications uploaded onto the devices were as follows:-



Football quiz



Memory match



Google




FIFA 13



Pocket Pond

Session 1 description

As the first session begins there is an indication that Elaine is hoping to achieve far more from these sessions than Steven so the researcher is alert to maintaining an equal focus on both participants. The session begins with a discussion about a recent newspaper article of an ex-professional football player who had been diagnosed with Alzheimer's disease. The blame for Stevens' condition is placed on years of heading a heavy leather football. Steven then has a quick outburst and consequently upsets Elaine by swearing.

Mode 1 – Verbatim transcription	Mode 2 – Description of non-verbal	Mode 3 – Visual representation
<p>Elaine: Well, he said heading the ball when it was wet was like heading a cannon ball...it's no wonder he's ended up like this. The Doctor said....</p> <p>Steven: Bigger off!!</p> <p>Elaine: Steven stop saying that, it's not funny....right?</p> <p>Steven: Right</p> <p>Elaine: Right then</p>	<p>Elaine points to Steven.</p> <p>Steven has an outburst.</p> <p>Elaine shouts at himshe is cross</p>	


The researcher moves the session on quickly by beginning with a football quiz, the sport which is Stevens' passion. This immediately causes a problem as Elaine knows all the answers and Steven does not recognise any of the clues. Steven keeps guessing which irritates Elaine until he finally gets the right answer.

Mode 1 – Verbatim transcription	Mode 2 – Description of non-verbal	Mode 3 – Visual representation
<p>Researcher: So this is the strip they wear, this is the manager and this is the logo. Any ideas? Elaine: Oh I know, I know Steven: Sheffield Wednesday!! Elaine: Don't be silly..... Researcher: Ahhh I see why you said that... the same colour strip don't they? Blue and white Steven: Yes they do Elaine: We watched them last night Steven: Who? Elaine: That.....Come on, who is it...Don't you know? Steven: No Researcher: No....Me and you are rubbish at this, Elaine is really good Elaine: Curly C it begins with....Oh you do know it, this is silly Steven: Arsenal?? Researcher: Can you think of another one? It begins with C? Steven: Chelsea? Researcher: Brilliant....you got it!!</p>	<p>The researcher gestures to the screen. We wait and look at Steven to see if he is going to have a guess. When Steven guesses incorrectly Elaine laughs Elaine raises her voice and nods her head at the screen. Elaine gives him the first letter as a clue. Steven proceeds to make another wrong guess which exasperates Elaine The researcher and Steven look at each other and smile and Elaine puts her head in her hands</p>	


This was not a productive or enjoyable game for Steven and it appears to illustrate his deficits quite considerably. There is a stage in the session when Steven physically withdraws away from the technology and into himself. Steven keeps guessing which irritates Elaine until he finally gets the right answer. The session is punctuated with conversations that are not necessarily related to the application yet take place whilst still interacting with the device. These conversations are instigated by Elaine and Steven generally sits quietly until someone addresses him.

Session 2 description

This session does not begin well as Steven makes a joke that Elaine appears not to find funny. Elaine then remarks that they had been looking forward to the visit having really enjoyed the session from last week.


<p>Mode 1 – Verbatim transcription</p> <p>Researcher: Can I sit next to you? Steven: Yes....as long as you don't bite? Researcher: I can't promise I'm afraid Elaine: We said to each other after seeing you last week that we'd both thoroughly enjoyed it. Researcher: Oh I am pleased....that is good news.</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher sits down next to Steven and they both smile.</p>	<p>Mode 3 – Visual representation</p> 
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The session begins with a card matching game. The researcher is keen to explore applications that will highlight Steven's strengths and promote feelings of achievement after the disappointments of last week's session. Steven makes a match on the first two cards he turns and the praise he gets from Elaine encourages him to carry on.

<p>Mode 1 – Verbatim transcription</p> <p>Researcher: This is obviously too easy for you, try another one Elaine: So remember where you've seen those two and then you might make two more pairs.....Oohh I've seen one like that before, can you remember?.....Noooo, you're not thinking now.....that's a monkey, where did you see one before? Steven: One what? Elaine: A monkey you silly thing....</p>	<p>Mode 2 – Description of non-verbal</p> <p>Elaine talks to Steven and he continues to interact with the technology. She encourages him and talks constantly.</p> <p>Steven begins to press any card quite randomly in the hope of matching a pair</p>	<p>Mode 3 – Visual representation</p> 
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Session 3 description

At the beginning of this session it becomes obvious that Steven has little recall of the previous session, technology or applications. He says that he remembers the researcher but only because his wife had just reminded him previous to her arrival. Elaine explains that part of Steven’s routine in the morning is for her to recount everything that they will be doing that day although he also needs constant reminders throughout the course of the day. Steven does not appear to have much enthusiasm for the session today and it takes some persuasion from Elaine to get him to turn off the TV and join us at the table. We begin the session by searching on the internet for information on the various football teams Steven has played for in the past.

Mode 1 – Verbatim transcription	Mode 2 – Description of non-verbal	Mode 3 – Visual representation
<p>Researcher: How would you feel about searching the internet for some of those football clubs you used to play for? Steven: Football clubs! Researcher: Do you fancy that? Steven: Yeah Researcher: So which football club do you have the fondest memories of Steven? Elaine: Bradford Steven: Bradford Park Avenue Researcher: Do you want to look at the South Normanton team now? Steven: No Elaine: Why not? Steven: South Normanton Athletic FC Elaine: Yeah, do you remember it? Steven: No Researcher: Do you have some good memories of playing football Steven: No</p>	<p>Steven appears enthusiastic when he hears the word football.</p> <p>Steven smiles and all begin to interact with the technology.</p> <p>Elaine answers a question that was directed at Steven.</p> <p>The researcher has already uploaded the web page and Steven reads from it</p> <p>Steven looks sad</p>	

Very quickly Steven begins to get upset, possibly because he has little recollection and the activity is only highlighting all that he has forgotten. Steven decides that he does not want to look at football teams anymore. Stevens’ mood appears particularly low


today and he has been far more animated in previous sessions. The researcher moves the session on to an activity that has engaged Steven well in previous sessions.

<p>Mode 1 – Verbatim transcription</p> <p>Researcher: So, last week we looked at a few games and puzzles on this computer Steven: Did we? Elaine: Do you not remember last week? Researcher: We did, you were brilliant at solitaire Elaine: Patience it was, you were good at it</p>	<p>Mode 2 – Description of non-verbal</p> <p>Steven has no recollection of the previous session. He looks at Elaine questioningly and she nods and compliments him.</p>	<p>Mode 3 – Visual representation</p> 
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Steven does not engage as well in this session as he has done in the previous two sessions. He appears apathetic and withdrawn which is possibly how his condition is being experienced at this particular point in time.

Session 4 description

Steven appears more enthusiastic as this session begins; he is asking questions and smiling more than the last session. In previous sessions the researcher has attempted to engage Steven with a football quiz in order to address his love of the game. However, Steven’s engagement has been limited with this quiz and he struggles to answer questions or guess team names which only highlights his memory impairment further and causes him to withdraw his interactions. This session, the researcher attempts a more practical activity that may engage Steven with actual skills and judgement in a virtual version of the game.

<p>Mode 1 – Verbatim transcription</p> <p>Researcher: So this game is a bit more practical than the football quiz. We have to try and score a goal Steven: Score a goal?.....there Researcher: That’s it...so this is a goal from an actual match and we’re going to try and replicate it, ermm copy it. Steven: OK</p>	<p>Mode 2 – Description of non-verbal</p> <p>Steven immediately engages with the screen. The researcher scores a goal which is saved. Steven takes a turn.</p>	<p>Mode 3 – Visual representation</p> 
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FIFA 13 is enjoyed by both Steven and Elaine; they both have an applied understanding of the game and how to score goals using tactical manoeuvres. This practical approach appears far more beneficial for Steven as he keeps scoring goals and his feelings of achievement are not reliant on his memory.

Mode 1 – Verbatim transcription	Mode 2 – Description of non-verbal	Mode 3 – Visual representation
<p>Elaine: Do a David Beckham Researcher: Yay, that's it you got it!! Do you want to try and score another one? Steven: Yeah Researcher: You have a go Elaine, I bet you're going to be good at this Steven: Did you score? Elaine: Yep Researcher: Do you want another go Steven? Steven: Yep</p>	<p>Steven scores a goal! He looks pleased with himself. Steven tries again Elaine has a go and really enjoys it. Steven seems much more enthusiastic interacting with this game</p>	

Overview of Steven and Elaine's participation

Overall, the sessions were reported as enjoyable although Steven and Elaine's situation is a challenging one. It is clear that Elaine attempts to be encouraging and supportive although reports Stevens lack of interest in usual activities as a challenge. Although this reluctance can be overcome with some cajoling which supports the evidence that activity participation may be maintained if initiated by those in a supporting role (Cook, Fay, & Rockwood, 2008). For Elaine, Steven's lack of desire to engage with activities, familiar or novel, coupled with increasing apathetic tendencies was considered more stressful than the memory impairment. The psychological and behavioural manifestations of dementia have been reported by family caregivers as being more burdensome than cognitive dysfunction, physical dependence or functional impairment (Brodsky & Arasaratnam, 2012). It was positive that the couple undertook the research together and clear that Elaine is gaining from the additional social contact afforded by the research sessions each week. The couple do everything together and Steven relies totally on Elaine but it is clear that Elaine requires additional support and someone to rely on. This supports evidence that informal carers who support a family member with dementia are affected more negatively by the responsibilities involved in

their role when compared with others who care for a family member with no dementia (Ory, Iii, Yee, Tennstedt, & Schulz, 1999).

It should not be assumed that a person's lifelong passion would mean that they have a good recall of it. In Steven's case, activities that highlight his memory impairment merely emphasise how many of his memories he had lost of his beloved game of football. Yet, Steven's ability to enjoy playing a virtual game of football was intact, akin to riding a bike, this activity was not forgotten. Thus, playing FIFA 13 reminded Steven of everything he was once so good at and the virtual translation of the game enabled him to be a 'real' player on the pitch. This suggests that Steven's ability to recall the facts of the game or to consciously declare these facts was impaired as a result of the condition. However, his knowledge of 'how' to play the game and to demonstrate this retained skill accordingly was maintained along with the enjoyment, passion and emotions this activity evoked. Impairment to explicit memory is a defining cognitive feature of dementia whereas a relatively intact implicit memory is the ability to improve task performance based on prior experience (Fleischman et al., 2005)

Compensatory strategies for a failing memory were frequently exhibited by Steven. As mentioned earlier Steven had some challenges finding the right word on occasion and rather than admit this failing he would skilfully turn a question round so the researcher was required to give an answer first, which he would then agree with. People with dementia use a multitude of compensatory strategies (Sabat, 2001) sometimes for 'self-preservation' purposes akin to Steven's strategy or maybe a more direct and candid approach akin to George. Balancing maintained abilities with those that have been lost by use of coping strategies may preserve feelings of wellbeing (Sorensen et al., 2008).

Participant 10 – Christine (78) and Michael



Christine and Michael have lived in Sheffield all their lives, been married for 50 years and have raised four children and now have grandchildren. The couple live in an exclusive development designed for retirement of the over 55's on the outskirts towards the north of Sheffield. The development is new and offers lakeside views and CCTV camera security but is some distance from any local shops and not on a local bus route. There is an activity calendar for residents including excursions, dances, quizzes and lunches as well as an onsite hairdressers and restaurant. There is a lift and 24 hour warden patrol. Christine and Michael have lived here 6 months but both report that Christine has not settled. Christine longs for her family home only a few miles away where everything was familiar and safe.

Michael had a stroke over 12 months ago and is now unable to walk so uses a wheel chair and this is the main reason they say they moved from the family home. Michael has also lost much of the use of his right arm and his speech is now slightly impaired. Christine is physically fit and questions being uprooted because of Michael's mobility issues; she explains that she could have looked after him in the family home where they belong and were managing perfectly well. Michael suggests that it is Christine's condition that made them downsize as she could not manage the large house and garden anymore. Michael's wheelchair is electric and can be problematic as they cannot get it on the community bus that is used for all the day trips. In consequence they both miss out on a lot of activities away from the development. Christine volunteers that she has little enthusiasm for anything anymore and she feels that is what the dementia has done to her. Michael says that she spends many hours staring

out of the window and he is worried for her. He admits that it was his idea that they get involved in this research to provide them with an activity to do as a couple. It is a poignant moment when Christine explains *'we're both broken in our own ways, him physically and me mentally. I can do what he can't and he can do what I can't, I suppose we're now two halves that makes up a whole'*.

The Context

The apartment is smart, clean and tastefully decorated and all the fittings are modern and contemporary. Before Michaels stroke he was an artist in his spare time and many of his paintings and photographs are hung on the walls around the apartment. The lounge and kitchen are open plan and the windows look out with a view across the development. He has a coffee machine which is his pride and joy and at every visit the researcher is treated to a cup. There is a large digital display with the time, day and date that is visible from the kitchen side. The couple are warm and friendly and very welcoming. In order to get them both in the video frame Christine is asked to move from her usual seat so that she can sit next to Michael in his chair.

The Interview

Michael has an Apple desktop computer in his office that he used to use far more than he does now, Christine has no past computer experience. Nowadays Michael uses his computer for emails and as an electronic diary. Christine has very little confidence in her abilities to use the technology and appears nervous in the interview which she explains as being grumpy nowadays. When asked if there are any activities that she misses doing Christine answers that there is nothing that she wants to do anymore and she cannot remember what activities she used to enjoy because she has lost her memory. Christine asks Michael for confirmation that she really had lost the initiative to do things and he agreed with her. She said she used to knit and crochet and always be making things but has no desire to continue with these activities. Christine and Michael indicated that they were happy for the researcher to select some applications in the first instance.



Matching pairs



Solitaire



YouTube




Jigsaw



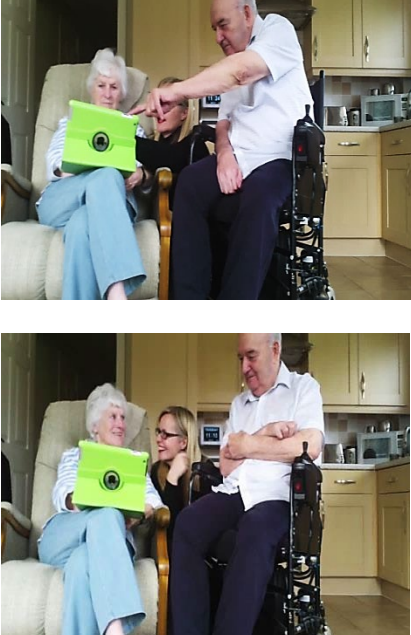
Pottery

Session 1 description

Christine looks worried as the researcher places a computer on her lap and she appears to look to Michael for help. She has concerns that she will not be any good with the computer but gives the impression that she really does not want to get involved. The researcher tries to reassure her that the session may be something that she will enjoy and begins with the card matching game.

<p>Mode 1 – Verbatim transcription</p> <p>Christine: I'm not going to be very good at this...</p> <p>Researcher: Please don't worry, If you were good at this there would be no reason for me to be here. I promise we will just have a bit of fun and you can do as much or as little as you like. OK?</p> <p>Christine: OK</p>	<p>Mode 2 – Description of non-verbal</p> <p>Christine appears concerned. She looks to her husband for support.</p> <p>The researcher comes to sit next to Christine and tries to reassure her.</p>	<p>Mode 3 – Visual representation</p> 
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Although Christine quickly understands how to navigate the touch screen, finding matching pairs in the card game appears challenging to her. Christine taps to turn any random card over without searching for a pair. It is coincidental when she finally makes a match but she appears pleased with her achievement.

Mode 1 – Verbatim transcription	Mode 2 – Description of non-verbal	Mode 3 – Visual representation
<p>Michael: They don't match.....look, they're not the same....one's a donkey look</p> <p>Christine: I'm the donkey (both laugh) no I am, I'm rubbish at this</p> <p>Researcher: Give over and give yourself a chance, you're doing brilliantly. Now try another square...there you see you did it!! That's you exercising your brain</p> <p>Christine: No it isn't, my brain doesn't work.</p> <p>Researcher: You look completely unimpressed with that</p> <p>Christine: I am, I suppose I could get into it</p>	<p>When Christine turns two cards she wonders why she has not made a pair. Michael points to the screen to show Christine what he means</p> <p>Christine reluctantly carries on and finishes the level</p> <p>The researcher and Christine laugh together</p>	


This was a difficult session for everyone involved. A fine line exists between gently cajoling Christine to participate and forcing her to do something she really does not want to do. The researcher was cautious and reassured Christine throughout the session that the ultimate aim was to enjoy the activities and not to cause feelings of anxiousness or insignificance. At this stage of the research it is considered that Christine has little desire to be involved at all but is rather going through the motions without gaining anything from the interactions, whether social or technological. At the end of the session Christine remarks that she is unaware what she has done during the last hour or why she has done it.

Session 2 description

It was essential to ascertain at the beginning of session 2 that Christine was happy for the session to go ahead. Although, Christine announces that she is not feeling well she is happy for the researcher to stay. Michael decides that the session should just involve Christine today and not him. This way Christine can stay seated in her usual place and does not have to move to allow Michael to be in the video frame. Christine is happier to just chat today, we are listening to some of Michael's favourite bands on YouTube and while he sings along, Christine talks to the researcher. Christine is quite emotional today; she talks about feeling apathetic and having little initiative to do even the simplest of tasks like taking a shower. She says that the worst time of day is when she wakes up in the morning as she has the whole day ahead of her to get through.

<p>Mode 1 – Verbatim transcription</p> <p>Christine: That's why I'm frightened to death of my dementia....</p> <p>Researcher: Well of course it is frightening.</p> <p>Christine: Well I knew it was in the family but I never thought it would get me</p>	<p>Mode 2 – Description of non-verbal</p> <p>Christine and the researcher sit side by side. Christine is talking about her condition as the researcher listens.</p>	<p>Mode 3 – Visual representation</p> 
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In contrast, Michael is enjoying the music and even though he decided not to be involved in this session he regularly shouts from across the room asking for a different singer to be found on YouTube.

<p>Mode 1 – Verbatim transcription</p> <p>Researcher: He knows all the words....</p> <p>Christine: Is that Frankie Lane?</p> <p>Researcher: Yes it is</p> <p>Michael: Can you find some Johnny Ray?</p> <p>Researcher: Of course</p> <p>Christine: Ahhh, that's better than going for a walk.</p>	<p>Mode 2 – Description of non-verbal</p> <p>Michael is singing along to the song and Christine recognises the artist.</p> <p>Christine is enjoying listening to the music and listening to her husband singing</p>	<p>Mode 3 – Visual representation</p> 
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Christine seems happier by the end of the session although she has not had much interaction with the technology herself, she has enjoyed the conversation and music facilitated by the device.

Session 3 description

Session 3 begins by exploring the virtual potter's wheel. The researcher has requested that Michael be involved in this session as is considered that he is a great support to Christine. He happily agreed and they both sat together for the session. A general discussion takes place before getting started with the technology but it becomes clear that Christine has already disengaged. At one point during the session Christine is interacting with the screen by touching it but her eyes are elsewhere.


<p>Mode 1 – Verbatim transcription</p> <p>Christine: What do I do just touch it? Researcher: Yeah, just like I showed you, pull your finger up like this or across like this.....did you ever enjoy doing any creative hobbies? Christine: No, he's the arty one</p>	<p>Mode 2 – Description of non-verbal</p> <p>The researcher demonstrates on the screen</p> <p>Christine looks at her husband and smiles</p>	<p>Mode 3 – Visual representation</p> 
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The session ends with the completion of a jigsaw. Christine and Michael do this together but it's actually Christine who places the pieces by of the puzzle independently. When the device flashes CONGRATULATIONS YOU'VE SOLVED THE PUZZLE across the screen, Christine does appear to express a sign of achievement or enjoyment.


<p>Mode 1 – Verbatim transcription</p> <p>Researcher: Can you see that OK Michael?</p>	<p>Mode 2 – Description of non-verbal</p> <p>Michael nods at the researcher. There is little conversation as Christine and Michael both complete a jigsaw together</p>	<p>Mode 3 – Visual representation</p> 
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Session 4 description

The final session begins positively; Christine especially appears more cheerful today compared to previous sessions. We begin with a jigsaw and Michael instantly engages although Christine hands the stylus over to him and turns towards the researcher and starts to chat.

