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# Front page

Exploring the use of a commercial digital gaming Technological Initiative to enable social inclusion for community-dwelling older men with dementia in rural England

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Dedications Ben Hicks PhD

# **Dedications**

In memory of my Dad, John Hicks, and my Gran, Florence Wilson. I will never forget all that you did for me.

Abstract Ben Hicks PhD

## **Abstract**

Exploring the use of a commercial digital gaming Technological Initiative to enable social inclusion for community-dwelling older men with dementia in rural England

Author: Ben Hicks

This PhD thesis addresses the challenges of social inclusion for older men (65+ years) with dementia in rural England. This applied study used an individually-tailored male-only Technological Initiative, drawing on commercially available computer game technology (e.g. iPad, Nintendo Wii and Microsoft Kinect) to deliver person-centred activities to older men with dementia residing in three rural areas of England over a nine week period.

Participatory Action Research (PAR) formed the framework for the conduct of the research. Multiple qualitative methods were employed to explore the perceived impact of the Technological Initiative on the men's social inclusion. These included focus group discussions, open interviews and extensive reflexive field notes. Twenty two men participated in the research alongside fifteen care partners and five community volunteers. A thematic analysis was undertaken to interpret the data.

The research demonstrated that whilst the men enjoyed rural life, aspects of rurality combined with their subjective experiences of dementia to hinder their social inclusion. The Technological Initiative appealed to the men and resulted in their increased social confidence and sense of well-being. Three features were integral to its success: the use of technology; the male-only environment; and the approach adopted. The technology enabled the men to re-engage with their old leisure interests, take part in new activities and so continue their learning and personal growth, and challenge assumptions about their abilities. The male-only environment promoted a sense of familiarity and camaraderie that relaxed the men and encouraged them to speak openly. The approach adopted sought to give voice to the men by situating them as experts in the evolution of the Technological Initiative.

The thesis concludes by arguing that community ecopsychosocial initiatives designed to enable male social inclusion would be advised to consider these gendered experiences and promote them through the activities offered, the environment created and the method of delivery.

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## **Acknowledgement**

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Author's declaration Ben Hicks PhD

# **Author's declaration**

This dissertation is submitted for the degree of Doctor of Philosophy at the Bournemouth University. The research described herein was conducted under the supervision of Professor Anthea Innes, Dr Samuel Nyman and Dr Marilyn Cash, between October 2012 and September 2016.

This work is, to the best of my knowledge, original except where acknowledgements and references are made to the previous work. Neither this, nor any substantially similar dissertation has been or is being submitted for any other degree, diploma or other qualification at any other university.

## **Chapter One: Introduction**

## 1.1 Introducing the research

This was an applied, exploratory, multi-method qualitative study situated within a Participatory Action Research (PAR) framework. An individually-tailored Technological Initiative drawing on commercially available computer game technologies (iPad, Nintendo Wii and Microsoft Kinect) was delivered over nine consecutive weeks in three rural locations in England. The focus of the Technological Initiative was to promote social inclusion in older men (65 years or older) with dementia residing within these environments.

The research concept was developed through discussions held in 2012 by the Grant Holder (Innes) and a charitable organisation, prior to my appointment as the Doctoral Researcher. These discussions concerned their aspirations in providing services and support for people with dementia across a challenging rural landscape in England. As a result of these conversations the charitable organisation agreed to part-fund this doctoral study in conjunction with Bournemouth University (BU), as part of the University's competitive grants process. The study aimed to address one of the charitable organisation's identified challenges; to explore and fund ways to support older men living with dementia in rural areas. This research can therefore be viewed as a real world study (Robson 2011) that aimed to address an on-going issue for the project funder within their region. Following a proposal by Innes, the charitable organisation selected a digital gaming Technological Initiative as a means to bring together older men with dementia living within rural areas, and established a set of research aims prior to my competitive appointment. These remained paramount throughout the study and sought to:

- 1. Develop an initiative using off-the-shelf digital gaming technological devices
- 2. Examine the impact this had for older men with dementia in rural areas
- 3. Produce guidance documentation that could be used by a lay audience to set up similar future initiatives

The initial research concept was primarily situated within a positivist paradigm and looked to address the impact of the Technological Initiative through a range of pre- and post-measures undertaken in five rural locations. However, upon my appointment, and after engagement with my supervisors and local rural stakeholders, as well as extensive reading throughout my first year of study, I chose to steer the research towards a qualitative approach that was situated within a Participatory Action Research framework. In doing so, I elected to work with a smaller sample of men, across fewer locations than initially proposed (three instead of five) and instead gather more in-depth accounts of the rural locations and the men's experiences of participating in the research. Adopting this framework also enabled me to position the men as co-collaborators in the research process who could actively inform the development of the Technological Initiative and the guidance documentation. In addition to this, using a participatory approach that placed an emphasis on 'action' committed me to seeking ways, and external funding, to ensure the Technological Initiative could continue beyond the research period.

On a practical level, I felt that implementing the Technological Initiative across three rural locations instead of five offered me benefits, as it meant that I did not have to spend as much of my limited studentship budget purchasing technological equipment or hiring rural venues. Furthermore, from a research perspective, I felt that this approach, and particularly that of Participatory Action Research, was better suited for exploratory research and offered the potential of more long-term benefits for the men and their rural communities than that proposed in the initial research concept. Additionally, this approach also sat well within the current dementia discourse where enabling 'Authentic Partnerships' (Dupuis et al, 2012, 2016) with people with dementia is perceived as beneficial for research outcomes and the empowerment of the co-collaborators. In deciding to use a Participatory Action Research approach it also meant that I was responsible for selecting a research design, and using research methods that ensured the men could engage meaningfully throughout the research and inform the final outcomes. I will address these areas again in more detail in sections 3.1.3 and 3.1.4.

During my first year of study, I also chose to use the sociological concepts of 'social inclusion' and 'hegemonic masculinity' to provide the lenses through which to understand the research. In reviewing the relevant literature, I developed definitions for both of these concepts and used them when interpreting my research findings. Sections 2.2.7 and 2.5.2 illustrate my definitions for 'social inclusion' and 'hegemonic masculinity' respectively, and section 3.6 outlines how I used them when analysing and interpreting my data.

As part of the Participatory Action Research approach, I chose to comprise my research of two distinct empirical phases. The first was a consultation phase designed to understand the feasibility of the study and provide an overview of the research environment. This is in accordance with Participatory Action researchers who have highlighted the importance of understanding the social context in which your co-collaborators operate during their daily lives (Swantz, 2008). Although this was an important part of the study, I viewed it as the developmental period of the research. As such, I have only briefly discussed it within the thesis as part of the Participatory Action Research approach (Section 3.2). This phase consisted of delivering four one-off technology sessions to a total of 23 older men (65 years +) with dementia in four rural areas. Each session introduced the men to a range of commercial gaming technological devices including iPads, Nintendo Wii, Nintendo DS and Microsoft Kinect. Qualitative data was collected at the sessions in the form of reflexive field-notes and verbal feedback from the men and the volunteers. The findings suggested that the proposed Technological Initiative could be feasibly used with older men with dementia with appropriate adjustments. A report produced following this phase of research can be accessed at:

http://blogs.bournemouth.ac.uk/dementia-institute/files/2016/08/Final-brief-report-on-consultation-with-older-men-with-dementia.pdf

This consultation phase was imperative to the design of the Technological Initiative and the methodological approach adopted but is not the core focus of this thesis. Instead, in this thesis I examine the implementation of the Technological Initiative within three rural areas of England

and explore the perceived impact on the social inclusion of older men (65 years +) with dementia residing in these locations, as reported by them. These findings are contextualised in accordance with the aims of this study within the everyday lives of the men and their care partners who participated. The research reported in this thesis addresses three main questions:

- 1. How does the rural environment impact on the sense of social inclusion of older men with dementia?
- 2. What is the impact of a Technological Initiative on the men's sense of social inclusion?
- 3. How does a Technological Initiative promote male social inclusion?

This thesis sets out the processes that I undertook to address these three research questions. In Chapter 2 I document the existing literature and knowledge base around social inclusion, dementia, rurality, masculinity and technology. I demonstrate that 'social inclusion' is a widely recognised concept within the political landscape and more specifically within current dementia policy, and as such is appropriate to draw upon when understanding the findings of this real world study (Robson 2011). However, I also illustrate that within the dementia field our understandings of promoting social inclusion often fail to acknowledge the importance of the geo-socio-cultural environment and the gendered identities of those living with dementia. Consequently, initiatives promoting social inclusion are often generic and assume their intended audience to be a homogenous, androgynous population. Within the chapter I demonstrate that rurality and the multiple masculinities can impact on the social inclusion of older men with dementia and must therefore be taken into account. However research within this field is still within its infancy and therefore a better understanding of promoting social inclusion within ruraldwelling older men with dementia is required. I conclude the second chapter by suggesting that commercial gaming technology, whilst rarely used with people with dementia, may be a feasible means to promote social inclusion within older men living with this condition, although further exploratory research is required.

Having established the existing literature and knowledge base within these aforementioned areas, in Chapter 3 I provide a detailed account of the research design I adopted to address these exploratory questions. I chose to situate my research within a Participatory Action Research framework as this enabled me to work in collaboration with the men to design and deliver the Technological Initiative and understand its perceived impact. Adopting this approach ensured I was promoting the social inclusion of the men throughout the implementation of the initiative. This is consistent with best practice guidance within the current dementia discourse that seeks to develop 'authentic partnerships' (Dupuis et al, 2012, 2016) with people with dementia throughout the research process. The approach also ensured that I committed to bringing about 'action' within the rural locations, thereby upholding my own principles of using research as a means to bring about social change and not just for research's sake. Within the chapter I also discuss the formation of the Technological Initiative and the research methods I used to understand its perceived impact. This was informed by the Consultation Phase of the study. Due to the exploratory nature of the research questions, I chose to undertake multiple

qualitative research methods including focus groups, interviews and extensive reflexive field-notes. This enabled me to collect a wide range of data from multiple sources including the co-collaborators (men with dementia) and secondary informants (their care partners, volunteers and my own reflections), and so provided a more detailed insight into the perceived impact of the Technological Initiative than could be elicited via positivist methods. I conclude the chapter by outlining the thematic analysis process that I undertook, guided by the work of Braun and Clarke (2006), to examine the qualitative data ascertained.

The second part of the thesis sets out my findings. These are presented in Chapters 4, 5 and 6. Within Chapter 4, I introduce the twenty-two men that took part in the Technological Initiative as well as the five male community volunteers. I provide demographic details of the men within each of the three groups as named by them; Old Boys, Done Roaming and Marching On. The final half of the chapter draws upon my reflexive field-notes to describe the processes of delivering the initiative within the rural groups, collecting the data and seeking the feedback from my co-collaborators. As I was integral to the research process, it was important to acknowledge my impact (Dugmore et al, 2015; Flick, 2014) in accordance with the Participatory Action Research approach (Chevalier and Buckle, 2013; Reason and Bradbury, 2008).

In Chapter 5 I provide a more detailed understanding of the three rural locations drawing from my own reflexive field-notes as well as the feedback from the men, their care partners and the volunteers. This affords a thick description (Geertz, 1973) of the rural areas and provides an important geo-socio-cultural context in which to situate the men's perceptions of the Technological Initiative; thus enabling a deeper comprehension of the findings (Phinney and Moody, 2011). Within this chapter, I highlight that predominantly across the three rural locations the men lived well with dementia. However, I also illustrate that the men faced challenges within their rural environment that were brought about through a lack of structured activities, a lack of dementia awareness and barriers associated with rural living. These were exacerbated by the men's health conditions that produced physical limitations as well as a sense of apathy to engage within the rural location. I conclude the chapter by adopting a social inclusion lens and demonstrating how these factors can restrict important facets of the men's sense of social inclusion including their ability to: participate within their rural area; maintain and develop meaningful relationships; and retain autonomy and respect.

In Chapter 6 I highlight the men's perceptions of the Technological Initiative. Throughout the chapter I demonstrate that the Technological Initiative was successful in addressing many of the challenges the men faced to their sense of social inclusion. Through the use of the technology the men were afforded an opportunity to: participate in a meaningful activity (Phinney et al, 2007) that was tailored towards their interests and capabilities; socialise and continue their lifelong learning; and challenge negative assumptions around dementia. These latter two aspects are particularly important for the wider social inclusion agenda (Zeisel et al, 2016). The male-only environment was also welcomed by the men and reported as important for creating a 'safe space' (Wiersma et al, 2016) whereby the men could relax, express their masculinities and so

develop a sense of comradeship and solidarity. This was necessary for enabling them to connect on a more emotional level and so form meaningful relationships. Within the chapter, I also highlight the challenges I faced when managing the conflicts within the groups (particularly the Marching On group). I conclude the chapter by discussing the benefits the Technological Initiative afforded the men including enhanced mood and social confidence. For two men in particular this social confidence prevailed beyond the confines of the research into their daily rural lives; thereby enhancing their sense of social inclusion within the rural environment.