<p>Mode 1 – Verbatim transcription</p> <p>Researcher: Right, what can you be bothered with today do you think? Christine: Not a lot Researcher: What about a jigsaw? Christine: I'm rubbish at jigsaws Researcher: Ooh you little fibber Michael: Get that corner piece... Christine: Where is it? Michael: This one, this one</p>	<p>Mode 2 – Description of non-verbal</p> <p>Michael leans across and engages with the device.</p> <p>Everyone laughs</p>	<p>Mode 3 – Visual representation</p> 
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Once the jigsaw is complete Michael sits back and the researcher attempts to engage Christine with the memory match game. She does engage and manages really well. The researcher encourages Christine and tells her that she's brilliant. She replies that when the researcher comes to her home she makes her feel better about herself.

<p>Mode 1 – Verbatim transcription</p> <p>Researcher: Come on Christine; show us how it's done. Wow, that's really good....so there are two dogs but they're different dogs.....brilliant! Michael: She's better at this now Researcher: She's brilliant, Christine you're doing amazing Christine: You come here and you make me feel better about myself. This game isn't easy.</p>	<p>Mode 2 – Description of non-verbal</p> <p>Michael sits back in his chair and watches Christine interacting with the technology. He acknowledges how familiar Christine has become with the device.</p>	<p>Mode 3 – Visual representation</p> 
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This is another really poignant moment during Christine and Michael's participation in the research. Christine explains that she has been making mistakes in the sessions which make her feel inadequate. Since she began to lose her memory and her husband had a stroke she says that every day is a struggle. It is clear that Christine has little self-esteem and no sense of achievement in her day to day life so when someone tells her she's brilliant she gets emotional. When Christine fails to make a correct match on this particular app then her self-esteem drops, thus applications that

do not highlight the individual's impairment would be more appropriate in Christine's circumstances. However, Christine has illustrated perseverance with the activities across the sessions which in consequence would appear to have given her more confidence to continue and feel like she is achieving something.

Overview of Christine and Michael's participation

Christine is a warm and friendly person and gives the impression that she just wants to please the researcher by doing as she is asked. There appears to be limited enjoyment being involved with the activities and restricted understanding of her participation although this does improve as the research progresses to sessions 3 and 4. Thus, towards the end of the research it was observed that Christine was more engaged with the social contact afforded by the visits rather than the technological interaction. Although when Christine is praised for doing something well in her technology use she responds positively and reports feelings of achievement. Christine never selected a specific application to engage with yet when presented with various options creative apps including virtual pottery or jigsaws appeared to be favoured. There is increasing evidence that cognitive impairment can decrease the persons desire to engage with activities yet when initiated by other they remain interested (Cook, Fay, & Rockwood, 2008). Addressing such barriers to activity and participation can therefore be expected to produce benefits for people with dementia and their family members (Clare et al., 2013).

Michael has a good knowledge of ICT in general and any difficulties engaging with the technology are purely physical in nature and cannot be attributed to lack of desire to participate. Although consistent with literature, Michael tends to use his computer for practical reasons rather than leisure activities (Broady, Chan and Caputi, 2010). Christine, in contrast, was vocal regarding her apathetic feelings and lack of desire to engage with familiar or new activities using the technology yet instances of engagement were observed throughout her participation.

There is a tension between Michael and Christine as dealing with two long term conditions will always be challenging but in addition to this Christine reports having limited desire to leave the apartment. Yet if Christine felt able to go out then the practicalities of participating in activities outside the home would be a challenge given Michaels wheelchair use. It is a challenge to understand whether Christine would have experienced such apathy had she remained in her beloved house and whether these

feelings will dissipate as time progresses. The majority of the literature focusing on transition periods in the dementia trajectory generally explore the person's move from home into residential care (Callahan et al., 2012; Runge, Gilham, & Peut, 2009). However, for Christine, as well as learning to live with dementia, the transition from her family home to a new apartment appears to have had a negative impact on her wellbeing. Dementia can impact the person's ability to adapt to changing environments and the loss of familiar surroundings can contribute to the manifestation of depression and withdrawal (Downs & Bowers, 2014). Christine constantly reflects on her beloved house and all the memories it holds for her which highlights the importance of a familiar context to the person with dementia (Preston, Marshall, & Bucks, 2007). This is in line with existing evidence that suggests the familiarity of the social and physical environment can provide a sense of continuity which consequently has implications for wellbeing and sense-of-self (Phinney, Chaudhury, & O'Connor, 2007).

6.5.2 Cross-case

As described in section 6.4.1, taking a cross-case approach enables the reoccurring experiences that have been expressed within-case (section 6.5.1) to be explored across-cases. The findings from within-cases illustrate numerous shared experiences. Other experiences were identified that only occurred in some cases and others in no additional cases. These varying experiences emphasise the uniqueness of each individual experience within case but can also illustrate the similarities cross-case. Although the process of data analysis mirrored that of study 1 (figure 5.1 page 120), the within case and cross case approach was different (figure 6.2 page 166) and it was at this stage that the identification of key themes and sub themes became clear. These are described **as expressed gains and limitations (technology interaction, social contact, and disengaged)** and **preferred activities (pro-active, active and passive)** and illustrated thematically in the typology of engagement depicted in figure 6.2.

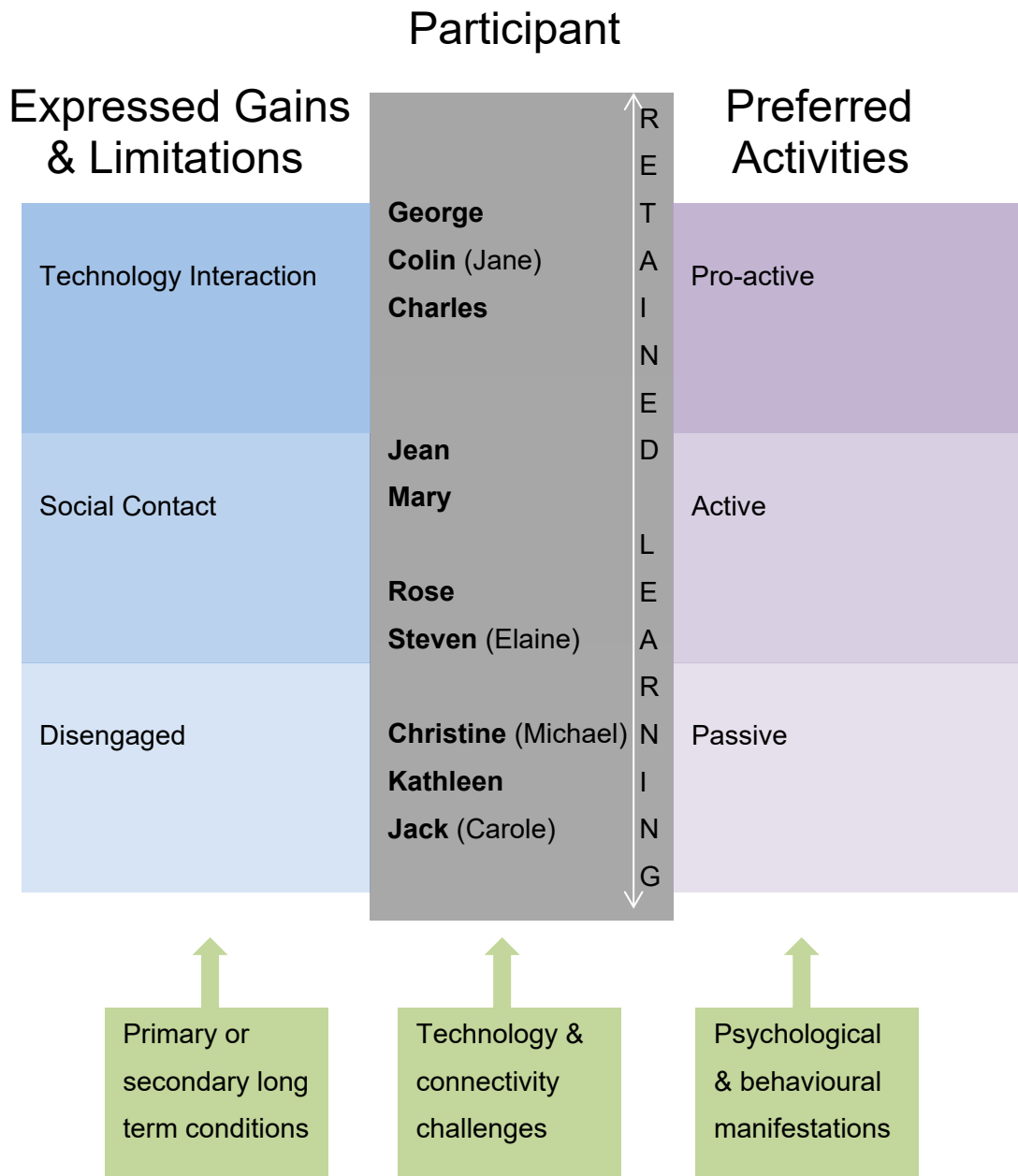
6.5.3 Developing a thematic structure

The development of a thematic structure to illustrate the main findings of the data required the researcher to make decisions regarding the most prominent findings that occurred across cases. First, which themes were key and reoccurred most often? Second, are there relationships between themes that are more meaningful than others? Third, the identification and discussion of other influencing factors that do not necessarily occur within each case or across all cases. The typology of engagement in figure 6.2 shares similarities with that described in study 1 (chapter 5) of this thesis. Typologies are an effective way of ordering the findings into numerous related yet independent themes that have emerged from the data (Ritchie and Lewis, 2003). Typologies have multiple dimensions and enable the findings to be illustrated thematically depicting the various similarities and differences expressed within case to be explored across case.

Figure 6.2 illustrates the emergent themes involving touch screen computers and enjoyable activities to be an individual experience (within-case), depicted in grey as a continuum of participation. The similarities and differences across cases are revealed within two clusters of themes and sub themes; **expressed gains and limitations (technology interaction, social contact and disengaged)** and **preferred activities (pro-active, active and passive)**. The input arrows at the base of the structure,

although not defined as specific themes, acknowledge the influence of additional factors that can impact technology participation for some.

Figure 6.3: Typology of engagement



6.5.4 Theme 1 Expressed gains and limitations

Participation with enjoyable activity in general is hypothesised to involve the pursuit or achievement of personal goals enabling a sense that one has gained something from participation (Adams et al., 2010). For the purpose of this project, the definition of 'gain' can be described as the personal and regular accomplishment of something that may impact the individuals' life in a positive way. The theme of **expressed gains and limitations** enables an understanding of how people can be motivated to participate in activities, or not, in order to accomplish diverse goals or purely for participations sake (Kielhofner 1980). Existing evidence does suggest that a person's overall quality of life can be influenced by the pursuit and accomplishment of goals, amongst other factors (Leung & Lee, 2005). The overarching theme of **expressed gains and limitations** was identified within each individual case and was sub-divided into **technology interaction, social contact and disengaged**.

Sub-theme 1- Technology interaction the majority of participants in the present study had no experience of computers and those that did generally used them pragmatically as a diary or to store photos, rarely for enjoyable activities and never for social networking. Nevertheless, there was a general interest overall in finding out more about what the touch screens had to offer based on participants willingness to be involved in the research. Technology interaction has been hypothesised as a mediator of relations in social situations (Latour, 2005), acting as a bridge or a catalyst for communication and interaction (Cutler et al., 2014).

The typology of engagement in figure 6.2 illustrates that George, Colin (and Jane) and Charles considered the ultimate gain derived from their participation to be their interaction with the technology. Specifically, George was explicit in his desire to search the internet and other applications for information on many topics that were close to his heart. He expressed his interest for a multitude of topics during the initial in-depth interview and this was carried forward throughout the research as George would regularly make notes between sessions regarding new information he wished to search for. George reported no previous computer experience but this did not deter him while interacting with technology, learning and gaining new knowledge. However, George did express on a few occasions the importance of meeting a new friend during the research thus the social contact was also an important part of the research alongside the technology use. The following expressions are taken from George's technology

sessions and illustrate the theme of expressed gains and what the technology interaction meant for him.

George: *'Oh good, I really have been looking forward to it'* (session 2)

George: *'May we see that again? I think it's fascinating'* (session 3)

George: *'Fantastic isn't it?'* (session 3)

Similarly to George, Charles reported specific activities that he wanted to engage with in order to use the technology session to his advantage. These activities included the adaption of his hand written family tree via the technology based ancestry application as well as searching and discussing the solar system exploring his passion for astronomy. Charles had some basic word processing skills from his computer use pre-retirement but reported these skills to have deteriorated over the years. The following expressions illustrate Charles expressed gains and why they are considered to be ultimately technology interaction. Although, like George, Charles also expressed enjoying the added social contact even though this appeared secondary to technology interaction.

Charles: *'ahhh well that's interesting because you know what I would love to do? I would love to track aeroplanes'* (session 1)

Charles: *'this is amazing, really interesting'* (session 2)

Charles: *'that is fantastic isn't it; I can't believe what they can do nowadays'* (session 3)

Colin and Jane were the only dyad that expressed the main gain of the research sessions to be the technology interaction. Similarly to George and Charles, Colin and Jane had specific goals they wanted to gain from the research and consistently informed the researcher how they would like the sessions to unfold. Neither had any previous experience of computers but both were observed to be quite able in their ICT usage. The following expressions capture the interest in technology interaction and the search for new information.

Colin: *'Are we going to get to touch that then and have a go with it?'* (session 1)

Colin: *'I'm going to do it myself if I can'* (session 1)

Jane: *'Oohh parks and gardens near Helsby, we've been there haven't we Colin?'* (session 3)

Jack and Carole participated as a dyad and both had previous and current computer experience. However, it was Carole, Jack's support that expressed gaining more from technology interaction during her participation in the research as she was keen to learn about touch screen computers in particular. Jack, in contrast, had limited engagement throughout the sessions neither expressing the gain of increased social contact or technology interaction. There was also limited verbal expression from Carole that may be considered illustrative of technology interaction being the main gain of the research sessions. Nevertheless, Carole had expressed to the researcher during their initial meeting that the purpose of her participation was to discover more about touch screen computers. It was therefore Carole's actions that expressed this main gain as on completion of the research Carole purchased a touch screen computer for her and one for Jack to enable them both to maintain their technology interactions.

For George, Charles, Colin, Jane and Carole, increased or new technology interaction was the ultimate aim of their research sessions. Gaining new knowledge of technology in general or using the technology as an instrument to further existing knowledge was observed and expressed throughout the sessions involving these particular participants.

Sub-theme 2 – Social contact for the purposes of this explanation may be defined as '*ways to stay connected with family, friends and the environment*' (Lauriks et al., 2007 p.225). Social interaction with others is also often perceived as a central component of leisure activity (Auld & Case cited in Leung & Lee 2005). The majority of participants reported that the increased social contact on a weekly basis provided an event to look forward to that was enjoyable and helped to relieve boredom. This supports existing evidence that suggest people with dementia living in their own homes have significantly more unmet needs when they have minimal contact with their communities (Miranda-Castillo, Woods, Galboda, et al., 2010). However, the extent to which participants placed importance on social contact was variable. The typology of engagement in figure 6.2 illustrates that for Jean, Mary and Rose, the opportunity for increased social contact enabled by their participation was the primary gain of their research sessions. The increased social contact was also expressed as a gain by George and Charles, albeit secondary to their technology interaction. All five individuals participated in the research independently and all expressed both verbally and non-verbally how they appreciated the regular social contact even over such a short space of time.

Jean: *'Oohh I have, I really do look forward to you coming'* (session 4)

Charles: *'Well I know what that feels like...being on your own'* (session 1)

George: *'I've been looking forward to seeing you all week'* (George, session 2)

Mary: *'Well, I feel like I'm doing something'* (session 1)

Some illustrated their ultimate gain to be social contact through their actions rather than words and numerous examples were observed of non-verbal behaviours that indicated how vital social contact can be. For example, Roses' gesture presenting the fan as a gift to the researcher at the beginning of session 2 appeared to demonstrate how appreciative she was of the company. Similarly, participants were often observed waiting at the window for the researcher to arrive at the beginning of each session. For all these individuals, participation was solo which may implicate their lack of regular informal support and company. Although Rose participated independently she did not live alone and reported the increased social contact as valuable in addition to her regular church activities.

The four participating dyads (Jack and Carole, Colin and Jane, Steven and Elaine, Christine and Michael) all reported the increased social contact as valuable. This is interesting as it could be assumed that couples living together may already provide a certain degree of social contact and support. Further, those in the supporting role from two of these dyads, Carole and Michael appear to place more importance on social contact than their spouse with the condition. One plausible explanation is that both dyads are also managing long term conditions in addition to dementia which has diminished their ability to get out of the house resulting in less social contact and increased feelings of isolation.

Sub-theme 3 – Disengaged. It was anticipated post-fieldwork, that all individuals involved may experience some positive gain from their participation irrespective of whether that was increased social contact or technology use due to the fact that they were self-selecting. The typology of engagement in figure 6.2 illustrates those who expressed limited gain and disengagement to be Jack, Steven and Christine, all of whom were participating as part of a dyad and gave limited indication of expressed gains, verbal or non-verbal. It is a consideration that these participants were encouraged to participate by those supporting them in an attempt to be united in an activity yet in reality it was the supporters that found more value in the social contact. However, all three supporters did indicate at different stages of the research process

that their loved ones had enjoyed that particular session or activity but expressed it after the event. In line with these findings Jack, Steven and Christine all expressed feelings of apathy which were reported by their spouse as resulting in a lack of desire to be involved with anything new or familiar. The following images illustrate this non-verbal expression of limited gain.



Kathleen did not report feelings of apathy but appeared to place limited importance or a sense of gain on the increased social contact or technology interaction. Kathleen's participation was solo and she reported that her day to day life involved sufficient social contact already; in fact Kathleen withdrew after the first session because the research was encroaching on her usual social activities.

6.5.5 Theme 2 – Preferred activities

The theme 'preferred activities' was intended to capture the preferences or positive feelings that the individual, supporter or dyad experienced during their research participation. Activities should aim to reflect the individuals past experiences, hobbies, interests and maintained abilities in order to facilitate meaning and engagement in the promotion of wellbeing (Cohen-Mansfield, Dakheel-Ali and Marx, 2009; Kolanowski and Richards, 2002; Leng et al., 2014). It was also anticipated that participants may express a desire to explore new activities that had not been considered previously. This theme relates to those activities enjoyed irrespective of whether technology use or social contact was expressed as the primary gain of the research sessions. However, interesting relationships can be illustrated between expressed gains and the type of activities preferred. Based on analysis of the data, the theme of **preferred activities** emerged and as illustrated in the typology of engagement in figure 6.2 has been further defined into three sub themes, **pro-active, active and passive**.

Sub-theme 1 - Pro-active applications These activities were an unexpected finding from the data and involved the participants own needs and requirements to be met with

minimal input from the researcher but maximum thought and preparation between sessions on behalf of the participant. George and Charles, who both participated independently, consistently came up with new ideas and topics to explore. Dyads including Colin and Jane were also pro-active in their activity choice as well as Jill who was in a supporting role with Jack. It has been suggested that people who engage in activity that has an end objective may experience a greater sense of purpose (Mak, 2010). Participants using pro-active applications on the technology and expressed preferences regarding how to use their technology sessions as illustrated in the following statements.

Jane: *'Well I've always enjoyed cake decorating and often made them for special occasions for family or friends, you know'* (session 2)

Charles: *'oh yes very much, there's one that's distinctive for me and that's a magpie, my other interest is blackbirds'* (session 2)

George: *'I enjoyed our trip to a million years BC you know last time'* (session 2)

Carole: *'He likes this jazz band that we go and see, Dave Brennan'* (session 1)

All these participants preferred using pro-active applications and were observed actively searching for activities that were purposeful and meaningful to them involving hobbies from the past and present. For example, the ancestry application, archaeology, astronomy or more generally using the World Wide Web to gather the required information. Figure 6.2 illustrates a coherent relationship between the use of pro-active applications and technology interaction as the primary expressed gain of each individuals participation in the research sessions.



Google Earth



Ancestry



Google



Solar System

Sub-them 2 - Active applications involved those activities that although requiring active interaction with the device, applications were possibly more familiar to participants and translated effectively from 'traditional' to 'technological activities'. In fact, it has been suggested that people with dementia achieved a greater sense of wellbeing using iPad applications compared to traditional activities including cooking and crafts (Leng, Yeo, George, & Barr, 2014). The preferred activities that were considered to involve active applications included jigsaw puzzles, word games and creative activities such as drawing, piano and virtual pottery.