Within my final chapter I bring the research together by answering my research questions and discussing my findings within the broader academic literature. In doing so I am able to highlight the novel contributions of my research, namely:

- Exploring the experiences of older men with dementia living in rural areas of England
- Examining the perceived impacts of an individually-tailored Technological Initiative to the social inclusion of rural-dwelling older men with dementia
- Adopting a social inclusion lens in conjunction with a masculinity lens to understand how my approach and the community ecopsychosocial initiative can appeal to, and enhance the social inclusion of older men with dementia

Through this I am also able to provide recommendations for theory, policy and practice including:

- Acknowledging the concept of rurality within conceptualisations of social inclusion as well as the policies and practices used to promote social inclusion for people with dementia.
- The possibilities for atypical activities such as commercial gaming technology to enable
  wider benefits for the social inclusion agenda through enabling people to continue their
  life-long learning as well as challenge negative assumptions around their condition.
- The importance of recognising the persistence of masculinities within older men with dementia and catering for them in community initiatives through the activities provided, the environment created and the approach adopted.

Having provided a brief outline of the thesis and my research, I now move on to introduce myself as the researcher and facilitator of the Technological Initiative.

## 1.2 Introducing the researcher

Throughout the write-up of my thesis I have elected to include myself within the accounts to acknowledge the important role I undertook within the research process (Flick, 2014). Therefore, in this section I outline my motivations for undertaking this research. This is in accordance with the Participatory Action Research approach adopted for this study, which I will discuss in Chapter 3. This approach encourages researchers to illustrate a degree of personal presence within their work (Chevalier and Buckles, 2013; Swantz, 2008) and to make explicit their motivations for undertaking the study (Gergen and Gergen, 2008), as these will impact on the conduct of the research and the findings ascertained.

My understanding of dementia and consequently the approach I chose to undertake throughout my Doctoral studies was influenced both through my professional training and personal experience. As an undergraduate psychology student I was drawn to units entitled 'Abnormal Psychology' and 'Personality Disorders,' and became intrigued as to how the brain could deviate from what was deemed a 'normal' developmental trajectory. Whilst these modules were interesting, their focus within biomedical discourses left me somewhat unfulfilled as they neglected to explain how people might experience and live with these various conditions. As such, following my graduation I sought out various roles that might elucidate these aspects of interest; firstly as a support worker for people with various learning difficulties and then as an assistant for the Disabled Students' Research Officer at the National Union for Students (NUS).

However, it was my first academic post at Goldsmiths University that began to shape my understanding of living with a chronic health condition and highlight the pivotal role of research in bettering the world for these individuals. The project involved working closely with people returning to work following periods of long-term sickness absence due to cancer, heart disease or mental health conditions with the aim of developing a manager's guidance tool-kit to successfully support this process (Munir et al, 2012). Listening to people living with these conditions, I began to realise the importance of the social environment and day-to-day relationships and interactions on their experiences. Many of our participants struggled when attempting to return to work, not as a consequence of their original diagnosis but by the stress and anxiety placed upon them by their working environment, the actions of others, or their own expectations to resume a 'normal' life after their condition had been 'cured.' These discussions emphasised the need to understand and manage health and well-being in more holistic terms; accounting for biomedical aspects, but also the social and cultural factors that interweave and impact on these experiences. Crucially, at an early stage, this project also provided me with the principles I wished to incorporate throughout my research career; to acknowledge and value the experiential knowledge of participants and to undertake applied research that could be used for social change.

Although I established these research principles early on in my career, when I look back now, I realise that it was some time before I was able to apply them to both my personal situation and my work with people with dementia. For instance, my first foray into dementia research was to develop a piece of guidance for the Social Care Institute for Excellence (SCIE) that could be used by care homes wishing to implement Information and Communication Technology (ICT) for residents with dementia (Hicks and Miller, 2012). The research was grounded in the views of experts including academics, care managers and staff as well as dementia practitioners. However, tellingly, I unconsciously excluded those who were living with the condition. I find it difficult to explain why I did not perceive people with dementia to be 'experts' in this project. Perhaps it was partly to do with the media perpetuating the 'tragedy discourse' (Zeilig, 2014) and portraying those with dementia as living a social death (Brannelly, 2011; Sweeting and Gilhouy, 1997), unable to contribute to their own situation as well as society more widely. Alternatively, it could have been my own fear or uneasiness around the 'D' word (Milne et al,

2010) that made me unwilling to learn more about the condition and so dispel these myths (ADI, 2012). Either way these views adversely impacted on both my early research approach in the dementia field, and more poignantly in the way I interacted with my Gran when she was diagnosed with Vascular Dementia.

Whilst, of course, I was never cruel or belittled her, I found myself, over time, slowly withdrawing from her company and reducing the amount of time I would sit next to her, play cards with her or engage her in meaningful conversations. I recall numerous instances where I sat in her living room talking with my other family members, never once considering ways to include her in the conversations. By attributing her with 'excess disability' (Sabat, 1994) and engaging in acts of malignant social psychology (Kitwood, 1997), I noted that, over time, my Gran began to slowly withdraw from discussions and activities. Eventually this once confident, joyful individual was reduced to sitting quietly in the corner as the world passed her by; physically present but never engaged. And so as I distanced myself from my Gran, probably as a means to soften the blow for the time when her demise would be complete, I also reduced the support I provided my Grandad, Bill. Instead I chose to watch from afar as he shouldered the responsibility of caring for my Gran on his own; his stoic sense of post-war male pride preventing him from asking for help.

On numerous occasions during these Doctoral studies, whilst I sat with my head buried in the academic literature, I found myself looking to the skies and thinking: 'God I wish I had known this before.' And after these moments of reflection, inevitably the pangs of guilt would engulf me and I would begin to ponder how life for both my Gran and Bill could have been different if I had been more dementia aware. Although the academic literature reports that my actions to disempower my Gran following a diagnosis of dementia are common (Bartlett and O'Connor, 2010; Kitwood, 1997; Innes, 2009) this offers me little solace. I suppose therefore that my PhD and the approach I have chosen to adopt have been partly born from a need to seek redemption. What I was unable to provide my Gran, through my lack of knowledge and understanding at the time, I am making up for through this research. Whilst conducting this study I have recalled the research principles that I learned in the early parts of my career, and that had guided me so well prior to embarking in the dementia field. I have vowed to provide a platform for the men to express themselves, to listen intently to their perspectives, to represent them fairly and situate their voices as central to the project. In doing so, I aim to collaborate with them to develop a piece of applied research that will bring about some positive change within their lives and also challenge the way people with dementia more widely are viewed by others. By raising awareness of the condition within the general public, I hope that people will avoid the pitfalls I so readily stumbled into when they are inevitably faced with supporting someone living with dementia. This research therefore serves as an apology and a lasting legacy to my Gran; it is down to her that I am on the side of the PERSON with dementia.

## Chapter 2: Literature review

#### 2.1 Introduction

This literature review aims to contextualise the use of a commercial digital gaming Technological Initiative designed to promote social inclusion in community-dwelling older men with dementia in rural England. I begin the review by outlining the relevance of social inclusion within the wider political discourse as well as the disability and dementia fields. In doing so, I set out a definition of social inclusion that is adopted throughout this thesis. Following this, I provide an overview of current dementia policy that seeks to promote social inclusion both nationally and globally, before critically examining the multiple constructions for understanding dementia and their potential impact on social inclusion. After this, I move on to consider the concept of rurality and how this geo-socio-cultural context can both promote and hinder the social inclusion of people with dementia. As part of this, I critically discuss the decision to implement the current initiative within this context. I then examine the importance of the multiple, socially constructed masculinities of older men with dementia. Within this, I argue that the multiple male identities persist despite a diagnosis of dementia and may detrimentally impact on the social inclusion of this population. Consequently, they must be considered within dementia research. I conclude this chapter by discussing the use of ecopsychosocial (Zeisel et al, 2016) initiatives more generally for promoting well-being and social inclusion in community-dwelling people with dementia before critically examining the potential for commercially available digital gaming technology to be used as one such initiative. I will argue that these devices can be used as an appealing, atypical activity to promote beneficial outcomes in older men with dementia.

## 2.2 Social inclusion

## 2.2.1 The political context and influencers of 'Social inclusion'

This section will briefly discuss the emergence of 'social inclusion' as a concept within the political landscape, as well as highlight the important influencers that helped to shape understandings of what it means to be socially included. In addressing the latter issue, I will predominantly draw on the 'disability' literature. As I will discuss in section 2.3, dementia can be viewed as a disability and so it is important to understand it within this wider discourse.

Social inclusion and social exclusion are closely related concepts, with one often considered the antithesis of the other (Brown et al, 2015). This makes it difficult to consider the former without reference to the latter. 'Social exclusion' was coined by French sociologists and came to prominence in 1970's political discourse during the French social reform (Buckmaster and Thomas, 2009). It was used to describe the lack of social and economic cohesion in the country at the time, and highlight the challenges faced by socially excluded communities (Saunders, 2015). Within Europe, the concept was introduced in 1989 when the Council of Ministers of Social Affairs of the European Community passed a resolution to combat social exclusion through the fostering of integration and solidarity (Buckmaster and Thomas, 2009). This culminated in the formation of the European Social Protocol, which was incorporated into the Amsterdam Treaty in 1997. In the same year, the UK New Labour Government at the time, by accepting the Amsterdam Treaty promoted social policy through a social exclusion agenda

(Buckmaster and Thomas, 2009; Zin, 2013). This agenda became synonymous with 'Third Way' politics that sought to bring together the market and the state in a philosophy that favoured growth, enterprise and wealth whilst also promoting greater social justice (Levitas, 2004). The focus of the Government was to ensure that its citizens were 'able to participate in the economy and thereby in social life.' (Buckmaster and Thomas, 2009; page 6). To achieve these aims, the Government set up a task force known as the Social Exclusion Unit (SEU). The remit of the SEU was to deliver 'joined-up policies' to combat a complex set of societal issues in areas such as education, health and housing (SEU, 1997; page 2). Much of their earlier work was focussed on younger populations who were economically excluded and it was only towards the end of their existence they also explored the social exclusion of older people (SEU, 2006).

The more positive concept of 'social inclusion' was introduced in South Australia in 2002. On becoming the inaugural Minister for Social Inclusion, Mike Rann established a Social Inclusion Initiative modelled on the UK New Labour Government's social exclusion policy framework (Buckmaster and Thomas, 2009; Saunders, 2015). Following this there began a change in political discourse throughout Europe to 'social inclusion' or 'social cohesion' as a more positive social framework for:

'pronouncing a goal rather than describing a problem...Inclusion calls attention to the supposed "opportunity" and openness of society, beckoning outsiders in, whereas exclusion points at exclusionary mechanisms of society, its potential breakdown, disorder, or incoherence.' (Daly and Silver, 2008; Page 551)

Over subsequent years and following a directive by the World Health Organisation (WHO) that social inclusion was the responsibility of Governments, (Popay et al, 2008) social inclusion policy grew throughout Europe and continues to develop, with the commitment of EU countries to the Europe 2020 strategy that includes policies aimed at social inclusion (Social Protection Committee, 2011). Whilst social inclusion policy directives are also apparent outside of Europe in Mexico, USA and China, Taket et al (2014) posits, these countries lag behind Europe in terms of the scope and coverage of their social inclusion policies.

Within the disability field, various factors have influenced the emergence of 'social inclusion' as a concept for promoting well-being for people with physical and intellectual disabilities. Most pertinently, within an academic context was the social model of disability. This understands disability as a socially constructed concept and determines the systematic barriers, negative attitudes, and exclusionary practices in society to be the primary factors for hindering a person's social inclusion (Harley et al, 2015). The model suggests that whilst disability may cause functional limitations, it is society that fails to consider and promote the inclusion of people living with varying abilities. Through these means, the model promotes equality and highlights the commonalities that people share, and the barriers that they all face for social inclusion (Oliver, 2004).

Within a political context, the World Health Organisation (WHO) has played a pertinent role in ensuring that social inclusion is considered within the policy agenda for people with disabilities. The WHO (2013) highlights the importance of social inclusion for all individuals through 'the promotion of health and reduction of heath inequities through addressing social determinants of health by 'whole-of-Government' and 'whole-of-society' approaches and improved 'governance for health' (page 2). They have also been responsible for developing the International Classification of Functioning, Disability and Health (ICF model) (WHO, 2001) that draws heavily on the social model of disability. This integrates the medical and social models of health to capture the various perspectives of functioning at the biological, individual and social levels. Similarly to the social model of disability it recognises disability as more than the medical function and outlines the importance of the social component that requires political responses in dealing with disability challenges. It includes micro (interactional- person and the environment), meso (community- social interactions and attitudes) and macro (structural- environmental barriers) factors as important to address when promoting social inclusion and well-being in people with disabilities (Hartley et al, 2015).

Finally social inclusion for people with disabilities has been endorsed by Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UN, 2008). This outlines a commitment to protect and promote the rights of persons, and ensure their social inclusion through their full participation in the resources and facilities of the society in which they live, through consuming, producing, politically engaging and socially interacting (Hartley et al, 2015). This has resulted in the emergence of a rights based model of disability, which is considered the most current model to understand what 'social inclusion' entails for people with disabilities, and how strategies can be developed to ensure they can remain socially included (Hartley et al, 2015). This model emphasises the civil, political, economic, social, cultural and developmental rights that all people are entitled to, despite differences between individuals.

These political and academic influencers have ensured that over the past twenty years, the concept of social inclusion has remained paramount for improving 'the ability, opportunity, and dignity of people disadvantaged on the basis of their identity to take part in society' (World Bank, 2013; page 4) and promoting the well-being of people with disabilities (Simplican et al, 2015). Furthermore it has provided an opportunity to understand the multiple ways that a person may be denied their full participation in society and their full rights as a citizen (Ward, 2009).

## 2.2.2 Definition of 'Social Inclusion'

Despite a growing interest in the concept, it is widely accepted that there is a lack of consensus on exactly what social inclusion constitutes (Buckmaster and Thomas, 2009; Cobigo et al, 2012; Davey and Gordon, 2017; World Bank, 2013). This has important implications for how social inclusion is communicated across service providers, policymakers and researchers, as well as ways that it can be measured (Simplican et al, 2015).

Whilst conceptualisations of social inclusion can differ throughout the world (Taket et al, 2014) within the UK policy context social inclusion is often defined as the opposite effect to 'social

exclusion,' which is viewed as a lack of opportunity to access and participate in mainstream activities and decision-making processes (Cobigo et al, 2012). Therefore social inclusion is concerned with taking positive action to change the circumstances and habits of socially excluded people or communities to enable them to fully participate in society. For instance the National Social Report (DWP, 2012) establishes the UK Governments priorities to address social exclusion by reducing poverty, providing adequate and sustainable pensions and ensuring accessible, high-quality and sustainable healthcare and long-term care; thereby promoting social inclusion for people and communities. Much of this policy is concerned with tackling economic issues that can result in social exclusion and this will be revisited in section 2.2.3.

Internationally more specific definitions of social inclusion have been provided to outline the concept. For instance the Australian Government determines that socially included individuals have the resources, opportunities and capabilities they need to learn (participate in education and training), work (participate in employment, voluntary work including family and carer responsibilities), engage (connect with people, use local services and participate in local, cultural, civic and recreational activities) and have a voice (influence decisions that affect them) (Australian Government, 2012).

UNESCO determines an inclusive society to be one that:

"...is defined as a society for all, in which every individual has an active role to play. Such a society is based on fundamental values of equity, equality, social justice, and human rights and freedoms, as well as on the principles of tolerance and embracing diversity" (UNESCO, 2012, page 1).

This definition in particular highlights a social justice and human-rights based approach to forming a socially inclusive society.

Numerous definitions of social inclusion have also been suggested within the disability literature. For instance, an often quoted definition within this field illustrates social inclusion as:

'A virtuous circle of improved rights of access to the social and economic world, new opportunities, recovery of status and meaning, and reduced impact of disability. Key issues will be availability of a range of opportunities that users can choose to pursue, with support and adjustment when necessary.' (Sayce, 2001; page 122).

Commonly, these definitions emphasise inter-personal relationships or community participation as well as the rights of people with disabilities (Davey and Gordon, 2017; Simplican et al, 2015). However, as Davey and Gordon (2017) suggest, the participatory definition has arguably gained a more substantial foothold in the literature due to policy motivations, where a focus on participation provides Governments with a clearer measurement when addressing social inclusion- such as objective measures of the number and type of participatory activities.

Following a review of the social inclusion literature for people with intellectual and developmental disabilities, Simplican et al (2015) highlighted conceptual differences between the definitions in terms of scope, setting and depth of social inclusion. The scope referred to the kinds of activities, relationships and environments that social inclusion encompassed. Researchers using a broad scope sought to define social inclusion as being accepted as an individual beyond disability, engaging in significant and reciprocal relationships, having appropriate living conditions, employment, informal and formal supports and being involved in the community. The setting included where the social inclusion may take place- either in a private setting such as a person's house or in a public dimension through accessing community facilities. As such, a person could have a high number of friends but a low level of social inclusion if they have no access to the community. Finally, the depth of social inclusion examined both the objective measurements (number of friendships) and subjective measurements (level of satisfaction). Those definitions that were considered to have significant depth shifted attention to the subjective attitudes of nondisabled people towards people with disabilities. A pertinent example of this is Cobigo et al (2012) who defined social inclusion as a series of complex interactions between environmental factors and personal characteristics that provide:

- opportunities to access public goods and services
- valued and expected social roles of ones choosing based on his/her age, gender and culture
- recognition as a competent individual and trusted person to perform social roles in the community and
- opportunities to belong to a social network within which one receives and contributes support.

In discussing the literature review, Simplican et al (2015) develop a definition for social inclusion that incorporates interpersonal relationships and community participation as overlapping yet distinct domains for inclusion, and situate this within an ecological model that understands disability as a product of individual, environmental and social factors. The facets outlined in their definition of social inclusion will be discussed in the following section.

Finally when developing a social inclusion tool for people with developmental disabilities, Neely-Barnes and Elswick (2016) draw from a meta-analysis conducted by Verdonschot et al (2009) to define social as consisting of four domains. These were:

- Domestic: the opportunity for carrying out everyday actions within the domestic environment such as household care, clothing etc
- Interpersonal life: the opportunity for relationships with others such as peer relationships, family relationships and intimate relationships
- Major life areas and activities: the opportunity to participate in education, employment and economic life

 Social, civic and community life: the opportunity for recreational and leisure activities, encompassing hobbies, sports and other extracurricular activities.

A selective examination of the extensive literature situated within the disability field rather than dementia, has highlighted the considerable disparity in the way that social inclusion has been defined and the contexts where it is applied. This makes it particularly difficult to draw on one definition. However, despite this disparity our understandings of social inclusion are often guided by various principles (Brown et al, 2015; Cobigo et al, 2012; Hunting et al, 2015). This has resulted in a general agreement on the structure of the concept, such as it being multi-dimensional and multi-levelled (Davey and Gordon, 2017), as well as it being viewed as a process rather than an outcome (Hunting et al, 2015; Taket et al, 2009, 2014). These principles will be discussed below in addition to the importance of incorporating the definition within a rights-based paradigm.

## 2.2.3 Principles of social inclusion

Multiple interacting levels of social inclusion

Taket et al (2009, 2014) posit that social exclusion/inclusion operates at multiple interacting levels consisting of the individual, community and society. Within each level the multiple dimensions of social inclusion/exclusion (discussed below) interact to bring about exclusion or inclusion for individuals or communities.

At an individual level the excluded are not a homogeneous population but heterogeneous and individuals may experience social exclusion and inclusion in varying ways and across multiple social locations and identities such as age, geography, and ethnicity (Hunting et al, 2015). As such they can be positioned on a fluid continuum of absolute inclusion through to absolute exclusion (Taket et al, 2009). Consequently people are likely to have differing needs and perspectives with regard to their social inclusion (Hunting et al, 2015). Importantly Taket et al (2009, 2014) also highlight the individual agency of people whereby they have the ability to choose whether to socially engage. This is in accordance with Brown et al (2015) who discuss the need to emphasise the person's self-determination to choose the activities and groups they wish to participate in. For Davey and Gordon (2017), the acknowledgment of this agency is important for definitions of social inclusion for people with mental health conditions and disabilities, yet is often omitted. They posit that if opportunities are available for people to participate yet they choose not to, then this could not be considered social exclusion unlike other situations where the social exclusion is enforced either through the lack of factual opportunities available for people to participate or through a social rule in place that prevents their participation. Consequently, definitions of social inclusion should incorporate the term 'opportunity' as it implies the option to take up participation rather than being forced into factual participation.

Social exclusion/inclusion can also operate at a community level whereby individuals or groups can be excluded within communities, or communities as a whole may be excluded from full

participation in the wider society. Taket et al (2009, 2014) suggest this may be particularly pertinent for socially excluded individuals within rural communities where the concept of the 'rural idyll' (Cloke and Milbourne 1992) can often mask the challenges that they face for social inclusion. Furthermore this exclusion is likely to be exacerbated at a community level as urban policy makers focussing on social inclusion are unlikely to take into account the perspectives of rural stakeholders (Blackstock et al, 2006; Taket et al, 2009). These issues will be discussed further in section 2.4. Finally social exclusion/inclusion can operate at a societal level where citizenship status and legislation have implications on the ability and rights of people to participate and be socially included in society. This rights-based approach to understanding social inclusion will be discussed later in this section.

## Social inclusion as a dynamic process

Social inclusion can be conceptualised as an on-going dynamic process for a person, group, community, organisation or population (Cobigo et al, 2012; Hunting et al, 2015; Taket et al, 2014; Ward, 2009). Individuals and communities can move in and out of social exclusion or inclusion and this can change over time, in different situations and as they grow older (Brown et al, 2015). Consequently certain individuals, groups and communities are not permanently cut off from society and may also experience positive aspects of social inclusion, such as close connections with their family or in close-knit communities, within their wider experiences of social exclusion (Davey and Gordon, 2017; Hunting et al, 2015). Hunting et al (2015) highlight the importance of understanding the dynamic relationship between social exclusion and social inclusion rather than constructing a false binary between the two concepts. In this way it is possible to understand that the processes and systems of power that shape social exclusion across populations (such as stigma or discrimination) can simultaneously shape experiences of social inclusion. They argue that it is necessary to understand the relationship between social inclusion and exclusion and the forces and processes that shape these experiences for individuals rather than focus solely on the groups or individuals deemed to be socially excluded. Discussing social inclusion from a social work perspective, Ward (2009), outlines the importance of understanding the concepts of social inclusion and exclusion as a dynamic process rather than just an outcome. In doing so, it is possible to examine the social processes that lead to exclusion and so enable people to 'identify where, when and how to intervene effectively' (Ward, 2009; page 238).

## Multidimensional and relational nature of social inclusion

Social inclusion has a number of dimensions including the economic, social, cultural and political (Taket et al, 2009, 2014) and social exclusion in one is likely to result in exclusion by another (Ward, 2009). The introduction of this multidimensional concept was initially welcomed by policy experts and academics as a tool for widening the poverty discourse (Zinn, 2013) and enabling the examination of the diverse sources of poverty and exclusion that people faced within society (Marston and Dee, 2015). However there have been issues with how it has been

used within both a political and academic context. These will be discussed below when outlining the multiple dimensions of social inclusion.

#### o Economic dimension

The economic dimension refers to people's access to employment. Many researchers have suggested this dimension is often focussed upon in the traditional Western paradigm of social inclusion, resulting in a narrow definition of the concept where it is merely associated with labour market inclusion (Brown et al, 2015; Daly and Silver, 2008; Levitas, 2004, 2012; Taket et al, 2009; Winlow and Hall, 2013; Zinn, 2013). Consequently, UK policy directives often focus on promoting social inclusion through economically driven strategies that tackle the 'material' factors (Ward, 2009) or indicators of social inclusion such as access to income, housing, goods and services through enabling people to enter employment and so contribute economically to society (Levitas, 2004; Ward, 2009). However, as authors argued (Levitas, 2012; Winlow and Hall, 2013; Wright and Stickley, 2013) it was not simply poverty or economic factors that caused exclusion but rather 'poverty in relation to unattainable wealth in unequal societies' (Wright and Stickley, 2013; page 72). Focussing on the economic determinants of social exclusion and those people who were unemployed, centred the blame on individuals or the 'moral underclass' (Levitas, 2004) for their social exclusion; thus ignoring the complex interactions and power relationships between individuals and the society, or communities where they lived (Cobigio et al, 2012; Hunting et al, 2015). Taket et al (2009) posited that these policy directives are weaker versions of the discourse on social exclusion as they focus solely on changing characteristics of the excluded individuals to ensure their social inclusion. There is, therefore, a need to incorporate stronger forms of the discourse within policy by emphasising the role of those perpetuating exclusion and aiming to reduce their power (Taket et al, 2009; page 10). Without addressing these wider societal structures it is unlikely that interventions designed to promote social inclusion will be successful (Hunting et al, 2015; Winlow and Hall, 2013). This is supported by Brown et al (2015) who suggest that the principles of social inclusion should not focus solely on economic advantages but must adopt a more holistic approach that encompasses participation within the community and emphasises feelings of trust and reciprocity within these groups; thereby enabling more meaningful participation. As such it is important for the current study to adopt a broader, stronger conceptualisation of social inclusion.