Kathleen: *'ooh yeah, I like to draw and paint, I think it relaxes you really'* (session 1)

Jean: *'it's lovely. I did play piano years ago....one or two notes are coming back to me'* (session 2)

Jean: *'I've always liked anything like this you know'* (session 4)

Mary: *'....I've saved my magazine over there as it's got one (word search) on the back'* (session 1)

Mary: *'yes and I used to play the board game solitaire'* (session 3)

The typology of engagement in figure 6.2 illustrates that overall; those participants that expressed the increased social contact as their primary gain of the research sessions were more likely to engage with and enjoy active applications. These findings imply that the technology sessions were meeting a social need as oppose to the desire to gain new knowledge of contemporary ICT's.



Word Search



Jigsaw



Pottery



Solitaire



Piano

Sub-theme 3- Passive applications These activities describe applications that may be enjoyed involving limited screen interaction. For example, watching videos on YouTube or listening to a favourite song or band. Passive applications could be watched or listened too but limited screen interaction was required on behalf of the participant. Although enjoyed, these activities generally prompted conversation or discussion on a particular topic or enabled a conversation to change topic based on non-technology related subjects. In this sense, the technology instigated communication rather than being utilised as a tool to gain new knowledge or fulfil a specific need. It was observed that these preferred activities appeared to engage those participants who also reported feeling apathetic with limited interest to be involved in any activities, familiar or novel.

The typology of engagement in figure 6.2 illustrates that Jack, Steven and Christine preferred to engage with passive applications that were more visual or audible in nature requiring limited screen interaction.

Christine: *'Is that Frankie Lane...Ahhh, that's better than going for a walk'* (session 2)

Christine: *'I'm rubbish at this...my brain doesn't work'* (session 1)

Steven and Jack were less vocal regarding their preferred activities and the choices of application were generally made by their spouse or the researcher. Yet instances were observed for both participants that suggest more active applications were appropriate if they were adjusted according to the specific need and requirements of the individual. For example, Jack's engagement increased with the solitaire game when the application had been altered by providing hints to direct the player through the game. Similarly, Steven engaged more actively in a virtual game of football as opposed to a quiz requiring facts of the game to be recalled. These findings do suggest that declining cognition dictates that familiar activities may require modification if continued participation is to be feasible (Menne, et al 2012).



Fireworks



Fish Pond



Bird Song



YouTube

6.5.6 Additional influencing factors

Although not developed as a theme, additional factors were observed and reported to be of influence across cases which are illustrated by the input arrows at the base of the typology of engagement in figure 6.2. These factors are described as **primary or secondary long term conditions, technology and connectivity challenges** and the **psychological and behavioural manifestations of dementia**. The reason these additional factors have not been further developed into an overarching themes is because they were not all apparent across participants yet require discussion as they had a definite impact on participation for some.

6.6 Discussion

The findings from this study indicate that touch screen computer technology has the potential to facilitate enjoyable activity with people living with a recent diagnosis of dementia when participants are supported appropriately by the same researcher. The emergent themes describing **expressed gains and limitations** and **preferred activities** will now enable exploration of the research questions. The **additional influencing factors** may also aid understandings of the nuances and complexities involved when researching with people with dementia using contemporary ICT's. The three research questions stated at the beginning of this chapter will be addressed in turn using various sensitizing concepts that have been identified and drawn from existing theories to aid explanations of the findings.

6.6.1 Does technology use involve new knowledge and retained learning, if so, in what ways?

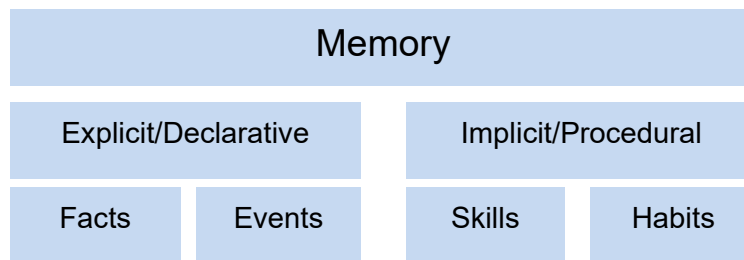
One of the aims of study 2 was to explore the possibilities of new knowledge and retained learning in relation to technology use and enjoyable activities when supported and scaffolded effectively by the same researcher. Predominantly, retained learning and new knowledge was observed across participants irrespective of their expressed gains or preferred activity as illustrated in the typology of engagement in figure 6.2.

Within the ICD-10 Classification of Mental and Behavioural Disorders (World Health Organisation, 1992) the diagnostic criteria for dementias that are recently diagnosed consider that 'the main function affected is the learning of new material'. Further, some evidence suggests that devising activities for people living with dementia to participate in is challenging as the symptoms of the condition, including memory impairment, challenges with communication and decreased concentration levels, make it unrealistic for this population to learn new skills (Riley et al., 2009). Until recently, many received a diagnosis of dementia when their symptoms had become well developed and there remained limited or no intervention suitable or available. This is changing and it is becoming common practice for interventions to target those with a recent diagnosis to explore all that is retained and maintained. For example, recent evidence suggests that performance of activities may be heightened if that performance is supported by increased experience of a particular activity (Martin et al., 2011). Although referring to cognitive training as an intervention for those with a recent diagnosis, this evidence implicates retained ability, new learning and behaviour change (Clare & Jones, 2008; Fernandez -Ballesteros, 2003) thus assumptions regarding limited learning ability could be considered outdated. Nevertheless, a distinction is potentially relevant here between 'retained learning' or 're-learning' of activities based on past experience (Astell, 2009) and the 'learning' of new material. The findings from the current study support the concept of retained learning and illustrate that the majority of participants maintained capacity to continue participating with familiar and novel activities when provided with appropriate support and opportunity.

Learning refers to the consistent exposure to a situation and the act of acquiring information or a skill that is triggered in that situation. Memory describes the process of storage and recall, thus when learning occurs, a memory is formed. Some memories can be consciously or 'explicitly' articulated whereas other memories cannot be articulated or expressed verbally and are therefore considered to be 'implicit'. There is

evidence that indicates people with dementia can learn to interact with computer based activities through implicit means (Astell et al., 2010). This distinction between explicit and implicit memories is helpful and is also characterised by knowing ‘what’ the Manager of Sheffield Wednesday football club is called and ‘how’ to play the game of football. This example was highlighted during Steven and Elaine’s participation (section 6.5).

Figure 6.4: A simple classification of memory



Impairment to explicit memory is a defining cognitive feature of dementia whereas implicit memory is the ability to improve task performance based on prior experience (Fleischman et al., 2005). Although, arguably not as black and white as this suggests, in general it is thought that implicit memory is relatively well spared post diagnosis of dementia. Thus, opportunities to retain information and learn new skills are achievable if this new learning exploits previously known information involving skills and habits (Mahendra, 2001) which supports the findings from this study. Furthermore, there is evidence to suggest that if the individual with dementia is pro-actively involved in a task that generates a response as oppose to being the passive recipient of a task, then the opportunities for learning are greatly facilitated (Mitchell, Hunt, & Schmitt, 1986). Similarly, the concept of ‘learning by doing’ is supported by procedural memory which enables the repetition and performance of tasks or behaviours to become habitual with implications for the learning of new material (Mahendra, 2001). The findings from study 2 of this thesis suggest that people with dementia can learn to interact with activities and gain new knowledge, although not through explicit means, which may have implications beyond individual engagement with touch screen computers, although this has yet to be proven.

The emergent theme of **preferred activities** illustrated in figure 6.2 therefore aids understanding of the potential of utilising **pro-active** and **active** applications during participation with technology when compared with more **passive** applications in the promotion of retained learning. Nevertheless, despite the choice of preferred activities, retained knowledge of the researcher and the previous research sessions was

apparent and explicitly expressed by the majority of participants for the duration of the study. This does indicate the potential for retained learning based on past experience for those with a more recent diagnosis of the condition. This can be achieved through the personalisation of the technologies that can effectively meet the needs and requirements of each individual or dyad.

Interestingly, the emergent theme of **preferred activities** also suggests that those who participated independently without support were more likely to be pro-active or active in their application use and technology interaction including Charles, George, Jean and Mary. This finding appears to indicate that those living independently retain their independence and desire to engage with activities for longer, possibly because they have no one else to regularly engage with or rely upon. These findings are consistent with the literature which suggests that people living independently can appear less impaired than those living with their spouse or others (Miranda-Castillo, Woods, & Orrell, 2010) even though they report having more unmet needs.

6.6.2 Does the device present observable challenges and possible gains, if so what are they?

The emergent theme of **expressed gains and limitations** was identified within each individual case and was sub-divided into **technology interaction, social contact and disengaged**. These sub-themes enable an understanding of the differences in the ways people are motivated to participate in activities in order to accomplish diverse goals or purely for participations sake (Kielhofner 1980), specifically technology interaction and social contact.

Technology interaction was considered by some participants to be their primary expressed gain of the research sessions, even though there was limited existing experience or knowledge of ICT involved. Technology interaction, specifically ICT use of older adults in general, has illustrated the potential positive impact to quality of life by increasing social connectivity thus psychosocial wellbeing (Adler, 2006; Czaja, Charness, Fisk, Hertzog, & Rogers, 2006). This supports the findings from this study as even those who reported technology participation as their primary gain also expressed the increased social contact as valuable. There is limited evidence to suggest that ICT use by people with dementia is any different to that of the rest of the older population. For example, Carpenter & Buday (2007) found that lack of interest or lack of support

were the two main influential factors that determined no computer use in older adults without a diagnosis of dementia. This study supports both these factors as some, although in the minority, did express limited interest in the devices it was the consistent and effective support by the researcher during the sessions that enabled technology interaction to be maintained. This support was considered to be essential and obviously characteristic of the research sessions and not that of everyday life. Nevertheless, it was concluded that people with dementia do not fear new technologies but rather lack knowledge and experience of using them (Rosenberg & Nygard, 2011) as well as effectively supported opportunities to do so. For some, the research sessions provided access to contemporary ICT's that they would not usually have had. This interest enabled these participants to utilise their sessions purposefully to their full advantage.

One of the initial aims of study 2 was to explore the range of social media applications with those participants who expressed an interest to do so including Facebook, Facetime, Skype and Twitter. However, limited interest was forthcoming from participants the main reason being that there was no one to connect 'with' using social media. Generally other family members were busy at work or did not use social media themselves and certainly FaceTime would have required 'others' to have an Apple product in order to connect with. The evidence suggests that older adults in general are the fastest growing demographic to use online social networking as it enhances life by providing a medium for people to stay in touch with family and friends (Lewis, 2010) which does not support the findings from this study. Contrasting evidence suggests a lack of desire from older people in general to engage with social media as the majority consider it to be an unnecessary use of ICT (Mikkola, Halonen, & Change, 2011). As mentioned earlier, the limited number of participants in the current study who had experience of engaging with ICT's tended to do so for pragmatic purposes only rather than as a facilitator of social connectivity. These findings are supported by a review of ICT use by people with dementia and their informal carers. The findings indicated that those who did engage with ICT did so using practical websites of available services that were directed mainly towards the caregiver and not the person with the condition (Lauriks et al., 2007).

Social contact or social connectivity has been found to have strong links with positive ageing, health & wellbeing (Feist, Parker, Howard, & Hugo, 2010) as well as being identified as a vital component in the maintenance of a good quality of life (Droes et al., 2006). These definitions were reflected in the Prime Ministers Challenge on Dementia

(Department of Health, 2012b) which stated one of societies challenges to be to *'promote individual and community based activities for people with dementia and their carers, contribute to the development of sustainable inclusive social activities and services and ensure people with dementia and their families have a voice and are able to maintain, and where necessary, increase their social contacts within their community'* (Department of Health, 2012 p. 9). Although the updated challenge considers some progress to have been made toward improving the quality of life for people with dementia (Department of Health, 2015a), 62% still report feeling lonely (Alzheimer's Society, 2013). The findings from this study exceed this percentage as all participants, including those in a supporting role, with the exception of one, reported feeling increasingly isolated as a consequence of the condition.

A complex association exists between social isolation, feeling lonely and living alone and further associations are apparent between loneliness and poor mental health including depression and anxiety (Cattan, White, Bond, & Learmouth, 2005; VanderWeele, Hawkey, Thisted, & Cacioppo, 2011). Loneliness has been categorised into two distinct concepts, emotional loneliness (divorce, widowed, absence of partner, best friend, intimate relationships) and social loneliness (broader social networks, extended family, neighbours, friends) (Wattmo, 2014). Much research has been undertaken with older adults in general exploring the concepts of social isolation and loneliness (Bernard & Perry, 2013; Victor, Scambler, Bond, & Bowling, 2014) yet the existing evidence in relation to dementia focuses mainly on loneliness as a potential risk factor of the condition (Holwerda et al., 2014; Pillai & Verghese, 2009; Wilson et al., 2007). Social isolation is a predictor of loneliness, as is the amount of time spent alone and loneliness is a risk factor for reduced activity, physical and mental health problems as well as cognitive decline (Dahlberg & McKee, 2014). The maintenance of social networks has been associated with less cognitive decline in older adults (Holwerda et al., 2014; Pitkala et al., 2009). The concept of loneliness has been interpreted in different ways and is often seen as the subjective equivalent to objectively quantifying social isolation, thus limited evidence exists concerning peoples' experiences of being lonely or why they class themselves as lonely (Victor et al., 2014). For the purposes of this explanation, loneliness can be considered as a psychological state whereas as social isolation is best described as a sociological category.

Emerging evidence is now beginning to demonstrate links between loneliness and dementia (Holwerda et al., 2014). Consequently, interventions designed to target

loneliness in older adults may be beneficial for preserving their mental health (Bekhet & Zauszniewski, 2013). All participants involved in study 2, with the exception of Kathleen who withdrew her participation after session 1, reported lacking social contact on a daily basis. Furthermore, those in a supporting role report equal if not greater social isolation as a consequence of the condition. The increased social contact was a primary expressed gain for the majority of participants although it was secondary to the opportunities to engage with the technologies for some. Assumptions that living with spouse may go some way toward alleviating social isolation should be questioned; many examples of loneliness or decreased social contact were expressed by the individual with a diagnosis as well as their spouse. Influencing factors ranged from the consequences and impact of primary or secondary long term conditions, loss of confidence in driving, exhausting caring roles and a decreased desire to stay socially connected outside the home.

Loneliness will be experienced differently by different populations thus requiring interventions specifically tailored to address certain needs. In order to maintain engagement within the community, meaningful opportunities are required that may enable people with dementia to socially connect with others outside the home. In turn, these opportunities may then target those who feel lonely as a consequence of the condition.

6.6.3 What factors shape engagement and interaction with the technology?

Other influencing factors were found to shape engagement and interaction with the technology including other long term health conditions, psychological and behavioural manifestations of dementia and technology and connectivity challenges. These additional findings are illustrated by the input arrows at the base of the thematic structure depicted in figure 6.2.

Long term health conditions are an unfortunate yet realistic outcome for an older population in general and the evidence suggests that over a third of people with a long-term condition are also living with dementia (Naylor, 2012) which concurs with the current findings. For those living with other health conditions, it was these conditions not the dementia that were having the greatest impact on their social connectivity rendering them isolated and bored relying on family members to take them out. Thus, mobility challenges associated with other conditions render people isolated from the

outside world. The Kings Fund and Centre for Mental Health report that as a result of these co-morbid problems, the prognosis for older adults long-term conditions and the quality of life they experience can both deteriorate markedly (Naylor, 2012).

Nevertheless, those living with secondary long-term conditions were all capable of engaging with the technology despite any additional impairment. For example, some preferred to use the stylus pen when interacting with the screen finding it simpler to direct their actions than touching the screen with their finger. Others preferred less interaction with the screen but the devices enabled enjoyable interaction through music and more visual applications. In this sense, the existence of other health conditions did not impact technology interaction.

The psychological and behavioural manifestations of dementia are multiple and varied confirming that the impairments experienced by the individual reach far beyond the biological manifestations of the brain (Spector & Orrell, 2010). It is now widely theorised that the interplay between an individual's biological, psychological and sociological factors are of the greatest importance (Downs, Clare and Anderson, 2008). As noted earlier, this combination of factors can result in behaviours including apathy, anxiety and depression and be expressed as 'excess disability' (Brody et al. 1971). The condition of dementia may impact behaviours that may or may not have been apparent before and could be exhibited by the person with a diagnosis of dementia or their spouse. A wealth of theorising exists concerning the impact of a 'malignant social psychology' and the possible influence this may have on 'excess disability' (Bartlett & Connor, 2007; Kitwood, 1997; Sabat, 2001). Malignant social psychology describes how certain behaviours towards the individual with the condition may render them disempowered with feelings of worthlessness and underachievement. Such behaviours may then lead to 'excess disability' which occurs when tasks are carried out for the person even though they may be done independently, if not with the care and attention previously known. It has been argued that such behaviours, albeit not intentional, often result in apathy, depression and 'learned helplessness' (Sabat, 2001). Furthermore, a continued focus on memory impairment and tasks that highlight all that is lost has been found in this study to have such a negative impact on the person's self-esteem and feeling of worth. The focus on strengths and skills that are implicit and that do not rely on the recall of facts may provide the person with a growing sense of achievement and empowerment as they are able to enjoy new or familiar activities despite a diagnosis of dementia (Astell, 2009).

Apathy is clinically defined as the absence or lack of feeling, emotion, interest, concern or motivation (Marin, Biedrzycki, & Firinciogullari, 1991). Apathy is considered to be a behavioural symptom associated with dementia and was observed in this study to impact the person's willingness or desire to participate in familiar activities in general. Jack, Steven and Christine all reported feelings of apathy and lacking the need to participate in any usual or familiar activities. Of course, providing enjoyable activities is not going to guarantee that the person will cease feeling apathetic although participants did report that regular activities gave them something to look forward to. Apathy is a common symptom of dementia and is described as a chronic behaviour change that is also significantly associated with depression (Starkstein 2000).

Depression is a symptom of dementia that is related to the unmet needs of both the person with a diagnosis and their informal caregiver, if they have one (Phung et al., 2013). It is widely agreed that psychosocial interventions that target the individual's symptoms have the potential to reduce reports of depression and increase overall feelings of wellbeing (Vernooij-Dassen, 2010). Although the incidence of depression was not considered one of the selection criteria during the recruitment process (section 6.2.4), the majority of participants, including supporters, reported feeling depressed on regular occasion throughout the research process, particularly those that also reported feeling apathetic.

A further factor contributing to technology interaction was the **connectivity challenges** which highlighted the reality and limitations involved when researching with contemporary ICT's. Specifically in George's case the geographical location of his house impeded the 3G connectivity enabling Wi-Fi access to the internet. This was an unavoidable challenge resulting in the researcher downloading as much information as possible between sessions with George. Having no existing knowledge of ICT, George's disappointment was directed at the technology itself and he questioned the use of such tablets if they could not carry out basic requests. Ironically, had the 3G connectivity worked effectively, the individual who may have benefitted the most from his participation with such devices was George.

6.7 Conclusion

The potential of touch-screen technology in the promotion of enjoyable activity with people experiencing the earlier manifestations of dementia was explicitly observed. Similarly to study 1, the devices were positively received by the majority of participants and the supporters who were involved. The heterogeneity of participants was obvious and evident and challenges and limitations have been identified. New knowledge and retained learning was exhibited by all participants across sessions suggesting that people with a recent diagnosis of dementia can retain new information. Furthermore, constant attention is required pertaining to individuals' retained strengths and caution should be exercised when utilising applications on the devices that can highlight deficits associated with the condition. The personalisation of the devices was essential in meeting the reported needs and requirements of the individual or dyad although connectivity challenges highlighted the ethical implications involved when raising participant expectations that are not met. By creating opportunities that exploit all that is retained, enjoyed and done well, technology use that is supported effectively can empower the person with new knowledge and feelings of achievement.