Furthermore, focussing on employment and economic participation as an indicator of social inclusion means little or no attention is given to people who have retired and so no longer contribute economically to society. Therefore they are often neglected within the social inclusion/exclusion policy agenda as highlighted by their late inclusion in the SEU's remit. As Zinn (2013) has suggested, where older people are included within this political discourse it is often framed as a means to harness their 'economic potential' and therefore their other experiences and life plans are devalued. This has implications for older people with dementia who may no longer demonstrate any 'economic potential.' In addition to this, the focus on material conditions can mean that most people who are deemed to be socially excluded are also assumed to be poor (Ward, 2009). This can result in those who are wealthy being excluded

from social inclusion research and policies, and so little attention is paid to the processes that may lead to their social exclusion (such as discrimination, stigmatisation and negative social attitudes, as will be discussed below). Marston and Dee (2015) posit that research approaches must include individuals across the income scales and so capture their diverse experiences and the relational understanding of social inclusion and exclusion. This may be particularly pertinent for the older men with dementia in the current study who may be financially privileged and therefore not necessarily experience social exclusion as defined by the traditional Westernised paradigm.

## Social, cultural and political dimensions

Consequently it is important to consider the social, cultural and political dimensions whereby people can be socially included or excluded. These indicators focus on: access to people or inter-personal relationships with friends, colleagues and family; access to community services that enable meaningful social participation (Buckmaster and Thomas, 2009; Simplican et al, 2015); opportunities for political expression; and recognition and valuing of identity in the relationships experienced (Ward, 2009). These facets of social inclusion may be restricted through the infrastructure and services present within communities (particularly within rural areas as will be discussed in section 2.4) or through 'discursive factors' (Ward, 2009) such as the devaluing of individuals, groups and communities. This latter determinant is reminiscent of Goffman's work on stigma that is a 'deeply discrediting attribute that globally devalues an individual' (Goffman, 1963; page 12) and is a challenge that is particularly pertinent for the social inclusion of older people through 'ageist' attitudes (Warburton et al, 2013), those with mental health conditions (Cobigio and Stuart, 2010; Hunting et al, 2015; Wright and Stickley, 2013) as well as dementia (Benbow and Jolley, 2012; Cantley and Bowes, 2004; Cook, 2008; Forbes et al, 2011; Kitwood, 1997). The stigma people experience can inform judgements and influence the feelings they have about their own identities (Goffman, 1963) and so limit a person's sense of social inclusion. As Taylor (1994) posits when discussing wider aspects of multiculturalism:

'Our identity is partly shaped by recognition or its absence, often by the misrecognition of others, and so a person or group of people can suffer real damage, real distortion, if the people or society around them mirror back to them a confining or demeaning or contemptible picture of themselves. Non-recognition or mis-recognition can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted and reduced mode of being.' (Taylor, 1994; page 25)

These social, cultural and political dimensions work in tandem and intersect economic dimensions of social exclusion/inclusion to exacerbate issues by detrimentally impacting on people's willingness and ability to be included within society, and so subsequently adversely impact on their health and prosperity (Ward, 2009). As Taket et al (2009) suggest, people may be economically included within societies (in terms of housing and employment status) but socially and culturally feel unwelcomed leading them to restrict their participation within certain

spaces and communities. It is, therefore, imperative that policy directives as well as research and practice understand 'social inclusion' as more than the economic ability of people. In doing so, it can examine ways to enhance social inclusion by providing opportunities for meaningful social participation and challenging the negative social and cultural discourses and processes that can socially exclude individuals and groups within society (Benbow and Jolley, 2012; Warburton et al, 2013; Wright and Stickley, 2013).

Furthermore, Davey and Gordon (2017) explain that these stigmatising views and discriminatory practices can mean that people with mental health conditions may participate in social and cultural activities but not disclose their condition; instead choosing to hide behind a 'social mask.' They posit that true social inclusion can only occur when people can participate within their community and be themselves. This is in accordance with Hall (2009) who found through a qualitative meta-analysis that a key criterion for social inclusion in people with intellectual and developmental disabilities was the need to be accepted as an individual beyond the disability. Davey and Gordon (2017) argue that current definitions of social inclusion do not take this into account and so advise that the words 'unconditional opportunity (bound by legal and moral limits¹)' should be incorporated into future definitions; emphasising that people should be able to participate without conditions placed upon them, thereby ensuring they can be themselves and feel socially included.

#### Social inclusion 'as a right' paradigm

As alluded to throughout the section, social inclusion can be situated within a human rights or citizenship framework. As authors have argued (Buckmaster and Thomas, 2009; Crisp et al, 2014; Marston and Dee, 2015; Taket et al, 2009, 2014) it is important for the concept of social inclusion to incorporate a rights-based approach thereby recognising individuals as capable actors/agents with social citizenship rights (Marston and Dee, 2015). These authors argue that broader conceptualisations of social inclusion should incorporate citizenship (Marshall, 1950) or social citizenship, human rights (Turner, 1993) and social justice. This will help to acknowledge the relations of power that underlie the divisions amongst social groups within society and ensure that regardless of whether people are in employment they are afforded social entitlements guaranteed by the state (Marston and Dee, 2015). Concepts of social citizenship link well with the concepts of social inclusion and emphasise the need for people to have economic security and equal access to health, education and genuine employment opportunities as well as highlight the role of political, social, cultural and economic factors in creating (and maintaining) social inclusion (Marshall, 1950; Taket et al, 2014). Incorporating a rights-based approach within the concept of social inclusion affords a rights-based language that can be used to strengthen the case for ensuring equal participation and integration of people within society (Taket et al, 2009, 2014). It also enables calls for equal freedoms and social justice (Marston and Dee, 2015). Thus, it can uncover structural injustice and detrimental

<sup>1</sup> This is important to acknowledge as on moral and legal grounds it should not be unconditional for a registered sex offender to participate in child care roles.

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processes that restrict equal freedoms for some people (rather than place the blame on them) and imply a moral imperative that justice is everyone's responsibility. After arriving at this conclusion it becomes much harder to absolve ourselves from having responsibility for social injustice (Marston and Dee, 2015) and so highlights the importance for society to provide equal opportunities to all people (Taket et al, 2014). Finally a rights-based understanding of social inclusion enables us to focus on the ends and not the means (Taket et al, 2014). Consequently authors have argued that this rights-based approach is fundamental within current conceptualisations of social inclusion for enabling an inclusive society (Buckmaster and Thomas, 2009; Marston and Dee, 2015; Taket et al, 2009, 2014).

Having outlined the definitions and conceptualisations of social inclusion and exclusion within the wider political discourse and academic literature, I will now discuss these concepts within the dementia discourse.

## 2.2.4 Defining social inclusion within the dementia discourse

There is also a lack of coherence in the definitions and conceptualisations of social inclusion within the dementia field. The book by Innes et al (2004) titled: 'Dementia and Social Inclusion: Marginalised groups and marginalised areas of dementia research, care and practice' was the first to address the experience of dementia under the banner of social inclusion. Throughout the chapters the various authors outline the meaning of social inclusion for people with dementia and the challenges they face to enact this human right. For instance Bell (2004) discusses the importance of authentic and meaningful social relationships yet warns of the difficulties this will entail as civil society begins to erode and social capital diminishes; leaving people to prefer to 'bowl alone' (Bell, 2004; page 27). This resonates with Winlow and Hall (2013) who argue the difficulties of a social inclusion agenda more broadly due to social disintegration, resulting in 'The end of the social?' Cantley and Bowes (2004) discuss social inclusion in the context of dementia suggesting people living with the condition experience 'social exclusion in different ways, at different times and to different degrees' (page 256). This resonates with authors discussed previously who have argued that social inclusion is an on-going, multi-dimensional process (Brown et al, 2015; Marston and Dee, 2015; Taket et al, 2009). Cantley and Bowes (2004) highlight that people with dementia are socially excluded through the more limited choice and control they have over their own lives and the difficulties they encounter when participating in decisions that affect their lives due to stigma and discrimination. They argue that 'social inclusion' for people with dementia is: ensuring their rights as citizens as well as their personhood (Kitwood 1997) are upheld; enabling them to participate in relationships where they are valued and retain as much control as possible; providing them access to services where staff are trained to support their human rights; and actively engaging them 'in 'owning' and shaping initiatives to promote their social inclusion at individual, community, service and policy levels' (Cantley and Bowes, 2004; page 269). These facets are akin to a rights based approach to understanding social inclusion whereby people with dementia can be excluded on a social, cultural and political level. Also pertinent for this research is the work of Innes and Sherlock (2004) who suggested that the geographical isolation of rural areas in Scotland militated against social exclusionary processes by obliging people to co-operate more fully with one another. This outlines the role that community can play in enhancing social inclusion for people with dementia and will be discussed later in the chapter.

Other authors (Cook, 2008; Forbes et al, 2011) have addressed the concept of social inclusion for people with dementia, defining it as the opposite process to social exclusion (Cook, 2008; page 60). Conceptually, these studies highlight social exclusion for people with dementia as a lack of: material well-being and social benefits; opportunities to have a voice in the community; engagement in meaningful social relationships; participation in civic activities; access to formal services; fair representation in decision-making that affects health; and participation in subsequent service delivery and evaluation (Forbes et al, 2011). These studies pertain to policy approaches for understanding social inclusion, whereby it is defined by the positive actions required to reduce the multiple facets of social exclusion.

Nay et al (2015) have also addressed social inclusion within the context of care partners of people with dementia in Australia. They posit that social inclusion is a separate concept from social participation with the former emphasising the ways whereby individuals feel they belong or are connected to a particular group, organisation or network and the latter focusing on the person's involvement in activities that provide interaction with others in society and the community. They understand social inclusion as incorporating acceptance, opportunity, equity, justice, citizenship, expression and validation (Nay et al, 2015). This work adopts a similar position to Buckmaster and Thomas (2009) who also view social inclusion as separate to social participation and call for a wider understanding of the inclusion concept.

Bartlett and O'Connor (2010) have also proposed a conceptual framework to understand the social inclusion of people with dementia. Similar to the work by Cantley and Bowes (2004) this draws on a citizenship framework and recognises people with dementia as active social agents with 'rights, history and competencies' (Bartlett and O'Connor, 2010; page 39). This is reminiscent of Bell (2004) who contextualises people with dementia as social agents in a changing social context. Bartlett and O'Connor (2010; page 39-47) emphasise the rights for people with dementia to have:

- The opportunity for growth where they can develop different aspects of themselves in the context of having one aspect deteriorating
- A social position that respects their status as an equal citizen
- Access to opportunities that provide purpose and meaning in their lives
- Opportunities to participate in their lives in the communities, towns and cities in which they live
- Solidarity with other people, to connect on both a political and emotional level and,
- Freedom from discrimination on both a macro and micro level.

Similarly to Cantley and Bowes (2004) this conceptualisation resonates with the wider literature that situates human rights (Buckmaster and Thomas, 2009; Lombe and Sherraden, 2008; Taket

et al, 2014; UNESCO, 2012), social participation (Buckmaster and Thomas, 2009) and social justice (Marston and Dee, 2015) as integral to the social inclusion agenda. These conceptualisations have enabled researchers and practitioners to re-frame their understanding and support of people with dementia by positioning them as active social agents and enabling them to enact their human rights as citizens through understanding the processes and power dynamics at play within wider society (Brannelly, 2011, 2016; Clarke and Bailey, 2016; Dupuis et al, 2016; Kelly and Innes, 2013; Osterholm and Hyden, 2014; Phinney et al, 2016; Wiersma et al, 2016). This is crucial to address when promoting a socially inclusive society for people with dementia.

I will now examine how social inclusion for people with dementia has been promoted through global and national policy directives.