The existence of secondary long-term conditions was not reported by participants to impact technology interaction when provided with opportunities to do so, although, the presence of such conditions was reported to negatively impact social contact with others. It is the psychological manifestations of dementia that have the potential to impact technology engagement as some participants reported a lack of desire to engage with activities in general or to alter their current situation. Others illustrate enthusiasm for the technologies and activities although the importance of such activity can appear secondary to the increased social contact for some. Thus, the majority of participants reported feeling increasingly lonely and isolated as a consequence of the condition with limited or no opportunities to change their current circumstances. The potential benefits of involving people with dementia in the research design and implementation process are two-fold. First, as researchers we will ultimately increase our knowledge of all that is retained, maintained and done well as the condition progresses. Second, the experience of participation can be enriching, empowering and sociable enabling the person with dementia feelings of increased wellbeing, self-worth and autonomy. As researchers, we no longer need to assume what the person is thinking or expressing, given effective communication skills, a focus on strengths not impairment in combination with personalised intuitive technologies, we can successfully elicit their expert opinions.

6.8 Researcher reflections

Undertaking study 2 of this research project was very different from my experience of study 1. Although I had more knowledge of the condition this time it was the experience gained during study 1 working with people with dementia that made me feel more confident in my approach. The most exciting prospect for me embarking on study 2 was the new research relationships that were about to develop. Unlike study 1, I had no prior knowledge of the participants, their circumstances or how they were experiencing the condition, the only knowledge I had was that included in the selection criteria set out at the recruitment stage. In this sense, study 2 felt like a clean slate involving people who had chosen to participate as they were interested in the research topic. The six week duration of the research involving the consent meetings, the interviews and the four subsequent sessions enabled firm research relationships to develop that were built on trust and understanding. All those involved in study 2 are unique individuals living with a devastating diagnosis yet providing invaluable contributions to a research project involving enjoyable activities and touch-screen technologies. Of course, there were many emotional instances that we experienced together but this only served to influence a stronger research relationship which I feel has positively impacted the content of this chapter.

As with study 1, it is relevant here to acknowledge my place as the researcher in the research process (Denzin, 2011). My role as a researcher is central to the ways the data has been collected, analysed and reported and my interpretations of the varying stages in this process will be subjective (Ritchie and Lewis, 2003). However, I felt there to be greater impact as a researcher during the fieldwork of this study as it quickly became apparent that participants looked forward to this increased social contact. Much evidence exists concerning how the skills of the researcher may impact the quality of the research and the experience of those involved (Lacey and Luff, 2009; Mason, 2002; Patton, 2002). This gave me a sense of responsibility to ensure that each individual was provided with as many opportunities as possible to enjoy activities during their participation. My enthusiasm for the topic and all the participants involved may have translated positively enabling enjoyable and interactive research experiences for everyone. However, I do acknowledge that this enthusiasm could also be interpreted as the intervention itself irrespective of the engagement and interactions with the technologies.

Chapter 7: Towards a model of technology use by people with dementia

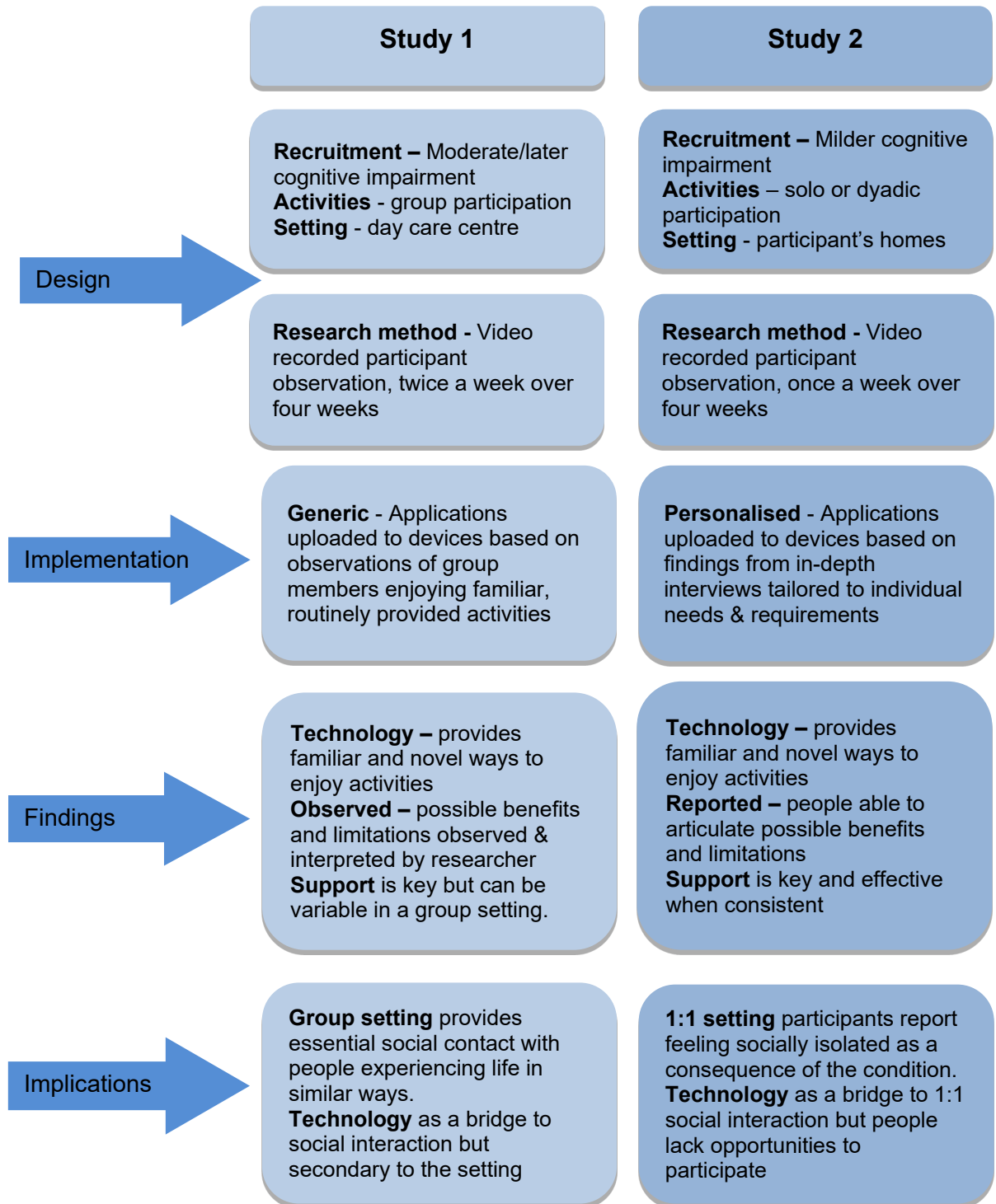
7.1 Introduction

The aim of this research was to explore the potential of existing 'off the shelf' touch screen computer technology in facilitating enjoyable activities with people with dementia, living in the community. In order to address this research aim, a number of research questions were posed. The findings explicated from reviewing the literature (chapter 3), study 1 (chapter 5) and study 2 (chapter 6) were discussed at length within the relevant chapters. The aims of this chapter are to synthesis and develop these findings further which are illustrated diagrammatically and described in section 7.2. The identification of five key factors derived from this synthesis has guided the development of proposed models to promote technology participation in section 7.3. Findings from both studies are discussed overall in section 7.4 and situated in the body of knowledge and evidence concerning dementia.

7.2 Synthesising the findings from study 1 and 2

The two studies were designed to explore technology use and enjoyable activities with people with varying levels of cognitive impairment and in different settings. Figure 7.1 illustrates the design, implementation, main findings and the implications that are characteristic of both studies. Both studies differed in regard to participant recruitment and research context yet applied the same methodology and utilised the same technologies. Implementation differed in that applications in study 1 were uploaded based on familiar activities and not personalised compared with applications being personalised to the individual or dyad in study 2. The findings indicate that technology can provide familiar or novel ways to enjoy activities whether observed or reported but that effective support is key to engagement. These findings imply that technology can act as a bridge to social interaction and enjoyment of activities if opportunities to participate are accessible.

Figure 7.1: Key characteristics of studies 1 & 2



The two studies enabled the emergence of various themes and sub-themes that were described and discussed in the relevant chapters (5 and 6). When combined, as shown below, it is clear how the themes from the two separate studies converge to illustrate technology interaction in different settings with people experiencing varying levels of cognitive impairment.

Figure 7.2 Study 1 themes and sub-themes

Study 1 themes and sub-themes

Technology interaction	Observed gains & limitations	Scaffolding & support
Primary	Achievement & mastery	Effective
Secondary	Conversation & laughter	Sufficient
Indifferent	Disengaged	Unsuccessful

Figure 7.3 Study 2 themes and sub-themes

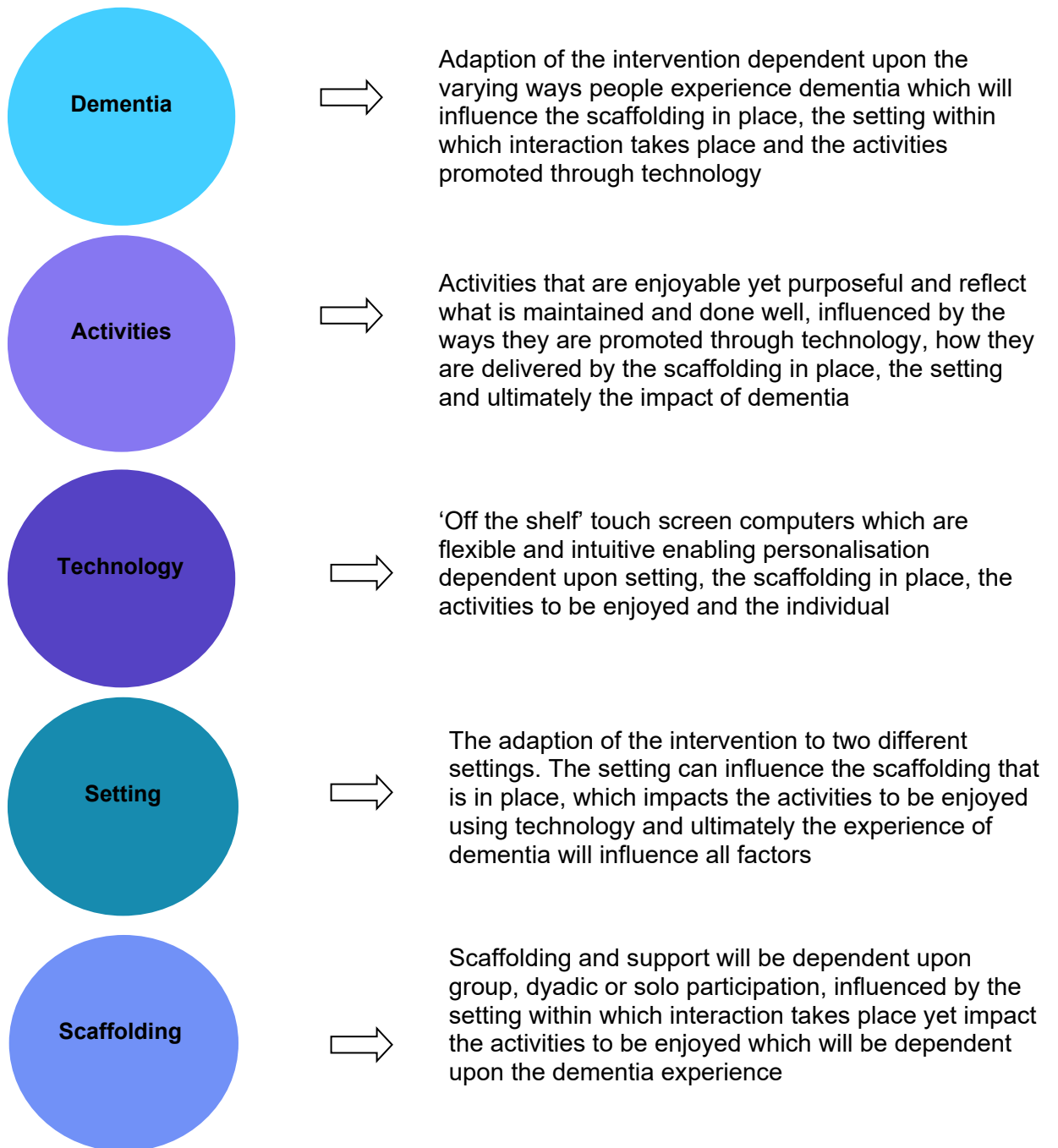
Study 2 themes and sub-themes

Preferred activities	Expressed gains & limitations	Other influencing factors
Pro-active	Technology interaction	Other health conditions
Active	Social contact	Connectivity challenges
Passive	Disengaged	Psychological & behavioural

7.3 Key factors to guide the development of models to promote technology participation

The project process and the convergent findings from the two studies have given rise to a set of key factors (figure 7.4) that postulate what activities may be enjoyable for whom and in what settings. Five key factors can be identified from the two studies that promote or alternatively dissuade engagement when applying technology based leisure solutions with people with dementia. All five factors are dynamic yet nuanced and characteristic of interdependent relationships between each factor.

Figure 7.4: Key factors



Each factor is illustrated in a linear format in figure 7.4 for descriptive purposes only. When all five factors are considered in combination the flexibility and interdependent relationships between each become clear. This may guide the development of models to promote technology participation as seen in figures 7.5 & 7.6.

Figure 7.5: Model to promote technology participation in a one-to-one setting

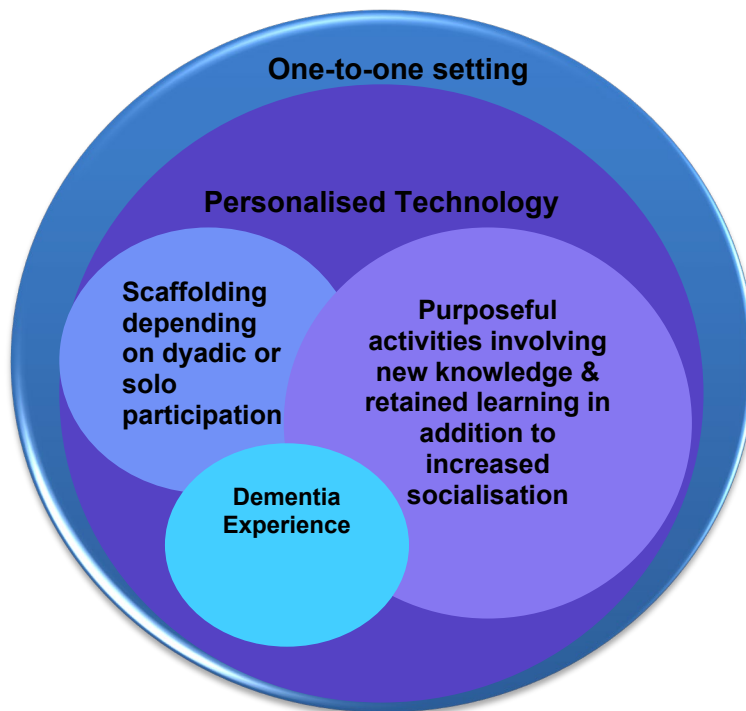
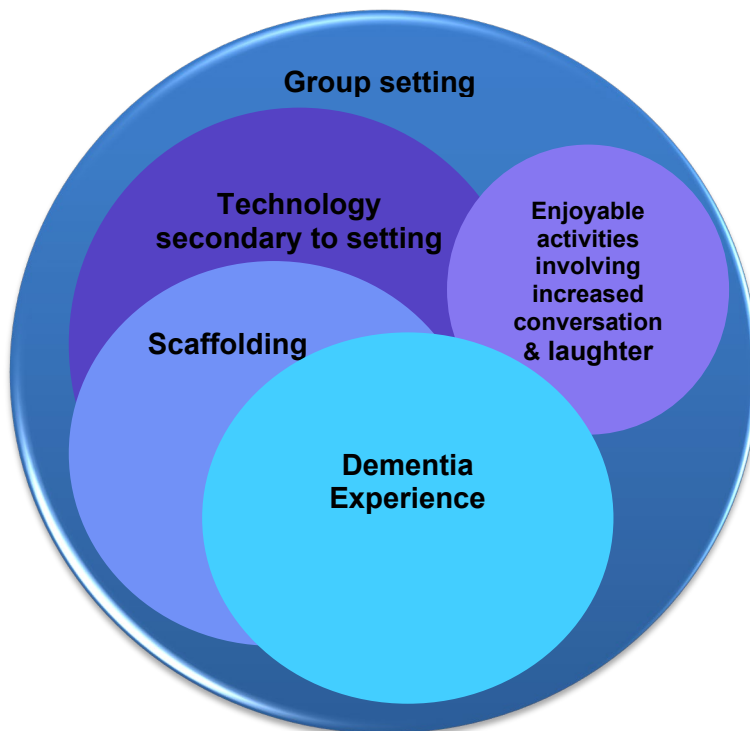


Figure 7.6: Model to promote technology participation in a group setting



7.4 Discussion

Five interacting factors were identified as being influential in enabling use of technology for engagement with leisure activities by people with dementia. The subsequent development of proposed models to promote technology participation enables increased understanding of people with dementia and their interactions with touch-screen computers and others in a particular setting. The findings from studies 1 and 2 both suggest that touch-screen computers can facilitate enjoyable activity with people with dementia irrespective of the level of cognitive impairment. It is clear that dementia and the way the condition is experienced is influenced by various factors including the setting, technology interaction, scaffolding and activities. The following discussion attempts to tease apart the complexity of technology interaction in the context of dementia by exploring each of the five factors in turn in sections 7.4.1-7.4.5. This discussion situates the overall findings of this thesis within dementia studies (Innes, 2009) thus highlighting the research that has previously been undertaken and how it supports or refutes the findings reported in this thesis.

7.4.1 Dementia

Dementia is experienced differently by each individual and it is acknowledged that the impairment caused by dementia reaches beyond biological factors (Clare et al., 2012; Downs et al. 2008; Sabat, 2011; Spector & Orrell, 2010). Whilst the cognitive and functional impairments are widely evidenced, the person's subjective experience has been less well understood until more recently. Evidence suggests that the way a person experiences the condition can be explained by a combination of the individual's psychology and the wider social context (Bartlett & Connor, 2007; MacRae, 2011). There is great variation in personal history; the ways the condition presents pathologically; emotional resilience, the existence and quality of social relationships; additional long term health conditions as well as sensory and physical impairments and personality differences (Alzheimer's Society, 2012c). The ways that all these factors interact will ultimately impact how the condition is experienced and be unique to the individual.

Traditionally, the bio-medical model of dementia has been the dominant paradigm and the prevailing focus on pathology and symptoms has also been most influential on dementia care policy and practice in the UK (Downs & Bowers, 2014; Innes &

Manthorpe, 2012). This well established medical model has focussed on the subsequent losses associated with dementia and signifies that *'the individual struggles to maintain a sense of self and becomes increasingly dependent. The person may show an increasing need for reassurance and shadowing of others. Eventually defence mechanisms fail and the individual becomes more distressed, showing aggression, agitation, hostility, outbursts, catastrophic reactions, isolation, despair and loneliness'* (Kasl-godley & Gatz, & 2000, p. 758). Other perspectives suggest immense variability concerning the person's own awareness of their condition, ranging from completely aware to having limited awareness (Clare, Canning, Driver, Kenny, & Litherland, 2003) which has additional implications for those in supporting roles (Phinney, 2002). It has also been postulated that those who are more aware of their condition are more likely to become depressed leading to decreased wellbeing (Bond, 1992). However, as clinicians, professionals and researchers we can only imagine what it is like to have a diagnosis of dementia, thus can lack knowledge of what life feels like to have the condition, the actual experience of having dementia (Hulko, 2009). Perspectives are therefore required that continue to question and explore the interactions between personality, biography, physical health, neurological impairment and social psychology, thus affording understandings of the person's unique experiences and perspectives (Kitwood, 1997).

The exploratory nature of qualitative research is appropriate for the study of lived experience providing subjective accounts that may elicit the complex and nuanced first-hand experience of living with dementia. In the past two decades, evidence exploring the lived experience of dementia has steadily accumulated (Beard & Neary, 2013; Harris, 2002; Sabat, 2001; Vikstrom, Josephsson, Stigsdotter-Neely, & Nygard, 2008) focusing on aspects of experience including 'sense of self and loss of self' (Harman & Clare, 2006; MacRae, 2011), identity (Caddell & Clare, 2011; Clare, Rowlands, & Quin, 2008; MacRae, 2010), race, ethnicity, class and gender (Hulko, 2009), coping and awareness (Clare, 2002; Clare, Canning, Driver, Kenny, & Litherland, 2003; Genoe, 2013; Phinney, Chaudhury, & O'Connor, 2007), and spirituality (Beuscher & Grando, 2009) as some examples.

However, the evidence is not always clear which immediately illustrates the complex nature of the condition and the various ways it is experienced which will be unique to the individual. It has been suggested that the dementia experience can be thought of as a continuum of perspectives that range from *'not a big deal'* to *'hellish'* in some case (Hulko, 2009 p.131). The suggestion of a continuum of experiences supports the

findings from this thesis as participants exhibited different levels of resilience stating on one hand that '*dementia has ruined my life*' and on the other hand '*it's the least of my worries*'. For some, dementia has been life changing and for others dementia maybe a hindrance as 72% consider themselves to be dealing with bigger problems including other long term health conditions (Alzheimer's Society, 2014b).

The literature reviews undertaken for this thesis found that a large body of evidence focuses on the positive experiences of dementia that can include meeting new people, spending more time with family, worrying less about insignificant things and adopting a positive attitude despite dementia (Beard & Fox, 2008; Genoe & Dupuis, 2012; Genoe, 2009). Others report that devising coping strategies in spite of cognitive loss can make sense of dementia thus optimizing well-being and increasing quality of life (Clare, 2002; Cooper et al., 2012; Preston et al., 2007). Yet, others argue that this evidence is based on white, well educated people with a recent diagnosis of dementia who are fortunate in their strong family support networks (Hulko, 2009). The findings from this thesis do not consistently support the positive outlook that has been reported by some as the majority of participants that could, expressed feelings of uncertainty, sadness and loneliness as a consequence of their condition. This is in line with other evidence that indicates people experience fear when they cannot remember things (Phinney, 2006) and stress of becoming too dependent on family members (Clare, 2002) as well as muddled thinking, fluctuating abilities and disquieting emotions (Genoe & Dupuis, 2012).

Nevertheless, this thesis does support a continuum of dementia experiences as some participants did use strategies in order to shift focus away from their memory loss including logging of information or keeping busy with familiar activities including household chores and church activities. This supports existing evidence as others report that downplaying the negative experiences of dementia may enable people to feel more 'normal' (Clare, 2002; Gillies, 2000) which involves balancing maintained abilities with those that have been lost by the use of coping strategies to preserve feelings of wellbeing (Sorensen et al., 2008). Of course, others report feeling apathetic on a daily basis and having limited desire to engage with any activities, familiar or new and as the condition progresses the ability to use compensatory strategies also deteriorates (Trahan et al., 2014).

However, much of the literature concerning the lived experience of dementia has involved people that are experiencing the milder manifestations of dementia (Caddell &

Clare, 2011; Clare et al., 2003; Harman & Clare, 2006; MacRae, 2011; Phinney, 2008; Preston, Marshall, & Bucks, 2007; Steeman, de Casterlé, Godderis, & Grypdonck, 2006). The majority of evidence concerning the dementia experience of those later in the trajectory of the condition has been undertaken in the context of residential care settings with participants from whom self-report is considered to be no longer achievable (de Rooij, Luijkx, Declercq, & Schols, 2011; Ellis, 2009). Although, the assumption that people experiencing later manifestations of dementia are unable to self-report should be questioned. It could be that the methods being utilised and ways to communicate are not effective in eliciting perspectives thus behaviour is observed rather than participants being asked about their experiences. There is limited evidence concerning people living at home with moderate to severe cognitive impairment which is not surprising and representative of a clear gap in the evidence base. This highlights a lack of appropriate methodology enabling researchers to access and capture the experiences of dementia that are not easily articulated. This thesis has highlighted that communication and interaction is achievable with people later in the trajectory using novel and creative methods. During study 1 of this thesis, participants rarely acknowledged or reflected on the positive or negative experiences of dementia but rather placed focus on the importance their visits to the day care centre held for them, in the here and now. One of the casualties of dementia is the skill of communication and due to the progressive nature of the condition these skills will inevitably decline resulting in challenges expressing and reflecting on thoughts and emotions (Alzheimer's Association, 2014).

It could be that the gradual progression of impairment has allowed the person to adjust, adapt and possibly become more accepting of their changing circumstances over time (de Boer et al., 2007). Others would argue that it is not about acceptance but more about deterioration as cognitive functioning fluctuates due to the progressive nature of the condition (Grand et al., 2011). This implicates the persons own decreasing awareness of their experiences of dementia as the condition progresses (Clare et al., 2003) as well as the unpredictable speed of deterioration. Thus as awareness decreases the acknowledgement of past experiences is also hindered (Steeman, Godderis, Grypdonck, De Bal, & Dierckx de Casterlé, 2007) as the struggles and stresses of the memory impairment become less relevant or are indeed forgotten.

This thesis, alongside a plethora of existing evidence, illustrates that for those in a caring role, the experience of living with dementia is also complex and nuanced (Beard et al., 2012; Dupuis et al., 2012; Innes et al., 2015; MacRae, 2011; Whitlatch, Judge,

Zarit, & Femia, 2006). Informal care from family and friends contributes 55% of the annual cost of dementia to the UK economy (Luengo-Fernandez, Leal & Gray, 2010). Considering this vast economic resource it is therefore vital that the perspective of the caregiver is also taken into account (Woods et al., 2012b). The findings from this thesis indicate that for some in a caring role, their loved ones lack of desire to engage with activities, familiar or novel, coupled with increasing apathetic tendencies was reported as more stressful than the memory impairment. This supports existing evidence that details declining functional capabilities and behavioural challenges have the most significant impact on carers quality of life (León-Salas, Olazarán, Muñiz, González-Salvador, & Martínez-Martín, 2011). In study 2, spouses have reported that personality and behavioural changes including aggression and frustration exhibited by the individual, never apparent pre-diagnosis, to be the most challenging. This supports other evidence as the psychological and behavioural manifestations of dementia have been reported by family caregivers as being more burdensome than cognitive dysfunction, physical dependence or functional impairment (Brodaty & Arasaratnam, 2012).

However, maintaining a focus on caregiver burden (Sussman & Regehr, 2009; Werner, 2012) provides limited consideration to the positive aspects of the caring role (Carbonneau, Caron, & Desrosiers, 2011). It was evident that the caring relationships of some participants involved in studies 1 and 2 were indicative of maintained support during the course of the research, an approach to the caregiving relationship that has been referred to as 'authentic partnerships' (Dupuis et al., 2011). Yet, effective support and the maintenance of activities may also be time consuming requiring the carers knowledge, imagination and creativity alongside having to continue with necessary routine caring tasks (Nygård, 2004). The research undertaken in this thesis, specifically in study 2, provided participants and those in a supporting role with opportunity to engage with novel activities that they would not usually participate with. This may indicate the possibilities of how engagement with enjoyable activities might contribute to the maintenance of satisfying relationships or 'authentic partnerships' between the person with dementia and the person in a supporting role (Carbonneau et al., 2011), if provided with the opportunity.

Increased understandings are required that may add to the existing knowledge regarding the complexities of the dementia experience and how unique those experiences will be to the person. The experiences of people with the moderate to later manifestations of the condition, living at home should be included in these

understandings, as illustrated in Figure 7.6; the experience of dementia has more influence on technology participation as the condition progresses. It is clear that two people with the condition will rarely share the experiences as they will be influenced by the interplay between numerous factors including emotional resilience, existing support networks as well as other long term health conditions (Knapp & Prince, 2007).

7.4.2 Activities

The promotion of enjoyable activities are at the core of this research project as people with dementia consistently report being bored and lacking something enjoyable to do during the day (Miranda-Castillo, Woods, & Orrell, 2013). The model derived from this research (figures 7.5 & 7.6) depicts enjoyable activities as dynamic, changeable yet also influenced by the four other factors in the model; setting, technology, scaffolding and the experience of dementia. This research has found that specific involvement with enjoyable activity may be beneficial, yet understanding and knowledge of activities involving people with dementia living in the community is limited. Evidence exists concerning the definition of activity (Phinney et al., 2007) preference of activities (Menne, Johnson, Whitlatch & Schwartz, 2012), exploring decreased initiation of activities (Cook et al., 2008) and the meaning of leisure activity (Genoe & Dupuis, 2012; Genoe, 2010). Limited evidence is available describing interventions that have been applied with people living at home. Rather, a number of systematic reviews of interventions, that although highlighting the need for post diagnostic psychosocial support, focus primarily on reducing caregiver burden using education and support programmes (Brodaty & Arasaratnam, 2012; Logsdon, McCurry & Teri, 2007; Marim, Silva, Taminato, & Barbosa, 2013). A large amount of the evidence that does exist concerning activities involving people living with dementia at home, maintains an emphasis on improving individuals abilities to perform activities of daily living although these interventions also aim to promote independence and participation in social activities, thus reducing caregiver burden (Graff et al., 2006, 2008; Graff, 2008). In addition, dyadic interventions with people post diagnosis in their own homes can support health, activities, resources, information and education (Reamy, Kim, Zarit & Whitlatch, 2011).

A systematic review of RCT's focusing on physical activity including walking, Tai-Chi and aerobics found that whilst showing some physical benefits, there was limited evidence to determine any positive effect on wellbeing for people with dementia (Potter, Ellard, Rees, & Thorogood, 2011). A further systematic review focusing on

physical activity with people with depression or dementia found significant improvement of quality of life among older adults with depression but not older adults with dementia (Tavares, Moraes, Deslandes & Laks, 2014). Other evidence has explored social recreation groups (Phinney & Moody, 2011), volunteer programmes (Kinney et al., 2011), museums and art (Rosenberg et al. 2009; Young et al., 2015; Zeilig et al., 2014) and eating out as enjoyable activities (Cassolato et al., 2010). Interestingly, it has been concluded that a diagnosis of dementia changes the choice and access to certain leisure activities as constraints and constrictions, both individual and societal, increase as the condition progresses (Cassolato et al., 2010). Whereas others report that it is little to do with the specific activity and more to do with increasing opportunities to socially interact with others (Rosenberg et al, 2009). Aside from two exceptions which are in the exploratory stages of research are small scale or of limited duration (Innes and Cutler, 2013; Leng et al., 2014), technology based interventions that emphasise enjoyable activities with people living in the community are noticeable by their absence.

To date, much of the research focus has been concentrated in the context of residential care including activities as therapeutic modalities including reminiscence, music, art, gardening and animal assisted therapy (AAT) (Beard, 2011; Filan & Llewellyn-Jones, 2006; Lee & Kim, 2008; Vink, 2014; Woods et al., 2009), activity based models of care (Brooker & Duce, 2000; Brooker & Woolley, 2007), activities as engagement (Cohen-Mansfield, Dakheel-Ali, and Marx, 2009), activities to promote quality of life (Fernández-mayoralas et al., 2014) and activities promoted through technology (Astell et al., 2010; Orpwood et al., 2009; Upton et al., 2011; Waterworth & Waterworth, 2006) as a few examples.

Numerous challenges have been encountered throughout this research concerning the person with dementias' participation with activities including physical, psychological and social barriers that have all been previously described in chapters 3, 5 and 6. There is evidence to suggest that wellbeing, happiness and life satisfaction for older adults in general is associated with participation in social activities that are personally meaningful and valued (Adams et al., 2010). People with dementia are less likely to participate with activities when compared with cognitively healthy older adults yet increased activity positively correlates with a higher quality of life (Johnson, Whitlatch, & Menne, 2014). However, dementia lessens a person's ability to continue creating their own enjoyable activities which threatens the persons' capacities to perform activities and to communicate; the initiative to be active and the performance capacity are also both hampered (Vernooij-Dassen, 2007). This decline in self-efficacy affects

the extent of social contact with a consequent negative impact upon wellbeing (Wardt, Bandelow, & Hogervorst, 2013). Yet evidence suggests that people are aware of this decline and consequently make attempts to adjust their activities to be more in line with their changing circumstances thus preserving their dignity (Sorensen et al., 2008). Nevertheless, dementia has a significant negative impact for the person when attempting to maintain engagement with cognitive and social activities (Paillard-Borg et al., 2009).

In addition, continued participation in activities can enable individuals to contradict the stereotypical images associated with dementia and challenge societal assumptions that people disengage once a diagnosis is received (Genoe & Dupuis, 2012). In the context of residential care, evidence indicates that participation in activities can create immediate pleasure and provide meaningful things to do (Brooker & Woolley, 2007). This suggests that people with dementia are keen to remain socially connected and engage with activities that are meaningful to them (Phinney & Moody, 2011). Yet, it is the distinction between what activities are meaningful, for whom and in what settings that highlights the uniqueness of each individual and stresses the importance of the notion that 'one size does not fit all'.

For example, figure 7.5 postulates that participation with enjoyable activities has a greater influence in a one-to-one setting when compared with figure 7.6 in a group setting. This may be because the meaning that an individual attributes to an activity and the subjective nature of what constitutes an enjoyable activity has been defined as something freely chosen by the person and not chosen 'for' the person (Shaw, 1985). The group setting in study 1 (figure 7.6) dictated that participants were not free to choose as activities were selected by the researcher based on more generic and familiar material that could be enjoyed within small groups. Predefining categories of activities to be enjoyed may limit individual choice as the person is required to participate with the most 'likely' option for the majority even if that particular activity holds no interest (Menne, Johnson, Whitlatch & Schwartz, 2012). Yet, for those with moderate to later cognitive impairment, decision making abilities including understanding, appreciation, reasoning and expressing choice are all increasingly compromised (Lai, Gill, Cooney, Hawkins & Karlawish, 2008). Consequently, declining cognition impacts decision making and choice of activities requiring strategies from those in a supporting role that may guide and support (Phinney, 2006) if continued participation is to be feasible.

'Yet participation in any form of leisure presupposes an ability to freely choose to partake in activities.....and in the case of dementia this ability is subject to a greater range of barriers....' (Innes, Page, & Cutler, 2015 p. 1). In this sense, the model in figure 7.6 depicts the persons' ability to freely choose activities has become increasingly compromised as the condition progresses and more barriers are apparent, although it should not be assumed that group activities are less enjoyable for people with dementia. Rather activities were observed to be enjoyed 'in the moment' for the majority of people with moderate to later manifestations of dementia and enjoyed because they are fun, enabling increased conversation and laughter in the moment or in the 'here and now'. In the dementia literature, 'living in the moment' is a concept defined as the way people choose to appreciate what they have today (Downs & Bowers, 2008) by enjoying activities without relying on short term memory (Alm et al., 2009).

For participants in study 2, figure 7.5 postulates the impact of activities to be greater and indicates how the option to freely choose activities might influence individual participation. This is because people experiencing the milder manifestations of dementia retain the capability to respond accurately and consistently to questions about health, individual preferences, IADL's and functioning (Lai, Gill, Cooney, Hawkins & Karlawish, 2008). It could be that activities enjoyed in leisure time may hold more significance after a diagnosis is received, enabling people to emphasise their intact abilities, keeping their minds active and prolonging engagement in activities that are meaningful to them (Genoe & Dupuis, 2012). This supports the findings from this thesis as activities preferred by participants in study 2 (figure 7.5) were identified as purposeful, involving new knowledge and retained learning as well as providing opportunities to socially connect. Evidence suggests that people who engage in leisure activity that has an end objective may experience a greater sense of purpose (Mak, 2010), purpose being an aspect of wellbeing that is highly valued by people with dementia in protecting and preserving a sense of self (MacRae, 2010). Thus freely chosen activities through personalised interventions may address expressed needs and requirements, enabling people to identify and engage in purposeful activities that they still enjoy (Clare, 2002).

Cognitive functions are already impaired even when the earlier manifestations of the condition are being experienced, yet others can be relatively spared enabling some new verbal and behavioural learning, although they are likely to require extra support to achieve it (Clare et al., 2013). The discussion of activities and hobbies through in-depth

interviews during study 2 enabled insight of those activities that emphasised the person's strengths, past and present, and were tailored to be personally meaningful thus promoting purposeful participation for the majority. These in-depth discussions also highlighted activities that were not required or may no longer be considered as achievable. *'By creating ways to be involved in meaningful activity and encouraging and facilitating the ability and desire of the person with dementia to use their remaining intact abilities to their fullest potential'* (MacRae, 2011 p. 447). The findings from this thesis illustrate the importance of enjoyable activities in providing purpose, feelings of achievement, fun, laughter and social connectedness for the majority. However, these findings implicate the importance or existence of scaffolding and support in the maintenance and participation of enjoyable activity. This highlights how these two factors from the model impact on each other and will be discussed in section 7.4.5.

7.4.3 Technology

Much of the existing evidence is concerned with applying technological solutions to people living with dementia to enable the person to navigate their day successfully and possibly remain at home for longer (Davies et al., 2009; Nygard, 2008; Topo, 2008). The majority of this evidence has not extended to the exploration of enjoyable activities but rather remains fixed on aspects of safety and security providing carer reassurance and in some instances to retain independence of the person with dementia (Chiu et al., 2009; Robinson, Brittain, Lindsay, Jackson, & Olivier, 2009; Shoval et al., 2008), daily functioning (Meiland et al., 2014), monitoring (Mahoney et al., 2007) and memory aids (Rosenberg & Nygard, 2011). This evidence matches the findings from a questionnaire administered to members of the Alzheimer's Society carers support groups which suggests that the areas of leisure, entertainment and social interaction were not well assisted by technologies, yet it was considered that these activities were paramount to maintaining quality of life (van den Heuvel et al. 2012). Despite this, the Alzheimer's Society proceeded to develop the Dementia-friendly technology charter (Alzheimer's Society, 2014a) that emphasises the ways technology may enhance quality of life through sensors, alarms and medication dispensers. Reviews concerning the ways technology interventions may translate from research into practice conclude that existing solutions can result in limited uptake because they are unreliable, due to training and support issues, high cost and ethical considerations (Bharucha et al., 2009; Carrillo, Dishman, & Plowman, 2009; Carswell et al., 2009; Lauriks et al., 2007), although this focus is beginning to change.

The technology literature review described in chapter 3 of this thesis found an increasing interest in exploring the possibilities of contemporary ICT's within dementia care settings. This new direction is beginning to shift the focus from the development of dementia specific technologies towards everyday technologies by considering the ways people living with dementia may benefit from existing 'off the shelf devices' in line with the rest of the population (Astell et al., 2010; Cutler et al., 2014; Lazar et al., 2015; Leng et al., 2014; Upton et al., 2011). To date, the majority of this research has taken place in the context of residential care despite the evidence that states people living with dementia in the community have greater unmet needs (Miranda-Castillo, Woods, & Orrell, 2010). However, this is changing (Innes & Cutler, 2013), possibly due to the recent policy push for increased psychosocial support for people post diagnosis of the condition (Department of Health, 2012b, 2015a).

It is possible however, to draw some comparisons from this particular evidence as some suggest that interacting with touch screen computers can be engaging and enjoyable for the person with dementia and those in a caring role providing a supportive interactive environment that positively benefits social relationships (Astell et al., 2010; Lazar et al., 2015; Leng et al., 2014). Nevertheless, this evidence is small scale and of limited duration as well as focusing on residential care settings. Findings from an evaluation that did involve larger sample sizes over a longer duration suggest *'there is a clear indication that the use of touch-screen technology may have a rehabilitative effect on dementia...'* (Upton et al., 2011 p. 28). The findings from the work of Upton et al. (2011) are in contrast to those of this thesis possibly due to the difference in study duration and setting but more likely due to the lack of reliability and quality indicators including rigour and robust evidence (Spencer, Ritchie, Lewis, & Dillon, 2003) that were considered. Although familiarity of the devices was observed within study 1 of this thesis and participants in study 2 exhibited new knowledge and retained learning this does not support the rehabilitative effects that such interventions may have. This is supported by a prominent Cochrane review that found no support for cognitive training involving people with dementia and no randomised controlled trials examining cognitive rehabilitation (Clare & Woods, 2008).

As mentioned, recent policy push recognises the need for more interventions to be undertaken to support people living with dementia post-diagnosis in their own homes (Department of Health, 2011, 2012b, 2015b). Thus, dementia studies, in particular those that apply contemporary ICT's as interventions to support leisure and enjoyable activity, including those recounted in this PhD thesis, are beginning to emerge.