## 2.2.5 Dementia Policy Directive

Global Policy initiatives

Today, over 46 million people live with dementia and this is predicted to rise to 131.5 million by 2050 (ADI, 2015). Unsurprisingly this has resulted in a global focus on dementia most notably reflected in the G8 (now G7) summit held in London in December 2013 that brought together ministers, researchers, pharmaceutical companies and charities to discuss ways of supporting people affected by the condition. The 12-point declaration primarily focussed on pursuing a cure and allocating money into research funding for this purpose. This decision provides evidence for Whitehouse's (2014) assertion that the global focus remains firmly on 'cure rather than care' (page 6). However the declaration also outlined the need for people with dementia to fulfil their human rights (point 9) and to enhance their contributions to their own care needs (point 10) as well as reduce stigma, social exclusion and fear for people living with the condition (point 11) (UK Government, 2013). This is indicative of a global dementia policy that is beginning to understand the importance of social inclusion for people with dementia and the processes that may impede this. In addition to this, the World Health Organisation identified 'dementia' as a priority (WHO, 2012) and focussed on the 'Six stages of Acceptance of Dementia' running from ignoring the problem to the normalisation of dementia and its acceptance as a disability. Following this many countries worldwide are beginning to publish their own dementia strategies and plans such as Australia, France, Israel, Japan, Netherlands and Norway (Pot and Petrea, 2013). These seek to adhere to ADI's ten key elements for addressing the needs of people with dementia through National Dementia Plans including: promoting public awareness and education of dementia and addressing stigma; improving diagnosis and treatment; identifying dementia support services; quantifying the number of people living with dementia; assessing and improving the quality of healthcare, social care and long-term care support and services as well as improving the dementia training of these professionals; assessing availability and access to diagnostic services; strengthening the support to family care partners; and recognising the role of innovative technologies (Pot and Petrea, 2013). This provides further support to the assertion that dementia is becoming a global priority and countries are

recognising the need to address barriers for supporting the health and social inclusion of people living with the condition.

## UK dementia policy

Within the UK, around 850,000 people are living with dementia, with 720,000 residing in England (Alzheimer's Society, 2014a). This comes at a cost of around £26 billion a year in care costs and lost productivity (Alzheimer's Society, 2014b). Consequently, it is unsurprising that 'dementia' is now receiving the due attention it deserves within the UK. For instance the Scottish Government released a National Dementia strategy in June 2010 (Scottish Government, 2010) and both Northern Ireland (Department of Health, Social Services and Public Safety, 2011) and Wales (Welsh Assembly Government, 2011) have released their vision for addressing dementia. In England, since 2009, there have been key policies and reports that have shaped research and support for people with dementia. In 2009 a Dementia strategy was published entitled 'Living Well with Dementia: a National Strategy' (Department of Health, 2009). The strategy outlined a list of 17 objectives that it aimed to achieve. Some of these objectives demonstrated the English Government's commitment to ensuring people with dementia could feel a sense of social inclusion within their communities. These included: ensuring better knowledge of dementia and removing stigma associated with the condition; ensuring early diagnosis and support for people with dementia and their care partners; and developing better services to meet the changing care needs of people with dementia and their care partners. In 2011 it was accompanied by a 'Good Practice Compendium' (Department of Health, 2011) that aimed to support the delivery of the National Dementia Strategy.

In 2010 a National Audit Office report was published aimed at 'Improving Dementia Services in England' (National Audit Office, 2010). The report identified the need for empowered local leadership for improving dementia services as well as funding to be made available to commission more memory services. It also encouraged the use of Key performance indicators that focussed on outcomes such as increasing early diagnosis rates as well advocating the user experience when measuring quality of life in care homes. This latter aspect is indicative of a more socially inclusive approach that seeks feedback from people living with dementia as experts in their own care requirements. In the same year, a report was published entitled 'Quality Outcomes for people with Dementia: Building on the work of the National Dementia Strategy' (Department of Health, 2010). This report documented the shift to an outcomes based framework for dementia and identified four key areas for policy: good quality early diagnosis and intervention for all; improved quality of care in general hospitals; living well with dementia in care homes; and reduced use of antipsychotic medicine. This latter aspect highlighted the need for alternative means to support the well-being of people with dementia such as ecopsychosocial initiatives. These will be discussed further in section 2.6. Other policy documents within this period included NICE Dementia Quality Standards (NICE, 2010) and NICE report on Dementia: independence and well-being (NICE, 2013). These addressed the care and support of people with dementia in all social care settings and services including the

community and provided a resource to support people to live well with dementia. As part of the ten key messages they recognised that people with dementia: had the choice and control to participate in decisions that impacted on their care needs and support; were enabled to develop and maintain relationships and take part in leisure activities based on their individual interest and choice; had access to services that maintained their physical and mental health and well-being; had the opportunities to participate in and influence the design, planning, evaluation and delivery of services including advocacy services; and to maintain and develop their involvement in and contribution to their community (NICE, 2013). Many of these messages overlapped with the Dementia Action Alliance Declaration that was published at this time and sought to commit families, communities and organisations to work together to better the lives of people with dementia. These messages align well with the concept of social inclusion for people with dementia and emphasise the need to adopt a more holistic approach to promoting well-being rather than focussing solely on biomedical requirements.

In 2012 the Prime Minister released his challenge on dementia and this was again updated in 2015 (Department of Health, 2012; Department of Health, 2015). These outlined the progress made following the implementation of the National Dementia Strategy's recommendations. They further emphasised the Government's aspirations to address issues associated with dementia over the prevailing years until 2020 by: improving public awareness of dementia and dementia training for professionals working with those affected by the condition; providing equal access for everyone to a diagnosis; improving access to post-diagnostic support and care; establishing dementia-friendly communities and ensuring businesses are dementia-friendly and; increasing the amount and quality of dementia research and the funding allocated to support this with an emphasis on finding a cure for the condition. These objectives align well with definitions of social inclusion that promote the need for socially excluded populations to be enabled to participate within society, free from discrimination. However as Bartlett et al (2016) note they pay little attention to the gendered experience of dementia and how this can impact on the social inclusion of those living with dementia and those supporting them. The importance of this issue will be discussed in section 2.5.3.

To enact the Prime Minister's challenge 2020, there has been funding directed towards a UK Dementia Research Institute led by the Medical Research Council that focuses on bringing leading experts in the field together to: support new drug treatments and clinical trials; develop and promote strategies for interventions that prevent the development and progression of dementia; and provide new insights and technology-based approaches to delivering more effective care and support for people with dementia and their care partners. Interestingly, predominantly the focus of this is on curing dementia or preventing its development as opposed to supporting the social inclusion of those currently living with the condition. Furthermore, there has been a declaration on improving post-diagnostic support and care by placing those with dementia at the centre of any decisions made (Department of Health, 2016a) as well as the implementation of Dementia Advisors (Department of Health, 2016b) to advise those living with dementia of post-diagnostic support available in their local area. This latter report suggests

Dementia Advisors are now prevalent within England with 81 out of the 89 commissioners surveyed stating that there was a dementia advisor or similar within their area, suggesting a recognition of the importance of providing people with dementia post-diagnostic support within their communities.

Finally the Alzheimer's Society has also been influential in advancing policy on the social inclusion of people with dementia and their care partners. Working alongside the James Lind Alliance (Alzheimer's Society, 2013a) they have generated 10 research priorities for supporting people with dementia via a consultation process. This process was inclusive of people with dementia and their care partners and is noteworthy for its focus on support and inclusion of people with dementia. Furthermore the Alzheimer's Society has also released a call for 'dementia-friendly' communities (Alzheimer's Society, 2013b). This initiative aims to ensure dementia-friendly communities are:

"...where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia-friendly community people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choice and control over their day-to-day lives' (Alzheimer's Society, 2013b, page 10).

The definition of 'community' within this policy directive is broad and still within its infancy (Bartlett 2016). However guidance produced following the initiative has promoted 'dementiafriendly' workplaces, art venues, technology, financial services, businesses and retail services. This demonstrates a wider understanding of a socially inclusive society where people with dementia are supported to contribute economically, socially, culturally and politically. At present however the initiative adopts a broad brush approach to promoting a 'dementia-friendly' community and does not differentiate between the geo-socio-cultural environments (such as rural and urban settings) or the gendered identities of people with dementia that are likely to influence their experiences of social inclusion (Bartlett and O'Connor, 2010; Bartlett et al. 2016; Blackstock et al, 2006; Hulko, 2009). The importance of recognising these aspects when promoting social inclusion will be critically discussed later in this chapter. Interestingly, Lin and Lewis (2015) suggest that policy directives also need to include the concept of 'dementia positive' alongside 'dementia friendly' and 'dementia capable' (as is the case in countries such as the USA). They posit that without this former concept, societies will merely be set-up to tolerate, respect and support people with dementia and their care partners rather than viewing them as equal contributors; thereby creating a pseudo-social inclusion. This emphasises the importance of respecting and valuing the knowledge of people with dementia rather than solely establishing communities that can support them. This ethos is one that guided me throughout my research.

## 2.2.6 My working definition of social inclusion for this thesis

As can be seen from my discussion of the literature above, the term 'social inclusion' is a common concept used within the wider political discourse and that of dementia, both nationally

and internationally. As such it is an appropriate term to use for this applied study. However, within the wider political discourse social inclusion often refers to the economic inclusion of individuals, groups and communities and neglects their social participation and social rights. As discussed previously, these are particularly important for stigmatised populations such as people with dementia. Therefore, in this study the term 'social inclusion' will be understood as a process rather than an outcome. It refers to the rights for people with dementia to have the economic and material means to be included within their communities as well as the agency and unconditional opportunity to access and participate in social and cultural experiences and inter-personal relationships that are meaningful to them, enable their personal growth and a sense of connection and solidarity, and ensure they feel valued, included and positioned as equals. I will use this definition of social inclusion as a lens through which to interpret and discuss my research findings in Chapter 7 of the thesis.

#### 2.3 Dementia

Within section 2.2.5 I highlighted the current global and national political focus on dementia. In the following sections I critically discuss the conceptualisations and constructions of dementia as they impact on the behaviour and understanding of professionals working within the field as well as the current policy directives (Innes, 2009; Innes and Manthorpe, 2013) outlined earlier. Understanding these various conceptualisations enables a better appreciation of the challenges people with dementia face in maintaining their social inclusion.

## 2.3.1 Constructions and conceptualisations of dementia

Although 'Dementia studies' is an emerging research field in its own right, it is nonetheless influenced by multiple discourses from various academic disciplines including neurology, genetics and other biomedical fields as well as psychology, sociology and gerontology. This can complicate matters when understanding dementia and supporting the social inclusion of those living with the condition. The way people with dementia are perceived influences:

- their care experience
- how care is delivered and how priorities are made
- the quality of relationships
- the options considered possible or appropriate in terms of caring for a person with dementia (Downs et al, 2006)

Although there are various theoretical constructions of dementia, those pertinent to this study include biomedical and psychosocial approaches. Innes and Manthorpe (2013) argue it is necessary to integrate approaches to broaden understandings of dementia and so advance dementia policy, practice and research.

## 2.3.2 Biomedical constructions

Biomedical constructions of dementia or the 'Standard Paradigm' (Kitwood, 1997) have been the dominant theory for most of the 20<sup>th</sup> century. Dementia is defined as a disease and viewed as an umbrella term for a group of clinical syndromes (Gubrium, 1986; Kitwood 1997). It is often

associated with increasing age (Stephan and Brayne, 2014) and is characterised by a progressive decline in cognition of sufficient severity to interfere with social and/or occupational functioning and may also include other symptoms such as language problems, deterioration in the ability to perform activities of daily living and behaviour changes (Downs et al, 2006; Innes and Manthorpe, 2013). Lyman (1989) establishes three characteristics of biomedical constructions: dementia is a pathological, abnormal condition; dementia is organic in aetiology and progresses through stages and; dementia is diagnosable using biomedical assessments such as the Mini-Mental State Examination (MMSE). Biomedical constructions have identified over 200 subtypes of dementia that vary in patterns of expression and neuropathology (Stephan and Brayne, 2014). Alzheimer's disease (AD) is the most prevalent of these subtypes accounting for between 60-70% of all cases (Alzheimer's Society, 2014). Other subtypes include: Vascular Dementia, Dementia with Lewy Body, Frontal Lobe Dementia, Pick's disease and Alcohol-related Dementia and with the considerable overlap in pathology of subtypes, mixed forms of dementia are also common (Stephan and Brayne, 2014).