However, the impact of dementia can result in apathy in individuals with the diagnosis (Rea et al., 2014) which can cause decreased initiation of social and leisure activities (Cook et al., 2008). Yet, the findings from this thesis indicate that when provided with the opportunity, supportive environments and personalised interventions, the majority of participants were keen to engage with familiar and novel activities facilitated through use of contemporary ICT's. There is recent evidence to support these findings which suggest that people with dementia achieved a greater sense of wellbeing using iPad applications compared to traditional activities including cooking and crafts (Leng, Yeo, George, & Barr, 2014). In addition, individual case studies have illustrated the re-learning of old technologies and the learning of new ones, with reported improvements in mood and wellbeing as participants re-engaged with technology (Astell et al. 2014). Again, it must be acknowledged that the strength of both these studies is limited as the findings are based on small qualitative studies utilising limited sample sizes.

Furthermore, in these two studies, activities were chosen for participants rather than by participants which differ from the studies in this thesis as participants, particularly those involved in study 2, were encouraged to choose how they wanted to spend their technology sessions. The concept of choice has been identified as one of twelve criteria as important to the person with dementias' subjective quality of life (Trigg, Watts, Jones, & Tod, 2011). Thus, choice in activities facilitated by the technologies provides *'something people want to do and, at a personally satisfying level using their abilities and resources, they succeed in doing'* (Stebbins, 2005 p.350).

In line with findings of this thesis, touch-screen computers have been found to be more intuitive and flexible in providing choice of personalised activities when compared with other existing 'off the shelf' technologies including Xbox, Wii and Nintendo consoles (Cutler et al., 2014). The study by Cutler et al. (2014) is still in the exploratory stages and is the only evidence found of this nature. Despite this, it provides further support for this thesis when comparing the preferred activities promoted through touch screen computers between care home residents and those living in their own homes. The technologies in the Cutler et al. (2014) study were used as a catalyst for conversation and reminiscence with care home residents and for the acquisition of new knowledge with those living at home, as preferred activities when compared with 'gaming' activities. This evidence supports and corresponds with the findings from study 1 and 2 of this thesis as the model illustrates technology interaction as secondary to the setting in study 1 (figure 7.6) yet when personalised, becomes more influential in meeting the needs and requirements of the individual in study 2 (figure 7.5).

Existing evidence is illustrating the potential of touch screen computers in the promotion of enjoyable activities with people experiencing varying levels of cognitive impairment. Although there is always going to be commonalities found across people with dementia, as with any other population, it is widely accepted that 'one size does not fit all' regarding technology use (Bjorneby, 2004) or anything else. There has been a tendency in dementia research to homogenise peoples experiences, that is to regard them as all the same (Bartlett & Connor, 2007); thus if one person has difficulties navigating cotemporary ICT it is assumed that the whole population of people with dementia will have the same difficulty. However, the evidence from this thesis is challenging this assumption and recognition and exploration of each individual's uniqueness coupled with the flexibility of touch screen computers, choice can be promoted which is considered to be the key to technology participation.

7.4.4 Setting

Two thirds of people with dementia live at home, either on their own or with informal care (Alzheimer's Society, 2014b). There are clear economic advantages for society if people remain for longer in their own homes and it has been argued that interventions provided at home in the early stages of the condition are one of the most cost effective solutions (Donnelly et al., 2008). Evidence indicates that 83% of people with a diagnosis of dementia would prefer to remain as long as possible in their own home, a desire that has been penned 'ageing in place' (Beard, Sakhtah, Imse, & Galvin, 2012) but most also have no choice, which can result in increased stress for both the person with dementia and their informal carer as the disease progresses (Phinney, Chaudhury, & O'Connor, 2007).

One of the research gaps identified in chapter 3 (page 80) of this thesis was a continued research focus within residential care settings despite estimations that two thirds of people living with dementia reside in their own homes (Alzheimer's Society, 2013). For this reason, and in line with the recent policy push to increase post diagnostic psychosocial provision (Department of Health, 2015a), this thesis has focused on people with dementia living at home and included two different settings; a social group context and a one-to-one context involving people experiencing varying levels of impairment. Each setting has the potential to be both enabling and disabling which corresponds with existing evidence and stresses the influence of social context on the way dementia is experienced (Gilliard, 2005). This thesis found that effective

communication, familiarity with the setting and the importance of personalised interventions can all be influential in creating supportive environments. This illustrates how meaningful, yet multifaceted the impact of context may be on the ways dementia is experienced (Smith & Mountain, 2012).

The setting can have important consequences for the person with dementia as familiarity of a person's surroundings can take on significant meaning and is able to compensate for reductions in physical and mental functioning associated with dementia (Chadhury, 2008). During this research it was observed that familiarity with the setting appeared to enhance participation, possibly eradicating the worry and concern associated with unfamiliar surroundings. This is in line with existing evidence that suggests familiarity of and continuity with the social and physical environment promotes engagement with activities and consequently has implications for wellbeing and sense-of-self (Phinney et al., 2007). Nevertheless, it is acknowledged that although the Phinney et al study was part of a larger qualitative investigation, the sample size was small involving 8 people with dementia living at home.

Existing evidence also suggests that social groups fill an important gap by providing people living with dementia with opportunities to engage with others and activities to look forward to (Phinney & Moody, 2011). This supports the findings from study 1 of this thesis as the majority of members from Darnall Dementia Group reported the day care sessions as being important to them in the maintenance of friendships and having fun. Informal caregivers also rely on this for respite from their care giving role. Yet, participants in study 2 were not yet engaging with community groups (including the Alzheimer's Society) attempting to continue with life in usual ways. This is also in line with the existing evidence that suggests people prefer to continue with familiar routines involving familiar activities that enable a sense of enduring and normal functioning (Clare, 2002).

Often, people experiencing memory decline attempt to normalise this loss as a part of the ageing process, thus help is sought later in the condition potentially missing important opportunities for intervention and support (Downs & Bowers, 2014). However, it has been argued that receiving a diagnosis of dementia instantly prevents the person engaging with usual social activities that the rest of us take for granted for example, bingo or trips to the cinema or theatre (Daker-White, Beattie, Means, & Gilliard, 2002). Instead, social groups are specifically formed enabling 'dementia friendly' trips and activities for those with a diagnosis. Yet the majority of participants

involved in study 2 of this research did report their reluctance to engage with such social groups outside the home even if they were available. One of the reported reasons included transport issues but more importantly, people did not want to attend busy, loud, crowded environments, yet did not know of any alternative options. This supports other evidence which indicates that some prefer to not engage in community groups and this does not alter after receiving a diagnosis of dementia (Innes, Szymczynska, & Stark, 2014). It has also been suggested that memory functioning can deteriorate through distress, noise and becoming generally overwhelmed with a new environment (Thompson & Heath, 2013).

People with a more recent diagnosis may not be ready to engage with dementia specific social groups and certainly the evidence from a recent community intervention focusing on reminiscence involving 350 dyads, showed no positive effects for the person but increased anxiety and stress on behalf of those in a caring role (Woods et al., 2012). Furthermore, one-to-one counselling, education and support programmes undertaken in the persons own home illustrated no positive long term effects for the person with dementia or those in a supporting role (Phung et al., 2013). Nevertheless, there is evidence of the positive effect that optimising the person's environment can have on adapting activities to meet the individuals' changing abilities (Graff et al., 2008). Community based occupational therapy has been found to be effective by improving the functioning of people with dementia, decreasing excess disability thus diminishing the burden of care on their primary caregivers (Graff et al., 2008). This indicates the importance of supportive social situations and environments whether at home or in a day care setting, which may have the potential to enable people in the maintenance of abilities and possibly function for longer.

Those designing interventions may not always be correct in their assumptions regarding what might be beneficial and appropriate in meeting the needs and requirements that are being reported by people with dementia. Although large scale randomised controlled trials are methodologically rigorous (Graff et al., 2008; Phung et al., 2013; Woods et al., 2012), there is a lack of consensus regarding appropriate measures to evaluate the effectiveness of psychosocial interventions (Moniz-Cook et al., 2008). The emphasis needs to focus on the importance of consulting people with dementia when designing interventions that can meet the expressed wishes of this group and it is possible that existing outcome measures are flawed. Expressing and communicating ones desired needs and requirements is an essential skill if we are to function effectively in society, however this skill can become impaired through the

course of the dementia trajectory (Bush, 2003). This implicates the importance of communication for maintaining meaningful social connectivity and if disrupted by dementia may lead to frustration and behaviours that are misunderstood by others (Spector & Orrell, 2010), thus difficult to measure.

The existing evidence highlights the importance of context and it is argued that the setting within which interaction takes place can also influence the ways people communicate with others (Killick & Allan, 2001). The findings from both studies of this thesis support the influence of the setting on communication whether in a day care facility or in the persons own home. Schweitzer and Bruce (2008) stress that creating supportive environments can be enabling through continued communication as well as maintaining relationships and social inclusion, despite dementia. However, the suggestion that enabling environments can enhance communication with the individual implies the existence of supportive and effective scaffolding relationships which in reality is not always the case.

7.4.5 Scaffolding and support

This thesis found that the extent of participation in enjoyable activities can be variable with people with dementia but this is not solely dependent upon the impact of the condition. The varying ways activities are enjoyed during leisure time can be dependent upon the level of support that is available once a diagnosis of dementia has been received (Innes et al., 2015) as well as access to appropriate opportunities to engage (Downs & Bowers, 2014) and individual interests. There has been limited attention given to the support of enjoyable activity with people with dementia living at home which is reflected in the current policy initiative to increase post-diagnostic psychosocial support for this demographic (Department of Health, 2015a). The evidence that does exist mainly focuses on the dyadic relationship between the carer and cared for and the impact a dementia diagnosis has had for both parties (Braun et al., 2009; Hulko, 2009), specifically on care giver burden (Chiu et al., 2009; Cook et al., 2008; León-Salas et al., 2011; Sussman & Regehr, 2009). This literature also illustrates that the priorities and perspectives of the two are not necessarily in accordance with one another (Miranda-Castillo et al., 2013). There has also been a focus on the possibilities of occupational therapy interventions to support and improve functioning of activities of daily living (ADL's) thus reducing caregiver burden (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010; Graff et al., 2006) and the importance of relationship-centred

care (Ryan et al., 2008). Aside from a couple of exceptions, limited attention has been given to the ways support and scaffolding may enable people to enjoy life through engagement with leisure activities (Innes et al., 2015; Phinney & Moody, 2011).

The model in figure 7.6 depicts technology participation within a group setting and suggests that effective scaffolding and support has more influence on the participation of enjoyable activity as people experience moderate to later cognitive impairment. This is due to the progressive nature of the condition involving memory loss, changes in mood, lack of motivation as well as the persons abilities to reason and communicate, which all require increased support as the condition progresses (Alzheimer's Society, 2014b). However, it can be more complex than this as the persons social context and personal reactions to the condition will also impact upon individual ability to engage and consequently influence the level of support required (Downs & Bowers, 2014). This complexity can also be contradictory as the findings from this thesis indicate that although participating in different activities, some individuals in a group setting (study 1) who had been living with the condition far longer, were observed to require less support and exhibited more independence in their participation of activities than others in a one-to-one setting (study 2) with a recent diagnosis. This implicates the individual and complex nature of the dementia experience.

The evidence that exists concerning the support of leisure orientated activities, although limited, illustrates this complexity and is also contradictory. One perspective is that people with dementia may have difficulty communicating their desired preference of activity yet they remain interested in that activity if initiated by those in a supporting role (Cook, Fay, & Rockwood, 2008). Others argue that people with dementia are understood in terms of activities that they can no longer do (Sabat 2001) when those with the diagnosis are more likely to focus on abilities that remain intact (MacRae 2008; Genoe et al 2009), although this is changing as society becomes more aware of dementia. It is possible then that not all challenges faced by people with dementia are a result of the condition but rather the way that people in a supporting role may react to the person as well as the ways the person may react to their supporters. This is important and implies that the reactions of others can significantly influence how the person with dementia experiences their condition (Sabat 2001) and implicates the importance of appropriate support and scaffolding.

The findings from this research have highlighted the importance and influence that scaffolding and support can have but this is not always indicative of a positive scenario. Negative influences from those in a supporting role can contribute to the development and maintenance of 'excess' disability where the extent of functional disablement is greater than would be predicted by the degree of impairment (Clare et al., 2013). Of course, not all scaffolding and support is negative and findings from this study also indicate how enabling support can be, both for the person with dementia and those in a caring role. Positive support can influence participation with enjoyable activities, thus overcome some of the challenges associated with the condition and promote feelings of wellbeing. It has been argued that supportive relationships should be viewed as a 'continuum of experiences' (Beard et al., 2012) and rather than expecting a perfect scenario, each relationship should be considered as 'working together', 'working alone' or 'working apart' (Keady & Nolan, 2003). In the context of residential care, Brooker & Woolley (2007) use the analogy of a 'locksmith' who, as the person in a formal supporting role, holds the responsibility of discovering and developing the master keys which enable the 'unlocking' of activity that may induce wellbeing in the individual. Others describe strategies used by informal carers to support activity but that can also sustain meaning for both parties including reducing demands, guiding, and accompanying (Phinney, 2006). Thus, addressing barriers to activity and participation can be expected to produce benefits for people with dementia and their formal and family carers (Clare et al., 2013; Innes et al., 2015).

As mentioned earlier, effective support relies on carers knowledge, imagination and creativity (Nygård, 2004) which may not necessarily be characteristic of the relationship pre-diagnosis. This may cause carers to limit their loved ones' engagement with activities if they perceive that person to be no longer capable of participating, thus reducing their own stress associated with maintaining involvement (Innes et al., 2015). This supports evidence that informal carers who care for a family member with dementia are affected more negatively by the responsibilities involved in their role when compared with others who care for a family member without a diagnosis (Ory et al., 1999). As mentioned earlier, the psychological and behavioural manifestations of the condition including apathy and depression can be more challenging to support than those memories that have been compromised. This is in line with evidence that reports that behavioural challenges, including apathy, are an overwhelming predictor of caregiver depression coupled with the realisation that the condition is progressive thus behaviours are not likely to improve (Ory et al., 1999).

Not all people with dementia have full-time informal care or supportive relationships with spouses, friends and family. As recent figures suggest, of the two thirds of people with dementia that live in their own homes, a third do so independently (Alzheimer's Society, 2014b). The existing evidence indicates that people with dementia who live alone are less cognitively and functionally impaired compared with those living with others (Miranda-Castillo, Woods, & Orrell, 2010). This findings from this thesis show some support for this as 40% of participants in study 2 were living alone reflecting the reduced availability of scaffolding and support with people in a one-to-one setting (figure 7.5). In addition, those living alone also preferred and participated with activities which were described as pro-active in the attainment of new knowledge. Nevertheless, those living alone without informal support, as with everyone, are compromised, lacking in opportunities to socially connect and are more likely to have unmet needs than those living with others (Miranda-Castillo, Woods, & Orrell, 2010).

Ultimately, the factor that dictates the extent of scaffolding and support is changeable and is influenced by the other factors. The existence of support needs to be effective in the promotion of enjoyable activity but realistically this is not always the case. Researchers, professionals and others working in the field of dementia need to want to be with the person with dementia if support is to be effective....'without this basic desire there can be little reward or meaning to the encounter' (Keady, 2003 p. 815). For informal supporters this positive scenario is not always realistic due to lack of knowledge and understanding of the condition or maybe a lack of a strong supportive relationship with the person. Others may not have any informal support to draw on at all.

7.5 Conclusion

Discussion was required in order to tease apart the complexities and contradictions that are apparent within each of the five main factors involved in technology participation. Ultimately, it is the varying ways that **dementia** manifests, progresses and is experienced that will influence the four other factors as this individual experience is not homogeneous. It was concluded that **activities** freely chosen by the person rather than being chosen for the person have the potential to meet the individual's preferences and can be reflective of past and present hobbies and interests. Although, the person's ability to decide and choose activities may become compromised thus the presence of effective scaffolding and support will inevitably be required to achieve this.

There is increasing recognition that 'off the shelf' **technologies** may offer the potential to promote enjoyable activity with people with varying levels of cognitive impairment. This is because they are flexible and easily personalised to the individual or group. The **setting** within which interaction takes place has been identified as influential in technology participation yet the effectiveness of the setting will depend on the support that is in place, the communication skills of those in a supporting role, preferences of activities and what is meaningful to different individuals and the varying ways the condition is being experienced. The level and quality of **scaffolding and support** will inevitably depend on the setting as well as the individual's experience of dementia. Yet it is not realistic to assume that any support in place will be a consistent, positive occurrence in the everyday lives of all people with dementia living in the community.

The development of the two models (figures 7.5 and 7.6) has provided a framework for technology participation. This was achieved by locating the findings from both studies in the context of dementia studies in general. The existing evidence was considered and the findings from this thesis confirmed or refuted aspects of the research that have taken place before. The quality of some of the evidence has been questioned and gaps remain in the existing literature concerning people living with dementia at home and their technology participation. Furthermore, the evidence can be contradictory and dementia studies have previously focused either on the setting, the activities, the support or the technology use of people living with dementia. This thesis in contrast, has identified five influencing factors of technology participation and illustrated the dynamic and changeable relationships that exist between all factors.

Chapter 8: Recommendations and conclusions

8.1 Introduction

The final chapter in this thesis details the insights and contributions that this research has identified. The new knowledge is evidenced by the publication and presentation record given at the beginning of this thesis (page 5). Section 8.2 discusses the contributions to new methodological insights for dementia research and provides some key recommendations from lessons learned for psychosocial dementia researchers. The findings have also contributed to existing evidence, building on work that has been undertaken previously and is discussed in section 8.3. Following this, the strengths and limitations of this thesis are acknowledged in sections 8.4 and 8.5. The findings also have implications for those practicing in the field and for policy and policy implementers, the recommendations for which are given in sections 8.6 and 8.7. The final section 8.8 outlines an agenda for future research to address the unmet psychosocial needs of people with dementia living at home.

8.2 Contributions to new methodological insights for dementia research and researchers

'There are no unique methodological challenges in researching dementia....rather the complex nature of dementia and dementia care highlight the methodological challenges of investigating complex social phenomena' (Bond & Corner, 2001 p. 95). This thesis has highlighted some of these methodological challenges and provided some essential insights for the undertaking of methodologically sound dementia research. These are visual methods, data analysis techniques, effective communication and ethical considerations.

Visual Methodologies in social science research are following societal trends in the use of the 'visual' in numerous aspects of life, made possible through technological advances (Margolis & Pauwels, 2011; Pink, 2001, 2012). This interest has not yet pervaded health services research and less so in dementia research where visual methods remain underexploited. Although video recordings have been utilised as a method of data collection and analysis for dementia research (Alm et al., 2007; Astell et al., 2010) or in the form of participatory film-making (Capstick, 2011). Visual methods in this project were also used for data collection but importantly these methods were essential for the capture of non-verbal communication, action and interaction when skills through writing, reading and speaking may have been compromised. Therefore,

at the core of this research project was the creation of strategies for the inclusive participation of people with dementia that are practical, reliable and sensitive enabling expression and allowing the significance of the non-verbal to come to the fore. Importantly, visual methods enabled the researcher to facilitate the research sessions without the distraction of taking field notes. This has the potential to unite the researcher and the researched resulting in a more collaborative research project.

The use of visual methods in this project has also highlighted issues concerning possible outcome measurement for psychosocial interventions. Recommended outcome measures for psychosocial research across Europe (Moniz-Cook et al., 2008) are currently being updated in order to refresh conceptual domains in light of more recent evidence. There are numerous existing measures including health related quality of life (HRQoL) questionnaires and interviews that provide one method specific to people living with dementia (Smith et al., 2005). Yet these measures rely on self-report and raise questions regarding how certain domains may be measured when they may not be easily articulated, communicated or indeed remembered. It has also been recommended elsewhere that future research should further consider the use of video analysis in order to capture nuanced and subtle behaviours that are not easily communicated in certain groups (Young et al., 2015). This thesis has highlighted the necessity for capturing enjoyment through observation as well as expression if and when it happened 'in the here and now' which was only achievable using visual methods. The challenge now is to adapt these methods so that they may be less time intensive and more accessible to other researchers in the future.