Biomedical constructions facilitate social inclusion

Receiving a diagnosis of dementia and understanding its prognosis within a biomedical construction can be beneficial for a person as it: permits them to receive licensed pharmacological treatment for their symptoms; provides them access to information and support when it is likely to be most beneficial; and provides care partners and practitioners an explanation for the needs of people with dementia and/or changes in their behaviour as well as a degree of prediction about possible future events (Innes and Manthorpe, 2013; Kitwood, 1997). These pharmacological interventions can help to alleviate some neurological issues that may prevent people's social inclusion within society. In addition to this, understanding dementia as something different from normal ageing enables the development of dementia specific services to support people living with the condition and their care partners (Innes and Manthorpe, 2013) including initiatives to promote their social inclusion.

Limitations of biomedical constructions for supporting social inclusion

Biomedical constructions of dementia have led to a fascination with establishing a cure for the condition and much of the Governmental funding directed towards dementia research has focused on this aim (Whitehouse, 2014). Consequently little attention or funding has previously been afforded those people currently living with the condition or examined how their well-being and social inclusion can be maintained. Whitehouse (2014) has questioned how long the assertion that a cure is close can maintain its credibility and has argued that future research focusing on supporting people to live well with the condition should be given precedence.

The medicalization of dementia emphasises the neurobiological and neuropsychological aspects of the condition. This has resulted in behaviours such as agitation, anxiety or distress being attributed to the 'disease.' Consequently, pharmacological interventions have been favoured to alleviate these issues rather than seeking other explanations for their cause (Power,

2010). This has the potential for the misuse of antipsychotic medication to treat these behaviours when they are considered challenging (Banerjee, 2009) and can adversely impact on the well-being of people with dementia (Ballard et al, 2009; Power, 2010) and subsequently their social inclusion within society.

Biomedical constructions also virtually ignore the intact cognitive and social abilities of people with dementia as well as the contexts where these abilities are displayed (Sabat, 2014). The emphasis on the deficits of an individual with dementia results in a 'tragedy discourse' whereby those living with dementia are viewed with despair and loss and seen only as patients or clients rather than people or citizens with rights (Bartlett and O'Connor, 2010; Dupuis et al, 2016). These ill-informed assumptions of people with dementia are prevalent throughout the public discourse (McParland, 2014; McParland et al, 2016) and are continually perpetuated through the media (Zeilig, 2014) and often prevalent in researchers' accounts of the condition (Hulko, 2009). The 'tragedy discourse' has influenced a global stigmatisation of the condition (ADI, 2012) and maintained perceptions that people with dementia are living 'the death that leaves the body behind' or a social death where they cease to be an active social agent (Behuniak, 2011; Sweeting and Gilhooly, 1997). Whilst it is important not to overlook the detrimental biomedical impacts of dementia, privileging these discourses within public and policy narratives adversely impacts on the language (Behuniak, 2011; Mitchell et al, 2013) and processes that enable people with dementia to exercise their citizenship rights (Dupuis et al, 2016; Nedlund and Nordh, 2015) and therefore maintain a sense of social inclusion. They can also serve to weaken a person's sense of self-worth and self-esteem and increase their sense of being burdensome on society (Sabat, 2014).

It is, therefore, necessary to broaden understandings of dementia beyond biomedical constructions, as:

'If carers, clinicians or neuroscientists were to mistake the disease model for the whole picture, the effect would be clinically, socially and ethically disastrous' (Hughes, 2011; page 128).

By widening the scope it is possible to understand how people can be supported to ensure their social inclusion and sustained well-being whilst living with the condition.

#### 2.3.3 Psychosocial constructions

From the late 1980's onwards new conceptualisations of dementia, based on psychosocial constructions were introduced to challenge the biomedical discourse. Although early pioneers questioned the biomedical model (Gubrium, 1986; Gubrium and Lynott, 1987; Lyman,1989) it was not until the seminal work of Kitwood (1997) in the UK and Sabat (2001) in the USA that the real challenge began.

Kitwood's work (1990, 1993, 1997), whilst still acknowledging the biomedical basis of dementia, challenged its narrow medical focus. He developed the concept of 'personhood,' defined as:

'A status or standing bestowed upon one human being, by others, in the context of social relationship and social being. It implies recognition, respect and trust and this should be preserved even if a person has received a diagnosis of dementia.' (Kitwood 1997; page 8).

Kitwood (1997) argued that the clinical manifestation of dementia could be understood as arising from a complex interaction of five factors: personality, biography, physical health status, neurological impairment and social psychology. The assumption is that these factors provided the foundation for addressing, promoting and respecting personhood (Bartlett and O'Connor, 2010). Kitwood (1997) posited that the dementia experience for an individual was not solely an outcome of their neurological impairment but was socially constructed through the relationships and interactions they engaged in with those around them. Positive relationships and interactions with others enabled the person with dementia to maintain identity and self-worth (Cowdell, 2006; Dewing, 2008a).

Kitwood (1997: 46-7) emphasised the importance of maintaining the personhood of an individual with dementia and coining the phrase, *'Malignant Social Psychology,'* he devised a list of 17 interactions that adversely impacted on this process. Table 1 summarises these behaviours and a more detailed description has been provided in Appendix 1.

Table 1: Kitwood's 17 types of personal detractions

1. Treachery	6. Stigmatization	11. Ignoring	16. Mockery
2. Disempowerment	7. Outpacing	12. Imposition	17. Disparagement
3. Infantilization	8. Invalidation	13. Withholding	
4. Intimidation	9. Banishment	14. Accusation	
5. Labelling	10. Objectification	15. Disruption	

These interactions occurred at varying levels ranging from mild (no malice intended in the actions) to very severe (care partners aware of their actions and the impact it will have on the person with dementia). Kitwood (1997: page 119-120) proposed 12 categories of positive actions people could undertake to support the well-being of people with dementia. These are set out in the Table 2 and more detail is provided in Appendix 2.

Table 2: Kitwood's 12 categories of positive person work

1. Recognition	4. Play	7. Relaxation	10. Facilitation
2. Negotiation	5. Timalation	8 Validation	11. Creation
3. Collaboration	6. Celebration	9. Holding	12. Giving

These ideas enabled scholars to challenge biomedical constructions that solely blamed neurological processes for the personal deterioration associated with dementia (Behuniak, 2011; Hughes, 2011; Power, 2010). The work emphasised the importance of a positive interpersonal social environment to promote the personhood and sense of personal competence of people with dementia. It also highlighted the importance placed on those without dementia to support an individual in retaining their personhood, well-being and subsequently their sense of social inclusion (Innes, 2009). This work has similarities with the social model of disability that highlights how the social environment and inter-personal relationships can impact on the lived experiences of people with physical and intellectual disabilities.

Other work conducted by Sabat and Harre (1992) explored the idea of the 'self' in people with dementia. Sabat (2001) identified three types of self through systematic collection of case studies. He developed a three-fold categorisation of self (Sabat, 2002) that included self-one: the singular self ('I like that'), self-two: the characteristics held by the individual such as their mental, physical, emotional beliefs ('I am good at cooking') and self-three: the publicly presented personae that involve the co-operation of others and the roles they play within these relationships (such as worker, parent, friend). He hypothesised that self-one remained even when dementia was very advanced, self-two was dependent on the situation (a person with dementia may choose not to participate in an activity as it is not in accordance with their abilities or interests; choosing not to engage may indicate a strong sense of self rather than a lack of ability) and self-three, which is the most vulnerable, requires skilled caregiving and interactions to uphold the previous relationship and role. This work highlighted that the 'self' or identity of a person with dementia is maintained and later research has demonstrated that it can be expressed even without the need for language (Kontos, 2012, 2014; Kontos and Martin, 2013), yet it requires others to recognise it and support it through a positive inter-personal social environment (Kelly, 2010, 2014).

• Psychosocial construction facilitates social inclusion

The foremost achievement of the psychosocial approach was to effectively bring the person with dementia into the picture (Innes, 2009; Innes and Manthorpe, 2013). In doing so, it provided a more hopeful outlook of dementia and demonstrated how people living with the condition could be supported to maintain a sense of self and well-being. Through this, an

extensive body of work explored the use of person-centred approaches to support people with dementia. These aimed to:

"...maintain personhood in the face of failing mental powers by showing empathy and gaining knowledge of the individual's personal history, personality and needs." (van Weert et al, 2005; page 25)

Kitwood (1997) posited that people with dementia could be supported to live well with the condition by enabling their comfort, identity, occupation, inclusion, attachment and love. Other research has also emphasised the need to value people with dementia and their caregiver, treat them as individuals, look at the world from their perspective and provide a positive social environment (Brooker, 2004; McCormack, 2004). Ryan et al (2008) have drawn on the 'Senses Framework' to demonstrate how relationship-centred care can be achieved in dementia care services for those with dementia, care staff and family care partners. They highlight the importance of security (feel safe and free from threat, harm and discomfort), continuity (recognition and value of personal biography), belonging (opportunities to form and maintain meaningful relationships), purpose (opportunities to engage in purposeful activities and to identify and pursue goals), achievement (opportunities to meet meaningful and valued goals) and significance (to feel recognised and valued as a person of worth) when engaging with people with dementia (Ryan et al, 2008). These facets are integral to ensuring people with dementia feel a sense of social inclusion (Cantley and Bowes, 2004; Cook, 2008).

In understanding how people could be supported to live well with dementia, psychosocial constructions enabled a gradual transition from the social death (Sweeting and Gilhooly, 1997) to a 'living well' discourse as highlighted within the current UK dementia policy directive (DH, 2009, 2015). This is also apparent in academic accounts that have discussed the possibility for people to live well with dementia. For instance a systematic review of qualitative literature documented a more balanced account of the dementia experience than the loss-deficit paradigm, highlighting the positive experiences of people with dementia and the strengths and resources they retained (Wolverson et al, 2016). This move, although not prevalent within the public discourse (McParland, 2014) has helped to demonstrate the possibilities for people with dementia to be actively socially included within society. However it is also important to note that McParland et al (2016) have warned against simply dichotomising dementia within the public discourse as either 'despair and loss' or 'living well' as this can result in people with dementia 'othering' or excluding those who are not living well with the condition; thereby reducing the support they could receive from people with first-hand knowledge of their condition.

Furthermore, emphasising the requirement to understand the '*PERSON* with dementia' (Kitwood 1997), encouraged a shift to including the voices of people with dementia into both research and practice (Clare, 2003, 2008; Dupuis et al, 2016; Genoe and Dupuis, 2011; Goldsmith, 1996; Innes et al, 2012; Wilkinson, 2002; Wolverson et al, 2016). This work repositioned people with dementia from 'sufferers', who lacked insight into and ability to articulate their experience (as promoted by biomedical constructions), to people who had an awareness

of their condition and could provide valuable experiential knowledge. This was an important shift in thinking and promoting the voice of people with dementia in their own care experience and research; thereby enhancing their sense of social inclusion.

Finally, psychosocial constructions also enabled a more holistic understanding of dementia to be ascertained by highlighting the interplay between biological, psychological and social factors in the construction of the dementia experience (Keady et al, 2013; Sabat, 2014; Spector and Orrell, 2010). For instance, people with dementia can experience a range of emotions such as embarrassment, anger, depression (Sabat, 2014) and apathy (Manera et al, 2015) when faced with neurological issues and this can impact on their behaviour, motivation and experience of dementia (such as seeking to avoid embarrassment and humiliation). This is reminiscent of work that emphasises people with dementia as active social agents (Bartlett and O'Connor, 2010; Bell, 2004; Cantley and Bowes, 2004) in their quest for social inclusion.

Limitations of the psychosocial construction for supporting social inclusion

Whilst psychosocial constructions have enabled a more holistic understanding of the dementia experience, authors (Bartlett and O'Connor, 2010; Hulko, 2009; Innes, 2009; O'Connor et al, 2009) have argued they rarely acknowledge other aspects of a person's identity such as gender, age, race, culture, socioeconomic status and/or sexual orientation that can impact on these experiences. For example, Hulko (2009) has demonstrated that those who are more privileged (due to their socioeconomic status, gender and/or race) are more devastated by the losses affiliated with dementia than those less privileged who viewed dementia as having little significance in the grand scheme of other issues they faced daily. This has resulted in concerns that our understandings of dementia are homogenised. This resonates with authors (Hunting et al, 2015; Taket et al, 2009, 2014) in the wider social inclusion field who have argued for a more heterogeneous experience of social inclusion, taking into account a person's social positioning. Therefore a more nuanced understanding of the dementia experience is required to identify the multiple factors that can impact on the social inclusion of people living with the condition.