Novel techniques to analyse visual data were required to evoke meaning to each individual's participation that may not always be possible through text alone. Development of a creative way to explore, analyse and present the data was a central component of this research project and has given expression to each individual's participation that was both appropriate and necessary. Visual methods have enabled the powerful documentation of events within the 2 studies of this thesis. Yet it is the novel and creative ways that the data were analysed that provides a description and explanation supported by the visual that would not have been as effective using alternative methods. The dissemination of this visual data captured the actions, interactions and first hand experiences of participation enabling other researchers, dementia practice and policy implementers to 'see' the potential of this intervention rather than purely 'reading' about it. It is appreciated that the timeline for many research projects may not permit the time intensive analysis of video data. Visual

methods in dementia research are still in their infancy and certainly analysing video data in this way is so far unique to this thesis. However, providing the right context, sensitive ethical considerations, inclusive participation and time, these methods may be adapted and be seen as one appropriate approach in this area.

Effective communication with people living with dementia is a skill that requires knowledge of dementia and creative approaches whilst recognising the impairments associated with the condition which will manifest differently. Time and effort was invested during this research to understand and explore the various ways to enhance communication with people who may be challenged in this domain. Developing these understandings involved the following commitments on behalf of the researcher:-

- Increased understandings about the various ways that dementia may manifest both psychologically and behaviourally was provided by shadowing clinicians at local memory services as well as Occupational Therapists in dementia care settings. This involvement continues to increase researcher knowledge on the process involved in diagnosis and the availability of post-diagnosis support.
- Regular involvement in community groups and events involving people with dementia and those in a supporting role enabled the researcher to gain experience of the condition and learn from those living with it.
- This experience then extended to the co-creation of a local Patient and Public Involvement (PPI) group that continues to enable increased understandings of effective ways in which research proposals may be communicated and considered by people with dementia. Although, the methods used in similar PPI groups were found to be lacking in eliciting the expert opinions and perspectives of people with dementia. Consequently, the group decided to change the ways researchers presented their proposals in favour of practical or visual demonstrations and presentations thus eradicating the need for pages of text to be considered.
- This ongoing development of expertise working with people with dementia led to the creation of valuable tools to enable communication during the fieldwork of this thesis. 'Aid-memoirs' and the tablet devices were an effective way to steer conversations back to the topic providing successful prompts if attention wavered. In addition, images of individual participation taken from previous sessions acted as powerful prompts in subsequent sessions to communicate effectively what had already taken place.

Effective communication with people with dementia requires empathy and an understanding of the individuality of that person despite the condition. Increased knowledge and understanding of ways to communicate effectively should be a prerequisite for all new researchers working in the dementia field. This knowledge may then enhance the communication skills of the researcher which in turn may support participation by promoting voice to those who may be marginalised. This research has illustrated the enthusiasm and willingness of people with dementia to share their first hand perspectives and opinions when presented with appropriate ways to do so. Promoting the varying ways that the person may contribute to the research process can empower the individual and provide feelings of self-worth and achievement.

Ethical considerations are heightened in dementia research possibly due to the number of ethical implications including vulnerability, confidentiality, anonymity and the effects of diminishing cognition. This research has highlighted the powerful nature of the visual in the capture, analysis and dissemination of participation but this is accompanied by the need for clear understandings of the ethical considerations this type of research involves. The following points are essential when undertaking ethically sound dementia research:-

- **The ethical review process** is required to be sensitive and comprehensive but most importantly explicit in the information provided to the local research ethics committees. This is because permissions need to be granted when collecting and presenting data using visual methods that cannot guarantee anonymity with populations considered as vulnerable. This process involved a detailed protocol defining a clear rationale for the use of visual methods in the representation of the findings when traditional methods may have sufficed. The study design and the use of visual methods required the researcher to attend the local Research Ethics Committee (REC) meeting and defend the choices made as the most appropriate in this case. An explicitly detailed and clearly defended proposal for the use of visual methods in dementia research enabled the local REC to make an informed and favourable decision.
- **Increased understandings of capacity and consent** are an essential consideration when undertaking ethically sound dementia research. Detailed yet clear information sheets and consent forms are required that can enable informed decisions to be reached by all those involved in the research. From the outset, the use of visual methods and images depicting individual

participation was explicitly detailed in all documentation. All participants were considered to retain the capacity to make independent informed decisions regarding their participation thus no consultee involvement was required. Nevertheless, attention was maintained throughout the research to any changes in capacity that may have been exhibited by participants. This was supported by clear understandings of and adherence to The Mental Capacity Act (2005) which is essential if ethically sound research is to be undertaken with people with dementia.

8.3 Contributions to new knowledge in dementia studies

Chapter 7 of this thesis described and discussed the combined findings from studies 1 and 2 in the context of the existing dementia literature. This has enabled the contribution this thesis has made to the current evidence base to be clearly described. The five essential factors for effective technology participation led to the identification of a conceptual model to aid understanding of people with dementias' interaction with technology (Chapter 7 Figures 7.5 & 7.6 p. 285). There was an existing evidence base for each of the factors and this work has added to that. This thesis provides confirmatory evidence for the importance and influence of the **setting, scaffolding and support** and for the pursuance of enjoyable **activities** by people with **dementia**.

This thesis makes a clear contribution to new knowledge in dementia studies by developing a framework that acknowledges the dynamic interplay within and between five identified factors involved in technology participation. Although evidenced separately in the existing literature, these five factors had not previously been considered in combination. This has confirmed the appropriateness of personalised technological interventions that are tailored to the individual. Personalising technologies and providing choice is of paramount importance to the success of the devices in meeting, and in some cases exceeding, the expectations of participants. The findings illustrate that solo or dyadic interventions in the person's own home is a realistic and effective goal that may meet some of the reported unmet needs of people living with dementia. Yet, opportunities, places and support that may enable participation in such activities are lacking even though the desire from people living with dementia is not. The implications of these findings for dementia practice and policy are addressed in sections 8.6 and 8.7.

8.4 Strengths of the study

The strengths of this study are rooted in the development of a novel visual methodology for data capture, analysis and dissemination which was both necessary and unique to this project. The visual methods also provided opportunities to disseminate the findings, enabling others to 'see' the potential of the intervention through images depicting enjoyable technology participation by people with varying levels of cognitive impairment. The data was rich and illustrative of the positive experiences enjoyed by the participants, supporters and the researcher.

A further strength of the study lies in the contrasting yet complimentary design of studies 1 and 2. The two different settings enabled the capture of technology participation involving a range of people experiencing varying levels of cognitive impairment. This allowed factors to be identified that are dependent upon setting, highlighting the importance of context, support, activities and technology use by people with dementia. Undertaking research, whether in the persons own home or in a day care centre, requires effective rapport between participants and the researcher creating trusting relationships that were considered vital to the conduct of this research.

The topic of the research was interesting and enjoyable which had a positive effect on the recruitment process and attracted typically enthusiastic participants, thereby creating optimum environments for technology participation and interaction with others. The ethical review process was stringent and complex yet the local REC provided a favourable decision with no required amendments which is also considered a strength of this study.

The dissemination of this research is underway and is illustrated in the publication record at the beginning of the thesis. In addition the opportunities to present the methodology and findings have been undertaken internationally, nationally and regionally. These opportunities continue to facilitate interest in the topic area enabling potential collaborations for the future.

8.5 Limitations of the study

The researcher can influence the environment and the participants. This is because the researcher may ultimately find themselves as much a part of the data as the

participants due to having a direct and intimate role in both data collection, analysis, interpretation and reporting (Corbin Dwyer & Buckle, 2009). Paradoxically, the researcher should always be sensitive to the experiences of their participants yet also aim for neutrality and an awareness of their own bias and preconceptions that may influence understandings of the topic of investigation. Attention was therefore required regarding what the researcher might bring to the data, the interpretations of it and the ways the findings are reported. To limit bias, the researcher maintained a reflexive diary and conducted on-going reflection of her role within the research process.

Critiques of visual methods have questioned researcher subjectivity, due to the ease which images may be manipulated or edited in order to depict an impression of events that may not necessarily be accurate, in other words, an ideological representation of events (Prosser, 2008). The choice of image to be incorporated is also subjective but it is argued that in this thesis they are a faithful representation of the data collected from the studies. The images included in this research were not meant to be persuasive in any way but rather a reflection of the engagement, achievement and participation that each individual contributed to the project. Therefore, images of participants were included who were less engaged as well as those that appeared to be more positively engaged.

The researchers' own enthusiasm for the topic, the participants, the technologies and the research sessions needs to be acknowledged as this may be considered to be a limitation of the study. This is because the majority of participants involved in study 2 reported feeling increasingly lonely as a consequence of the condition. Thus, the regular social contact each week could be considered an equivalent intervention to the activities promoted through the technology. Previous studies involving technological interventions have highlighted the possibilities of positive impact being tied to social influences rather than the intervention itself (Blaschke, Freddolino, & Mullen, 2009; Dickinson & Gregor, 2006). Although this may also be illustrative of the lack of opportunities that this population currently have in gaining access to social situations that may help alleviate boredom and loneliness.

Enjoyable activities have been defined as something freely chosen 'by' the person rather than chosen 'for' the person (Shaw, 1984). This is important as the activities enjoyed by participants in study 1 were chosen by the researcher and not by the group members themselves which could be considered a limitation. The group setting dictated that application choice would remain with the researcher although suggestions

of additional applications as the sessions progressed were welcomed from staff and volunteers of the group. Applications were uploaded to the devices based on observations of familiar activities usually enjoyed by group members that were considered to transfer effectively as a technological application. Thus, activities were not personalised to the individual but rather chosen to be enjoyed by the majority of members, staff, volunteers and the researcher.

The reliance on 3G connectivity of the technology in a particular area of Sheffield whilst data collecting during study 2 (chapter 6) was a limitation. Ironically, Wi-Fi challenges were encountered whilst data collecting with one participant who, given the opportunity, may have gained most from his experience interacting with technology, but this has not been proven. An understandable lack of knowledge regarding the connectivity challenges led to a deleterious impact on the use of technology for this participant. Raising participant expectations is an ethical concern and in this particular case, expectations of participation were not met.

It was initially assumed that some participant's involved in study 2 may have expressed an interest to socially connect with others using the technology through social media including Facebook, Twitter and Facetime for example. This was because during the in-depth interviews, some participants had reported missing family members and friends that lived away. However, these assumptions were premature as no one expressed a desire to socially connect using the devices for three reasons. First, no participants knew of anyone who owned a similar device or that was currently using social media; second, those that did have family members and friends with smart phones and tablets reported their reluctance to bother them or interrupt their day; and third, the notion of engaging with social media was understandably not easily reconciled with existing knowledge for the majority of participants.

It should be acknowledged that the participants in study 2 were self-selecting which may be a limitation when attempting to evaluate the effectiveness of an intervention. This is because self-selecting participants may volunteer their participation based on previous technology experience and an interest in learning more for example. This was a consideration when designing the study and varying levels of technology experience would have made for interesting comparisons. Nevertheless, this was not the case as limited previous ICT experience was reported by participants.

Finally, there has been critique throughout this thesis regarding the quality of evidence provided by small scale qualitative research projects. This thesis is also qualitative, small scale and exploratory in nature. However, the topic of technology use to promote enjoyable activity with people with dementia using visual methods is still in its infancy and exploratory studies, including this thesis, are essential for laying the ground work in research areas that are not well understood. These exploratory qualitative studies can provide detailed understandings of individual experience as well as informing the feasibility for larger studies in the future. Nevertheless, it has been argued that if a researcher remains faithful to the principles of qualitative research, sample size in the majority of qualitative studies should generally follow the concept of saturation (Charmaz, 2006). Saturation describes a point in the collection of new data that does not shed any further light on the issue under investigation. Although it is considered here that more data does not necessarily lead to more knowledge, saturation was not reached in this thesis. This was due to numerous constraints including the time limit imparted by the PhD funding council, University time scales, the time intensive nature of visual data analysis and the local REC requiring justification of the numbers of participants and how long their involvement would last for ethical consideration. Despite the fact that saturation was not reached in this thesis, which could be considered a limitation, others have argued that the skill of the researcher clearly has an effect on the quality of data collected and this will have a subsequent effect in achieving saturation, thus the sample size becomes irrelevant as the quality of data is the measurement of its value (Morse, 2008).

8.6 Recommendations for dementia practice

People with dementia remain one of the most stigmatised and marginalised groups in contemporary society (Bartlett & Connor, 2007), specifically in the provision of health and social care (Downs & Bowers, 2008). Coupled with these challenges are the multifaceted issues surrounding the use of technology by people with dementia which can range from memory decline to a lack of knowledge and technical problems to a lack of support (Mitseva et al., 2010). This project has demonstrated that people with dementia can enjoy interacting with contemporary ICT's for social and leisure irrespective of their level of impairment yet can lack the opportunity to do so.

One of the essential requirements illustrated through the model of technology participation (chapter 7 figures 7.5 & 7.6) is the existence of effective scaffolding and

support which is consistent and embedded in dementia practice generally. This support can involve delivery of competent and compassionate care by skilled, knowledgeable and resourceful staff and others in a supporting role. The challenge is to develop and implement this new knowledge of what may work for whom into the provision of meaningful, individualised activities with people in different settings with different levels of impairment. This may then inform the education and training of relevant professionals as well as formal and family carers. This could further our understandings of the multitude of possible ways that technology interaction could begin to address issues of boredom; marginalisation, loneliness and stigma that have been identified during this project.

In 2012 the Prime Minister's Challenge on Dementia (Department of Health, 2012b) launched a programme of action to deliver sustainable improvements in health and social care. Progress has been made with over 400,000 NHS staff and 100,000 social care staff now trained more effectively in supporting people living with dementia (Department of Health, 2015a). As in the 2012 challenge, the 2020 challenge is also focusing on the increased provision of post-diagnostic support including personalised information, dementia advisors and access to counselling and ongoing specialist care. People newly diagnosed with dementia, and their carers are now able to sign up to a new NHS email service that provides advice and support in adjusting to the diagnosis. This is interesting as out of all the participants and supporters involved in this research, only one person regularly had access to the internet.

The Prime Ministers Challenge on Dementia 2012 stated that major improvements to dementia care and research would be made by 2015 (Department of Health, 2012b). Some improvements have been made, and the Prime Minister's Challenge on Dementia 2020 (Department of Health, 2015a) illustrates examples of health and social care settings that are shown to be delivering best services and innovation. Yet, these improvements remain variable across the UK and the aim now is to provide this quality of services more consistently to all parts of the country. This is going to take time, resources and money and place considerable strain on a NHS and social care system that is already under pressure. One possible solution to help alleviate this pressure is to focus on society as a whole by considering how communities might contribute to the growing number of people living with dementia by offering opportunities for participation.

There have been recent initiatives to raise awareness of the ways society currently engages with people living with dementia and their advocacy needs (Department of Health, 2012b, 2015a). These initiatives propose the empowerment of individuals in their aspirations, confidence and contributions to their communities. Although some progress is being made, there remains a need for opportunities that can promote social citizenship and participation in society with people living with dementia that goes beyond research studies focused on medicine and care to encompass people's rights and status in society (Bartlett & Connor, 2007). A clear example where this is beginning to be achieved is the research and development project to create a Dementia Friendly Community in York realised through the production of the Four Cornerstones model (Joseph Rowntree Foundation, 2012). Strategies need to be refined and refreshed whereby the best services and innovation, like York, are delivered everywhere enabling consistency of access to a standard of care that is less variable but involves participation as citizens in addition to service users.

People living with dementia deserve opportunities to participate in society as well as psychosocial provision through all phases of the dementia journey including post-diagnosis when many are reporting this need as unmet (Miranda-Castillo, Woods, & Orrell, 2010). This additional provision should be alongside existing informal carer support workshops that aim to provide resources for their loved ones' changing circumstances. There remains limited provision to signpost people post-diagnosis to access any psychosocial provision or community based opportunities. People with dementia need places to meet where they can access normal activities and patterns of life that can maximise choice and control. Such opportunities may enable people to engage with technology and each other on a regular basis promoting social connectivity in line with the rest of the population. These opportunities may then begin to address increasing contemporary issues including marginalisation, stigmatisation and loneliness.

Nevertheless, community awareness is increasing with over 1 million people now trained to be Dementia Friends which, in addition to an online presence, was also launched as a TV campaign involving well known celebrities making it much more accessible to people with no internet access. The development of a dementia friendly generation is also in progress involving schools and youth movements around the country (Department of Health, 2015a). One example is the BT Internet Rangers established by Age UK that encourages the younger generation to volunteer their knowledge of ICT to support older adults in the community. This could be extended to

involve people living with dementia by incorporating a form of knowledge exchange, ICT support in exchange for local history information or grammar tuition for example. The PM's Challenge (Department of Health, 2015a) refers to these type of initiatives as 'social action solutions' and the aim will be to provide peer support and befriending services that may enable people with dementia and their carers to access practical and emotional support. Although awareness is increasing, many of these social interventions are still being evaluated but the aim is to provide equal access for all by 2020.

This thesis has illustrated the retained ability post-diagnosis that people with dementia have in acquiring new knowledge and learning new skills when supported effectively. This has far reaching implications for dementia practice and policy but also for the individual as the condition progresses and their circumstance change. These findings stress the importance of personalised interventions which is also reflected in the future of the health and social care agenda. The Prime Minister's challenge on dementia 2020 states *'we wish to encourage greater personalisation in the provision of post-diagnostic services – this means building support around the individual with dementia, their carer and family and providing them with more choice, control and flexibility in the way they receive care and support...this requires greater efforts in making working in homecare an attractive profession.....incorporating new ideas including technology solutions into everyday practice* (Department of Health, 2015a, p. 28 & 32).

8.7 Recommendations for policy and policy implementers

Dementia is a national priority and the findings from this thesis overall, contribute to the Prime Minister's Challenge on Dementia (Department of Health, 2012b, 2015a) by highlighting to policy implementers, the urgent necessity to provide post diagnostic psychosocial support for people with dementia living at home. Policy is about building momentum on the interest that the topic of dementia has conveyed since the Prime Minister's Challenge in 2012 (Department of Health, 2012b). In the last three years there has been a noticeable shift, not only in the health and social care sector and community initiatives as mentioned above but in dementia research funding and the role of the third sector. The Alzheimer's Society have pledged £10 million annually for the next ten years on dementia research that was once focused primarily on a 'cure' for the condition but now involves research on care of those with the condition. This is also reflected in a £20 million social science research programme creating a network of

Doctoral Training Centres across the UK enabling more psychosocial dementia research to be undertaken at a PhD level (Department of Health, 2015a). The Medical Research Council also launched collaboration between industry and academia in 2014 referred to as Dementia Platform UK with funding of £53 million.

Dementia policy has focused on two necessary areas; research funding into prevention and cure and provision of funding for services that support professional and family caregivers (Downs & Bowers, 2014). Although vital, this continued focus places unequal attention on the person with the condition and their needs, requirements and perspectives. Realistically, it could be argued that highlighting the negative consequences associated with dementia gains political support for policy change as well as attracting media attention and ultimately research funding. Yet, such negative connotations view the person with the condition as a burden on health services, families and society as a whole which results in the further marginalisation of this group. Future policy needs to direct more attention to the positive ways people with dementia can contribute to their communities by providing opportunities that can enable them to do this.

Promoting citizenship with people with dementia has wider implications for policy implementers and could go some way towards alleviating the increasing loneliness experienced and expressed by people post diagnosis. Loneliness is a huge societal concern reported by older people in general, yet for people with dementia this can be magnified due to greater challenges accessing services. One of main findings from this research highlighted that the majority of participants, including those participating as dyads, reported feeling increasingly lonely as a consequence of the condition. Yet three years on from the Prime Minister's Challenge on Dementia 2012, 34% of people with dementia still report not feeling part of their communities and 40% feel lonely on a regular basis, a similar impact is reported by carers (Department of Health, 2015a). The findings from this thesis suggest these estimated figures are far greater.

Community groups specifically for people with dementia are rare with the exception of Dementia Cafés that are facilitated by the local Alzheimer's Society. Lacking opportunities to come together and socialise with people experiencing life in similar ways renders people feeling lonely and isolated. As with any initiative, funding is vital to enable such activities to become established. The dementia care research agenda is buoyant due to recent policy initiatives and local Clinical Commission Groups (CCG's) have been provided with targets to reduce loneliness for older adults in general. Yet

this provision is rarely accessible unless recommended by the NICE clinical guidelines. Although currently being updated, the NICE guideline for 'promoting and maintaining independence of people with dementia' list psychosocial interventions supported by Cochrane Reviews and RCT's in the areas of cognitive stimulation, creative art and music, reminiscence and physical exercise. These non-pharmacological interventions are recommended for the cognitive symptoms, the behaviours that challenge and the maintenance of function for people with dementia. There is currently limited indication within these guidelines of any psychosocial interventions to promote opportunities and participation with enjoyable activities that may alleviate boredom, isolation and loneliness with people with dementia. In fact, NICE have stated that the direction of the current recommendations should not change (NICE-SCIE, 2015 p.84).