Psychosocial constructions of dementia can also position those living with the condition as passive recipients of care. Researchers such as Bartlett and O'Connor (2010) have argued against this and called for people with dementia to be re-positioned as 'active social agents' who have the power in their interpersonal and social relationships to influence their experience of living with dementia and consequently their social inclusion. For instance Bartlett (2014) has demonstrated how some people with dementia can participate in dementia activism movements to bring about social change and so positively influence their experience of social inclusion. This is evident in the Dementia Engagement and Empowerment project (DEEP). Again, this resonates with authors who highlight the individual agency that people retain in their experiences of social inclusion and exclusion (Brown et al, 2015; Hunting et al, 2015; Taket et al, 2009, 2014).

# 2.3.4 Dementia and ageing

It is worth acknowledging at this juncture that people with dementia are ageing and therefore their experiences need to be contextualised within these paradigms. The emergence of the 'successful ageing' movement across Western countries has emphasised the importance of individual agency and control, independence and the value of remaining physically and cognitively active (Lamb, 2014). A loss of these abilities moves older people from the 'third age' to the 'fourth age' that is synonymous with frailty, incapacity, isolation and reduction of autonomy (Gilleard and Higgs, 2015). The fear of the 'fourth age' can result in younger, healthier people distancing themselves from older, incapacitated people (Brannelly, 2011). Therefore those older people with dementia can be further excluded within the context of 'successful ageing' as they have failed to maintain a third age status (Van Dyk, 2014). This can make it particularly challenging for people with dementia who must negotiate the 'multiple jeopardies' (Benbow and Jolley, 2012; Innes, 2003) and forms of discrimination that are associated with being old, being mentally ill and having dementia in order to form positive interpersonal social environments that will support their sense of social inclusion.

Having outlined how conceptualisations of dementia can impact on the social inclusion of people living with the condition, I will now widen the discussion to demonstrate the importance of acknowledging the geo-socio-cultural environment where people reside, and particularly that of rurality. This is also likely to impact on the social inclusion of people with dementia.

## 2.4 Rurality

# 2.4.1 An ageing rural landscape

Demographic figures suggest that globally, 48 per cent of the population 65 years and older live in rural areas (Hennessy et al, 2014). Furthermore, research has suggested that internationally rural areas will continue to have higher proportions of older people when compared to urban areas (Buckner et al, 2013; Innes et al, 2011; Menec, 2015). This has primarily been attributed to the decline in the rural economy, out migration of younger rural residents who wish to pursue educational and employment opportunities within urban or larger regional centres, and the inmigration of middle-aged and retired people for lifestyle reasons (Buckner et al, 2013; Francis, 2012; Keating et al, 2013). The perception of a 'Rural Idyll' is another important pull-factor in the draw of older people to rural areas (Walsh et al, 2012). Cloke and Milbourne (1992) have defined this as:

"Happy, healthy and problem-free images of rural life safely nestling with both a close social community and a contiguous natural environment." (page 359)

This narrative portrays a positive and healthy way of life for older people that is free from crime and enables them to immerse themselves within nature (Butler and Cohen, 2010; Menec et al, 2011). This idyll promotes perceptions of strong family support networks, integrated and trusted communities and a low demand for external services (Menec et al, 2011; Wenger et al, 2002). With continuing higher proportions of older people in rural areas (Menec et al, 2015), it is reasonable to assume that a greater proportion of the rural population will be at risk of dementia

(Buckner et al, 2013; Innes et al, 2005) due to its positive correlation with age (Stephan and Brayne, 2014). Furthermore, Russ et al (2012) through a systematic review with a meta-analysis have also posited that there is evidence that rural living is associated with an increased risk in developing Alzheimer's Disease, and that early rural living may increase this risk.

Given this trend, dementia research and policy must be sensitive to the rural context (Blackstock et al, 2006; Clarke and Bailey, 2016; Innes and Sherlock, 2004; Innes et al, 2006) and seek to understand its impact on the social inclusion or exclusion of people with dementia. However, at present research and policy typically reflect the experiences and needs of an urban ageing population or the broadly defined 'ageing population' (Hennessy et al, 2014; Menec et al, 2011; Walker et al, 2013). This is particularly the case within the context of dementia research (Blackstock et al, 2006). Where rural research does exist it is sparsely distributed over various countries such as Australia (e.g. Alexander and Fraser, 2008; Greenway-Crombie et al, 2012; Hansen et al, 2005; Orpin et al, 2014), Canada (e.g. Dal Bello-Haas et al, 2014; Forbes et al, 2006; Forbes et al, 2011; Morgan et al, 2009; Wiersma et al, 2013), the USA (e.g. Boise et al, 2010; Meuser et al, 2004), Germany (von Kutzleben et al, 2016) and the UK and Ireland (e.g. Blackstock et al, 2006; Clarke and Bailey, 2016; Hennessey et al, 2014; Innes et al, 2005; Innes et al, 2014; Walsh et al, 2012). Caution must be taken when generalising these results due to differing cultures and welfare states. For instance rural caregivers were found to have a lower sense of obligation to care than urban caregivers in the US (Kosloski et al, 2002) but in Japan, rural caregivers believed it was their duty to care (Arai et al, 2000). Following an extensive review of the literature, no studies were found that explored the experiences of older men with dementia living in rural England. It is therefore crucial that this specific context is addressed given the ageing population trend in rural settings.

# 2.4.2 Defining my rural context

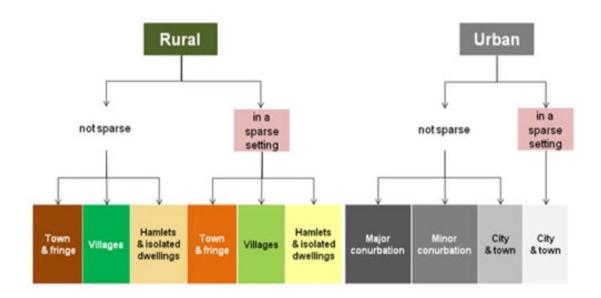
Prior to examining the impact of rurality on people with dementia it is necessary to define the term 'rural.' Historically there has been no standardised classification for the definition of rurality, and research has demonstrated heterogeneity (Russ et al, 2012) in how the term has been applied across studies. As Hennessy et al (2014) suggest, this reflects the evolving range of rural typologies and definitions as well as the growing acceptance of qualitative and ethnographic methods and the changing conditions in rural places themselves. To delineate between urban areas, the term 'rural' has commonly incorporated measures of population size, density and distance alongside socio-demographic and cultural characteristics, whilst also acknowledging the diversity of the rural place and the experiences of those within them (Menec et al, 2015). Martin et al (2000) have suggested that no "univariate measure of rurality can hope to adequately capture such a complex multidimensional concept" (page 739), making the task of selecting a comprehensive and operational measure of rurality a complex one for the present study.

This issue is also salient within the field of dementia research (Russ et al, 2012). Two systematic reviews of both informal and formal dementia care in rural and remote settings

(Innes et al, 2011; Morgan et al, 2011) found that only 10 papers (out of 72 reviewed) used a standardized definition of 'rural' based on national census divisions, government departments or health surveys. In addition to this, no definition of 'rural' was provided in 32 of the papers. This limits the ability to generalise the research findings from rural studies and so make definitive recommendations for dementia care, service delivery and practice.

To assist with policy development, within England and Wales the Government has devised the Rural-Urban Classification (RUC) and suggests this should be used wherever possible to distinguish between rural and urban areas (DEFRA 2013). The RUC was introduced in 2004 following a review of the rural and urban definitions in the White Papers published in 2000 that advocated a new definition based on rural and urban 'settlement structures.' It classified geographical areas to one of six rural or four urban classifications according to their settlement type. For an overview of the classification areas see Figure 1 below.

Figure 1: The Rural-Urban Classification (DEFRA 2015)



Rural areas were identified as those consisting of below 10,000 people or were open countryside. In the 2011 census England was divided into 171,372 Output Areas (OA) with each one being assigned a classification of urban or rural based on whether its centre was within or outside a built up area of greater than 10,000 people. The classification also took into account dwelling density for every 100m x 100m square, and at various distances around each square. This allowed a comparison of 'density profiles' for different types of areas and thus provided a typology for the first time within Government definitions (DEFRA, 2015). This definition is useful for Governmental policy as it identifies a single more permanent feature or dimension of rurality, namely settlement pattern. This meant that the need to use other rapidly changing data (such as economic or demographic) to identify rural areas could be avoided and it enabled other data to be used in conjunction with it to elicit a clear picture of associated patterns (the proportion of older people in villages and hamlets in sparsely populated areas) (The Countryside Agency, 2004). It should be noted however that this definition does not pay heed to arguments for a

socially constructed definition of 'rural' that is based on a collection of cultural constructs rather than a set of bordered spaces (Hennessy et al, 2014).

I have elected to use the RUC classification to identify the rural locations for the research. As this is a real world study (Robson, 2011), it is important that the definitions used are understood and can be applied by practitioners working with people with dementia. However, in supplementing this data with participants' experiential accounts of the rural locations (see Chapter 5) I will also be able to establish a socially constructed understanding of the environments.

# 2.4.3 Impact of rurality on the social inclusion of people with dementia

Research has suggested limited differences between UK rural areas on economic and health indicators when compared to urban areas (Pateman, 2011; Teckle et al, 2012). Potentially this is because rural areas in the UK have closer proximity to urban areas than in other more expansive countries (where health inequality has been demonstrated) and so rural residents can still benefit from the health and employment services in urban locations. Consequently this may explain why there is limited UK Government policy to address social inclusion specifically within the rural context.

However, poverty and social exclusion of older people may be masked in these large scale statistical analyses due to the surrounding wealth in the rural areas (Action with Communities in Rural England, 2014). As such, qualitative studies provide a better understanding of the lived experience of older people and those with dementia in rural areas. Unfortunately as Innes and Sherlock (2004) noted over ten years ago, there is a lack of empirical evidence that seeks to understand the experiences of people with dementia and this continues to be the case particularly within the UK. Where studies do exist, many have understood the rural experience from the perspectives of formal and informal caregivers, thereby neglecting the experiences of people living with dementia. These proxy views may not accurately reflect those of people living with dementia (Heid et al, 2015) and this approach may also serve to undermine the position of people with dementia by perpetuating the myth that their accounts are unreliable (Bartlett and O'Connor, 2010).

Furthermore Keating et al (2013) have also posited how different rural communities can impact on the social inclusion of older people depending on the 'best-fit' between older people's needs and the resources provided by the rural communities. Typically rural communities can be seen as 'bypassed' communities or 'bucolic' communities. Bypassed communities are isolated, often with poor services and economically depressed. They have difficulties providing health and social services and this is exacerbated by the impact of a reduced government commitment to support them. However, they have a strong sense of community and a willingness to endure despite limited resources. Keating et al (2013) posits that this can support older people facing social exclusion as there are other people in a similar position to them sharing limited resources in the face of long-term deprivation. Conversely, 'bucolic' communities have considerable resources and assets, including their natural beauty and slow pace of life, and often attract

recent retirees. Over time resources in the area can increase with population growth and the inmigration of retirees who contribute to the local economy. However it can become difficult for long-term older residents who can become socially excluded due to the increase in costs of living and limited social connections. Keating et al (2013) posit that as the community benefits very little from these long-term older residents then they can go unnoticed and further excluded from society. These experiences of 'best-fit' within communities are likely to impact on the social inclusion of these populations and will only become apparent through research that seeks to understand experiential accounts of people living in the communities.

2.4.4 Can rural environments promote social inclusion for people with dementia?

Menec et al (2015) have noted the benefits of living in rural areas for the social inclusion of older people generally. These include the strong community networks, the strong attachment to place, a learned self-reliance and a healthier lifestyle due to access to the natural environment. These findings are in accordance with other studies that have sought to understand the experience of living with dementia in rural locations (Blackstock et al, 2006; Clarke and Bailey, 2016; Di Gregorio et al, 2015; Forbes et al, 2011; Innes et al, 2014; Wiersma and Denton, 2016). Participants in Forbes et al (2011) and Blackstock et al (2006) demonstrated that both people with dementia and their care partners drew from the 'Rural Idyll' narrative when describing their experiences of living in rural Canada and Scotland respectively. Their participants discussed personal relationships that facilitated service access and enhanced individualised care whilst the informal social networks mitigated the impact of low population density and limited service provision. They also outlined a strong connection with place and a sense of self-sufficiency although on occasions this was juxtaposed to their particular situation, with participants discussing cases of stigma and isolation. Nevertheless both those with dementia and their care partners felt they were better off living in a rural area rather than an urban one. This interconnectedness or "community embeddedness" (Lauder et al, 2006) is viewed as a uniquely rural phenomenon (Baernholdt et al, 2010) and can be beneficial for the dementia experience. For instance in Scotland (Innes et al, 2005) and Northern Ireland (Gilmour et al, 2003) research has noted that the close relationships within rural communities and people's familiarity with rural residents prior to their dementia diagnosis helped to limit their social exclusion, as residents were more willing to tolerate socially unacceptable behaviours and offer support when required. This work is also supported by Clarke and Bailey (2016) who found that people with dementia's familiarity with the rural locations and the local community in northern England promoted their social inclusion as they felt safe and connected and people were willing to support them. This sense of security is important for the social inclusion of people with dementia (Ryans et al, 2008). However Clarke and Bailey (2016) also noted that this familiarity could be debilitating as it created a social barrier and sense of estrangement. Some participants reported that the sense of being 'known' created tensions, feelings of embarrassment for being different and a belief that their standing in the rural community had been compromised by having a diagnosis of dementia. As such they opted to socially withdraw from the community highlighting the role that people with dementia undertake as 'active social agents' in their social exclusion (Bartlett and O'Connor, 2010).