Evidence is illustrating that people with a recent diagnosis of dementia are becoming increasingly isolated from society and lonely as a consequence of the condition. Yet, assumptions remain that people with dementia are unable or unwilling to fully participate in society post diagnosis, although the findings and experiences from this research indicate otherwise. It is opportunities to participate that are sorely lacking. If the needs and requirements of the person with dementia consistently report the same identified unmet needs it is essential that current and future policy implementation focuses on the provision of social resources and begins to prioritise these areas by providing such opportunities.

8.8 Agendas for future research

A recurring theme in the evidence base highlights the use of inappropriate outcome measures from projects concerning people living with dementia. There is also considerable debate in dementia research regarding which psychosocial domains are relevant and how they should be measured (Moniz-Cook et al., 2008). The result is an inconsistency with the methods used for data capture and analysis and overall uncertainty as researchers regarding the 'best' way to measure outcomes. In qualitative, exploratory studies such as this thesis, existing methodologies can be drawn from or novel methodologies are harnessed which can be unique to the project. Yet these novel methods would not be appropriate for all dementia researchers as they are labour intensive, interpretive and subjective, highlighting the challenges when attempting to combine creative approaches with methodological rigour. Further research is required in the development of new outcomes that will highlight the

inappropriateness of existing standardised measures and their inadequacy at capturing the sensitive and the subtle outcomes when researching with people with dementia. The agenda for future research requires more focus on '*developing sensitive and conceptually valid outcome measures for psychosocial intervention research*' (Moniz-Cook et al., 2008 p.25).

There is a need to address the increasing isolation and loneliness that people post diagnosis are consistently reporting (Alzheimer's Society, 2013). A coherent way to do this would be to focus on a group setting as an appropriate environment for people post-diagnosis to come together and socialise whilst providing opportunities to interact with contemporary ICT's, possibly supported by volunteers. Within this group intervention it would be interesting to measure specific aspects of wellbeing and loneliness before, during and after the intervention utilising the devices with large numbers of participants, both dyadic and solo. Future research in this area may then confirm that the provision of opportunities to come together socially and participate with contemporary ICT is a viable option. The findings from this thesis support the potential development of 'technology clubs' (Innes & Cutler, 2013) that may provide people living with dementia with opportunity to interact with contemporary ICT's and others if they choose. However, it should also be acknowledged that not everyone, with or without a diagnosis of dementia, would wish be part of a social group or technology club. Additional research would be required to explore interventions with people that would prefer one-to-one provision of interventions.

Alternatively, it would be interesting to explore the use of contemporary ICT's with people post diagnosis that involved an intervention of two phases. Phase 1 would involve a one-to-one intervention with the person and a facilitator for a period of six weeks, followed by group interactions with the technologies and others for a further period of six weeks. This design may then enable the person with the knowledge and experience of contemporary ICT's and the confidence to contribute to a group intervention whilst gaining opportunities to socialise with others.

A further variable of interest would be research that could examine comparisons of older adults with a diagnosis of dementia with older adults without a diagnosis and their use of touch-screen computers. It would be interesting to explore whether the influencing factor in limited technology interaction is related to dementia specifically or older age in general thus exploring the societal preconceptions of dementia that remain. Related to this is the viable option of people with dementia connecting with

others through social media. This option was considered during this study yet participants considered that they had no one to connect with who was currently using such applications. Ultimately, future agendas should focus on the novel and creative ways that people with dementia may participate effectively in research thus highlighting how valuable their contributions can be.

8.9 Conclusions

The agenda for research, policy and practice was a very different one when embarking on this thesis in 2011. Over 3 years later the interest in the topic of dementia overall is gathering momentum with exciting possibilities for the future. The importance of limiting excess disability and enabling people to experience life as well possible have come to the fore in ways that were just not anticipated. Only a few years ago the focus was on increasing the numbers of people receiving a diagnosis. There is now an additional emphasis in providing resources that may enable participation and treatment through psychosocial interventions. It is also being realised that caring, working or researching with people living with dementia provides great rewards for everyone involved; in this case the amount of reciprocal learning enjoyed throughout. This thesis is only the beginning and there remains a huge amount that is yet to be achieved, but it is reassuring to see research, policy and practice moving in the right direction. It is of growing concern that people with dementia have limited or no knowledge regarding the potential of contemporary ICT usage and no regular meeting place where they can learn such skills and meet others in the process. There is a real need for research, policy and practice to prioritise their strategies and target the reported unmet needs of people living with dementia who live in the community.

Word Count 96,617

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Appendix: Ethics, recruitment and interview documents

Study 1: I University Ethics approval

II Information summary for participants

III Information summary for carers

IV Consent form

Study 2: V NHS Ethic's approval

VI Study flyer

VII Information summary

VIII Consent form

IX Topic guide



The
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Our ref: 0601/KW

14 November 2012

Sarah Smith
ScHARR

Dear Sarah

Touch-screen computer technology and the potential to facilitate social and leisure activity for people with a diagnosis of dementia?

Thank you for submitting the above research project for approval by the ScHARR Research Ethics Committee. On behalf of the University Chair of Ethics who reviewed your project, I am pleased to inform you that on 14 November 2012 the project was approved on ethics grounds, on the basis that you will adhere to the documents that you submitted for ethics review.

The research must be conducted within the requirements of the hosting/employing organisation or the organisation where the research is being undertaken. You are also required to ensure that you meet any research ethics and governance requirements in the country in which you are researching. It is your responsibility to find out what these are.

If during the course of the project you need to deviate significantly from the documents you submitted for review, please inform me since written approval will be required. Please also inform me should you decide to terminate the project prematurely.

Yours sincerely



Kirsty Woodhead
Ethics Committee Administrator



Information summary for participants (study 1)

Research project title: A study to explore if enjoyable and meaningful activities can be promoted using touch screen computer technology with people living with memory loss.

You have been invited to take part in a research project and it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the research?

This research is looking to explore how successful touch screen computer technology may be in promoting enjoyable and meaningful activity. We want to understand whether familiar activities can be enjoyed using the touch screen so that people with memory loss may benefit from technology use in line with the rest of the population. I will be writing up the study as part of a PhD.

Why have I been chosen?

You were chosen for this research because you are a member of this community group in Darnall. All group members will be given the opportunity to take part.

Do I have to take part?

It is up to you to decide whether or not to take part in this research. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. However, you can still withdraw at any time without penalty or giving a reason.

What will happen to me if I take part?

You will participate as usual as a member of the group and the touch screen will be introduced as an activity to be explored and enjoyed during a usual session at the group.

What are the possible disadvantages and benefits of taking part?

It is not anticipated that you will be disadvantaged by taking part in this research. The technology will not measure or test memory neither will it compare abilities. Whilst there are no immediate benefits it is hoped that your participation will be enjoyable, interactive and fun.

What if something goes wrong?

If you wish to make a complaint about this research please contact the project supervisor: Professor Gail Mountain, ScHARR, Regent Court, 30 Regent Street, Sheffield, S1 4DA.

Will my taking part in this project be kept confidential?

The information that I collect from you during the course of the research will be kept confidential. You will not be able to be identified in any reports or publications.

Will I be recorded, and how will the recorded media be used?

Video/audio recordings of the group interacting with the technology will be made so that the researcher can take part and study the recordings at a later stage. Images taken from the videos will be used to illustrate findings to an academic audience. The recordings will not be used for any other reason without your written permission.

Who will have access to the data and where will it be held?

All data will be held in confidence at the University of Sheffield under my supervision. I will delete all video/audio material when the project ends. No one outside the research team will have access to the data.

What will happen to the results of the research project?

The findings will be presented nationally and internationally with the aim of increasing knowledge on the use of technology in promoting enjoyable leisure activities for people with memory problems. Participants, carers, staff or volunteers will not be identifiable by name in any of the reported material.

Please contact me if you have any questions about this research.

Sarah Kate Smith

Tel: 0114 2226382

Email: sarah.kate.smith@sheffield.ac.uk

Address : School of Health & Related Research (SchARR)

University of Sheffield, Regent Court, 30 Regent Street,

Sheffield S1 4DA

THANK YOU FOR TAKING THE TIME TO CONSIDER THIS RESEARCH



The
University
Of
Sheffield.

Information summary for carers (study 1)

Research project title: A study to explore if enjoyable and meaningful activities can be promoted using touch screen computer technology with people living with memory loss.

The person you care for has been invited to take part in a research project and it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish them to take part. Thank you for reading this.

What is the purpose of the research?

This research is looking to explore how successful touch screen computer technology may be in promoting enjoyable and meaningful activity. We want to understand whether familiar activities can be enjoyed using the touch screen so that people with memory loss may benefit from technology use in line with the rest of the population. I will be writing up the study as part of a PhD.

Why has the person I care for been chosen?

The person you care for was chosen for this research because they are a member of this community group in Darnall. All members of the group will be given the choice to take part.

Do they have to take part?

It is up to you and the person you care for to decide whether or not to take part in this research. If you do decide that you want them to take part you will be given this information sheet to keep and be asked to sign a consent form. The person you care for can still withdraw at any time without penalty or giving a reason.

What will happen to them if they take part?

They will participate as usual as a member of the group and the touch screen will be introduced as an activity to be explored and enjoyed during a usual group session.

What are the possible disadvantages and benefits of taking part?

It is not anticipated that the person you care for will be disadvantaged by taking part in this research. The technology will not measure or test memory neither will it compare abilities. Whilst there are no immediate benefits for participants, it is hoped that the activities will be enjoyable, interactive and fun.

What if something goes wrong?

If you wish to make a complaint about this research please contact the project supervisor: Professor Gail Mountain, ScHARR, Regent Court, 30 Regent Street, Sheffield, S1 4DA.

Will their taking part in this project be kept confidential?

The information that I collect from the person you care for during the course of the research will be kept confidential. They will not be able to be identified in any reports or publications.

Will they be recorded, and how will the recorded media be used?

Video/audio recordings of the group interacting with the touch screen will be made so that the researcher can take part and study the recordings at a later stage. Images taken from the videos will be used to illustrate findings to an academic audience. The recordings will not be used for any other reason without written permission from you and the person you care for.

Who will have access to the data and where will it be held?

All data will be held in confidence at the University of Sheffield under my supervision. I will delete all video/audio material when the project ends. No one outside the research team will have access to the data.

What will happen to the results of the research project?

The findings will be presented nationally and internationally with the aim of informing practice and increasing knowledge on the use of touch screen technology in promoting enjoyable leisure activities for people with memory loss. Participants, carers, staff or volunteers will not be identifiable by name in any of the reported material.

Please contact me if you have any questions about this research.

Sarah Kate Smith

Tel: 0114 2226382

Email: sarah.kate.smith@sheffield.ac.uk

Address : School of Health & Related Research (SchARR)

University of Sheffield, Regent Court, 30 Regent Street,

Sheffield S1 4DA

THANK YOU FOR TAKING THE TIME TO CONSIDER THIS RESEARCH



The
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Consent Form (study 1)

Participant

Carer

Staff/volunteer

A study to explore if enjoyable meaningful activities can be promoted using touch screen computer technology with people living with memory loss.

Name of Researcher: Sarah Kate Smith

Please initial box

I confirm that I have read and understand the information summary (dated 25/10/2012 / version 1) explaining the above research project and I have had the opportunity to ask questions about the project.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences.

I understand that video recordings will be made for use by the researcher only and my name will not be linked with the research materials. I will not be identified by name in the video recordings or any reports that result from the research.

I agree to take part in the above research project.

Name of consentor

Date

Signature

Name of researcher

Date

Signature

To be signed and dated in presence of the participant

Any further questions?

Please contact: Sarah Kate Smith

Telephone: 0114 2226382

Email: sarah.kate.smith@sheffield.ac.uk

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University of Sheffield

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Health Research Authority

NRES Committee Yorkshire & the Humber - South Yorkshire

North East REC Centre
Unit 002, TEDCO Business Centre
Rolling Mill Road
Jarrow
Tyne and Wear
NE32 3DT

Telephone: 0191 428 3566
Facsimile: 0191 428 3432

04 December 2013

Mrs Sarah Kate Smith
PhD Student
University of Sheffield, School of Health & Related Research (ScHaRR)
Regents Court
30 Regents Street
Sheffield
S1 4DA

Dear Mrs Smith

Study title: Exploring the possibilities of touch screen computer technology in the facilitation of enjoyable activity with people living with dementia.

REC reference: 13/YH/0370

IRAS project ID: 122714

The Research Ethics Committee reviewed the above application at the meeting held on the 28 November 2013. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Joan Brown, nrescommittee.yorkandhumber-southyorks@nhs.net.

Ethical opinion

It was observed this was an interesting study.

The Committee felt that capacity should be continually assessed specific to the study and you observed that you completely agreed. You explained that there would be a lot of clinical contact with the person before they got to you and that capacity was not related to the severity of dementia. Capacity was a very individual thing. You would assume that the participant had capacity and was able to give informed consent. If you did feel that there was a challenge you would err on the side of caution. You confirmed that you did not foresee any problems with capacity but you would definitely be aware of it.



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School of Health &
Related Research

Would you like to be involved in some new research involving enjoyable activities and touch screen computers?

The School of Health & Related Research is carrying out a study to identify what activities may be enjoyable for people living with memory loss. We want to understand if familiar or new activities can be promoted using touch screen computer technology.

You can choose somebody to take part with you or you can participate independently. Your involvement would take approximately one hour a week over a six week period. You could choose whether the researcher came to your home or you could come to the University if you wish.

Either way it is hoped that the sessions will be interactive, enjoyable and fun. If you think you might be interested contact Sarah on the details below.



To find out more:

Please contact me on

Tel: 0114 2226382

Email:

sarah.kate.smith@sheffield.ac.uk

Address: School of Health &
Related Research (SchARR)

University of Sheffield

Regents Court

30, Regent Street

Sheffield S1 4DA



Information summary (study2)

Research project title: Exploring the potential of touch screen computer technology as a facilitator of enjoyable activity for people experiencing memory problems.

You have been invited to take part in a research project and it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the research?

This research is going to explore if touch screen computer technology may be successful in promoting enjoyable activity. I want to understand whether familiar or new activities can be enjoyed using the touch screen by people with memory problems. I will be writing up the study as part of a PhD thesis.

What is touch-screen computer technology?

Touch-screens are the new generation of computers. They are smaller than traditional computers and don't have a separate monitor, keyboard and mouse. They are considered quite straight forward to use for everyone.

Why have I been chosen?

You were suggested for this research because you attended the Memory Clinic in Sheffield and have received a diagnosis of dementia.

Do I have to take part?

It is up to you to decide whether or not to take part in this research. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. However, you can still withdraw at any time without penalty or giving a reason.

What will happen to me if I take part?

We will have an initial chat about your hobbies and interests, past and present and also about opportunities that the technology may offer in the future. This will take about one hour and can take place at your home or in a meeting room at the University. From this visit I hope to understand what activities you enjoy, past and present and how the technology may enable these activities. This will be followed up by one visit a week for four weeks to the same venue of choice. Each visit will take approximately one hour. The technology will be personalised to your wishes and brought to each session by the researcher so we can explore it together.

What are the possible disadvantages and benefits of taking part?

It is not anticipated that there will be any disadvantages to taking part in this research. The technology will not measure or test memory, neither will it compare abilities with others. Whilst there are no immediate benefits it is hoped that your participation will be enjoyable, interactive and fun.

What if something goes wrong?

If you wish to make a complaint about this research please contact the project supervisor: Professor Gail Mountain, ScHARR, Regent Court, 30 Regent Street, Sheffield, S1 4DA.

Will my taking part in this project be kept confidential?

The information that I collect from you during the course of the research will be kept confidential. You will not be able to be identified by name in any reports or publications.

Will I be recorded, and how will the recorded media be used?

Video recordings of our sessions with the technology will be made so that the researcher may study the recordings at a later stage. With your permission, images from the recordings will be used when presenting the research to an academic audience, in the final PhD thesis and any publications as a result of the study. Before images are used you will have the opportunity to view them. If you decide that you do not want to be video recorded you do not have to take part in the study. Unfortunately, the study is a video based project so will require written consent from all participants to use the videos in the dissemination of the research.

Who will have access to the data and where will it be held?

All data will be held in confidence at the University of Sheffield under my supervision. I will delete all video material 12 months after the project ends. No one outside the research team will have access to the data.

What will happen to the results of the research project?

The findings will be presented nationally and internationally with the aim of increasing knowledge on the use of technology in promoting enjoyable activities for people with memory problems. You will receive a summary of the research results if you wish.

Please contact me if you have any questions about this research.

Sarah Kate Smith

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Email: sarah.kate.smith@sheffield.ac.uk

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THANK YOU FOR TAKING THE TIME TO CONSIDER THIS RESEARCH



The University Of Sheffield.

Consent Form (study 2)

Exploring the potential of touch screen computers in promoting enjoyable activity with people experiencing memory problems.

Participant

Supporter

Please initial box

I confirm that I have read and understand the information summary explaining the above research project and I have had the opportunity

I understand that my participation is voluntary and I am free to withdraw at any time without giving any reason and without there being any negative consequences. Any data collected will be included in the study unless I inform the researcher otherwise.

I understand that my responses will be kept strictly confidential within the research team. I understand that my name will not be linked with the research materials, and I will not be identifiable by name in any reports that result from the research.

I understand that video recordings will be made for use by the researcher

I agree that video images of my participation may be used to pre research in the final thesis and to an academic audience in the presentations and publications.

I agree to my GP being informed of my participation in the study and their

contact details are.....

Name of Participant

Date

Signature

Lead Researcher

Date

Signature

To be signed and dated in presence of the participant



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Topic Guide Study 2

I. Opening

Hello, my name is Sarah and I work at the University of Sheffield. **(establish rapport)**
We're talking today because you kindly agreed to take part in some research that I'm doing using touch-screen technology. I would like to ask you some questions about the types of activities and hobbies you enjoy as well as your experiences using technology. **(purpose)**

I hope to use this information to personalise the device to suit your needs and requirements for the upcoming sessions. **(motivation)**

The interview should take about 1 hour. How does this sound to you? **(timeline)**

Let me begin by asking you some quite general questions about day-to-day living for you. **(Transition)**

II. Middle

Hobbies, interests & activities enjoyed

Tell me what a typically good day is like for you? What would it involve?

What kinds of things do you enjoy doing? (type - hobbies, interests, clubs, pastimes, social occasions with family friends) (context – at home, in the community, independently, shared, group interest)

What makes those activities enjoyable for you? Could you describe a recent occasion when you did something you really enjoyed? What circumstances enabled you to do this?

As you look back on the past, tell me about some things (if any) you feel unable to do now? What prevents you doing this? Have they been abandoned? Would you ever resume them?

How would you say your interests and hobbies have changed over time? Could you describe a hobby that no longer interests you? Why do you think this is the case?

Can you describe some of the things that you would like to do more of?

Thank you, I wondered if we could move onto the next topic? This time we're going to talk about computer use. **(transition to next topic)**

Technology questions

How would you describe your past experiences with computers?

Positive/Negative/Indifferent

Tell me about your current computer use, if any. Maybe you have a home computer or perhaps you use/used a computer at work or at a family member's house?

Could you describe what, if anything, you use a computer for?

Would you describe computer use as part of your daily life?

Have you ever used a touch screen before either at the supermarket/bank/train station/library?

Do you already use an iPad? If so what's the main purpose of use? If not, what were your first impressions of the iPad?

Shall I show you a few things we can do on the iPad, weather forecast, news headlines, YouTube?

III. Validation summary

I just wanted to check that I have understood everything we have talked about.

I have written here that you enjoy walking/painting/crosswords/shopping

I've also written here that you enjoy using your home computer/have never used a computer/don't know what an iPad is

I also have here that you miss taking part in swimming/church/bingo/travel

Is there anything else that you think I should know that would help me understand better?

Can you think of anything else you would like to ask me?

III. Closing

Well, it's been a pleasure finding out more about you. I've asked many questions and your answers have been comprehensive so thank you.

Is there anything else that you want to add at this time?

OK so, I should have all the information I need until our next meeting but you can contact me in the meantime if you need to ask anything at all.