Health services provided for people with dementia both during the diagnostic process and post diagnostic can also benefit from the interconnectedness of rural communities. For instance, health service providers in rural East Anglia in the UK, worked together with community members such as the police, clergy and shop keepers to support people with dementia living within the community (McDonald and Heath, 2009). O'Reilly and Strong (1997) found that care partners of people with dementia living in rural Australia, indicated that they were more comfortable knowing the person who was going to provide the formal care for their family member. This is consistent with other research that has found that care partners of people with dementia were more comfortable with health workers they were already accustomed to and their existing relationships with these professionals enabled them to become more aware of services they could access for support (Dal Bello-Haas et al, 2014; Innes et al, 2005; Wiersma and Denton, 2016). Innes et al (2006) demonstrated how rural cultures could positively impact on the services for people with dementia by enabling them to deliver services that were appropriate to need, provide loving care and positive social interaction particularly with service providers as well as stimulating activities. Again this has also been supported by other research in rural Canada (Di Gregorio et al, 2015; Kosteniuk et al, 2014b). These respectful relationships are important in enabling a sense of social inclusion for people with dementia (Cantley and Bowes, 2004; Cook, 2008) and were appreciated by people with dementia and their care partners when using rural support services in Scotland (Blackstock et al. 2006).

### 2.4.5 Can rural environments hinder social inclusion of people with dementia?

Aspects of the rural environment and rural cultures can interact to adversely impact on the social inclusion of people with dementia (Bowes et al, 2016). For instance, although stigma associated with dementia traverses the urban and rural context (ADI, 2012), Innes et al (2014) have suggested that it may be more prevalent in rural areas due to the closeness of the rural community. This can result in a reluctance to disclose the diagnosis to other members of the community. This contention is discussed by Forbes et al (2011) who interviewed people with dementia and their informal and formal care providers in rural Canada. They found that the stigmatisation of dementia coupled with the 'anti-social' symptoms associated with the condition, especially in public places, often resulted in further social exclusion of the person with dementia. Consequently, friends and neighbours tended to withdraw from support networks over time as the symptoms progressed.

Rural cultures can also adversely impact on the use of specialist dementia services (Szymczynska et al, 2011). For example, Hansen et al (2005) found that Australian service providers were viewed as 'outsiders' and therefore an element of mistrust was associated with them. This was also supported by Gessert et al (2006) who reported resistance to formal care providers from rural care workers who actively participated in their relative's care to avoid the need for formal support services. Stigma of dementia within rural areas internationally and nationally has also been shown to hinder the use of formal dementia services (Bowes et al, 2016; Innes et al, 2014; Morgan et al, 2002, 2011); although Bowes et al (2016) note that within their rural European test sites, talking about dementia was now becoming more acceptable and

this was increasing the likelihood of people seeking support from services. This has important implications for the recruitment of male co-collaborators in the current study, who may view me and the Technological Initiative with an element of suspicion. Furthermore, other barriers associated with rural cultures have also restricted the use of dementia services including: a lack of privacy and anonymity due to the close nature of the rural community; attitudes of self-reliance and family responsibility and a lack of awareness of people with dementia on the need for formal services and the availability of those services (Di Gregorio et al, 2015; Innes et al, 2011; Morgan et al, 2002, 2011). Forbes and Hawranik (2012) have also noted that formal, rural healthcare providers are also limited in the availability of, and opportunities for, education and dementia training. If the person with dementia requires more specialist support from professionals to ensure their social inclusion then such factors can be detrimental to this process.

Finally, the geographical landscape of the rural area and availability of resources can adversely impact on the ability of people with dementia to connect with their community; thereby inhibiting the social inclusion of people with dementia (Clarke and Bailey, 2016; Innes et al, 2006; Morgan et al, 2002, 2011; Szymczynska et al, 2011). In Scotland, Blackstock et al (2006) suggested that the picturesque nature of the rural environments that once attracted people to them became difficult to traverse later in life due to issues associated with ageing and dementia. Consequently this restricted people's ability and willingness to engage within the rural locations. Furthermore a lack of specialist services has also been discussed in Canada (Morgan et al, 2015), Scotland (Innes et al., 2006, 2014) and northern England (Clarke and Bailey, 2016), which hinders the ability for people with dementia to access support and engage with their rural community. This issue is exacerbated due to the limited transport options available within rural areas (Menec et al, 2015; Orpin et al, 2014; Szymczynska et al, 2011). In the coming years with an emphasis on fiscal restraints, it is unlikely there will be any significant increases in provision of specialist health services (such as those for dementia) in rural areas and, quite possibly, a contraction in such services or concentration in single, central locations (Menec et al, 2015; Miller et al, 2011). Consequently rural people will be required to travel to larger population centres to access a full range of health services making it particularly onerous for people with dementia particularly if they can no longer drive. This may be pertinent in 'bypassed' rural communities (Keating et al, 2013) where financial resources are diverted to more affluent areas. Furthermore, Clarke and Bailey (2016) suggest that health and social care interventions can be restricted in rural areas due to public and political perceptions of what is an appropriate activity for people with dementia. These perceptions tend to be based on biomedical constructions of dementia meaning that activities such as art and painting are not viewed as appropriate. Clarke and Bailey (2016) argue the need to provide a better understanding of the dementia discourse so there is political and social will to supply a range of activities and services within rural areas that will appeal to people with dementia and enable them to fulfil their rights for social inclusion.

The research discussed provides mixed opinion on the ability of rural communities to support the social inclusion of people with dementia. However, it highlights the importance of exploring and understanding the experiences of people with dementia living in these areas so that the support can be tailored to their unmet needs taking into account facets of their rural community. Interestingly, none of the research exploring the experiences of people living with dementia in rural areas has examined it from a gendered perspective, and it is this that I now turn to.

### 2.5 Men with dementia

## 2.5.1 Why focus on men?

The wider health literature has pointed to the importance of gender as a factor mediating the health and well-being of people. For instance, within the UK, Teckle et al (2012) have demonstrated that there are stronger relationships between compositional determinants such as age, gender and socio-economic status and health outcomes than contextual factors including rurality. Other research has also suggested that men with a similar level of disadvantage to women experience poorer health outcomes (Evans et al, 2011) but that men's health seeking behaviours are significantly worse than those of women across Europe (White et al, 2011) and in the UK (White, 2011). This has resulted in a call by the World Health Organisation to draw attention to men in the global health agenda (WHO, 2014) and led to a specific focus on men's health policies in countries such as Australia (Australian Government, 2010), Ireland (Baker, 2015) and Brazil (Spindler, 2015).

A European Report on the state of men's health in Europe (White et al, 2011) highlighted the fact that many men find it difficult to address issues relating to their mental and emotional well-being as well as their physical health. The report notes that within an ageing society the issue of social exclusion amongst older men will become particularly prevalent within the future. In part, this is due to older men's resistance to participation in community-based social groups that are often dominated by- and targeted at- older women as well as community-based health services and preventative health activities (White, 2011; White et al, 2011). Therefore, whilst there is a tendency for research to construe older men as androgynous and stripped of their gendered, sexual identity (Milligan et al, 2015), work such as that by White (ibid) demonstrates that gender still remains an important determinant for health behaviour in later life. As such it is necessary to adopt a more refined understanding of how to promote social inclusion in the growing population of older men more widely (Milligan et al, 2015) as well as those living with dementia.

# 2.5.2 Masculinity theories

To determine how to support the social inclusion of older men as well as those with dementia, it is important to understand how gender is acquired and demonstrated within Western Society. Historically a sex-role approach was adopted to comprehend gender and masculinity. This treated gender as a variable rather than a theoretical construct, viewing it as something that was dichotomous and static and formed by the social expectations that defined proper behaviour for women and men (Connell, 2005). However, Connell (2005) successfully argued for sex-role theory to be discarded on the grounds that it was: unable to theorize power and social interest; dependent on biological dichotomy; dependent on a normal standard case and; unable to address a way to theorize gender.

Consequently, gender is now understood as a culturally defined term (Connell and Pearse, 2015; Thompson and Bennett, 2015; Wharton, 2012) constructed by individuals to perceive and make sense of the world around them (Wharton, 2012). Gender is a 'performative' act that males and females do in particular contexts to establish themselves as 'male' or 'female' in the eyes of others. Therefore gender is not fixed but varies depending on the historic time period, the place and social situation as well as the culture, and is politically bound up with the power relations between men and women (Connell and Messerschmidt, 2005). As such, it is a process that is continually being produced and reproduced in context (Wharton, 2012).

Masculinity ideologies (masculinities) from the social constructionist perspective specifically refer to those cultural attitudes and beliefs that are thought to be 'male.' It is posited that these beliefs are obtained during childhood through interactions with family and friends, and then developed, moulded and reinforced throughout a lifetime in accordance with the culture of the society for that particular time and place (Brizedine, 2010). As Connell (2005) highlights individuals are overwhelmed with implicit lessons about what it is to be male (or female) and what differences are significant between men and women within that culture. Therefore by adulthood, the majority of men have learned to behave in a gender-appropriate manner (Brizedine, 2010) and are aware of the standards and expectations that are associated with being masculine (Connell, 2005). However, as Connell and Messerschmidt (2005) posit, these masculinities are configurations of practice that are accomplished in social action and can differ in accordance with the gender relations in a particular setting. From this perspective masculinities are properties of particular time, places and groups, not individuals (Thompson and Bennett, 2016). This also highlights the relational process that is apparent in the formation of gender and masculinity whereby women and other men are also part of the development of masculinities (Connell and Messerschmidt, 2005).

Connell's (2005) concept of 'hegemonic masculinity' was instrumental for understanding men, gender and social hierarchy. Hegemonic masculinity was distinguished from other masculinities, especially those considered subordinate, and:

'...embodied the currently most honoured way of being a man, it required all men to position themselves in relation to it and it ideologically legitimated the global subordination of women to men' (Connell and Messerschmidt, 2005; page 832).

The concept of hegemonic masculinity is not fixed, rather a pattern of practice that can vary and evolve over time within differing social environments and settings, and as social definitions of masculinity change. As Thompson and Bennett (2016) suggest hegemonic masculinities are the most widely accepted forms of being a man as defined by the historical era, social institution, or community. Equally, hegemonic masculinities are something that are only achieved by a minority of men; however they are viewed as the benchmark whereby other men position themselves and judge their achievements (Connell and Messerschmidt, 2005). As Connell (2005) posits, even though the number of men practising the hegemonic pattern may be small, it is likely to have influenced the majority of men's life experiences in Western Society through:

- witnessing or experiencing the subordination of other groups of men such as homosexuals by political and cultural exclusion, cultural abuse, legal violence, street violence and economic discrimination.
- being complicit in the patriarchal dividend and reaping the advantages gained from the overall subordination of women, and
- witnessing or experiencing the marginalisation of masculinities who occupy subordinated classes or ethnic groups

### 2.5.3 Characteristics of hegemonic masculinity

Kimmel (1996) posits that the traditional and dominating image of post-war masculinities portrayed men as stoic, emotionally impenetrable with unwavering and fierce resolve and no apparent weaknesses. These men were white, middle class, in their early midlife and heterosexual; displaying strength, success, reliability, capability and a sense of being in control (Kimmel, 1996). They were expected to follow conventional heteronormative masculinities and succeed in a career, as husbands and as fathers (Thompson and Langendoerfer, 2016). Furthermore, Kilmartin (2000) has identified 12 distinctive beliefs that traditional men exhibited. These were strength, independence, achievement, hard work, dominance, heterosexuality, toughness, aggressiveness, unemotional, physicality, competitiveness and forcefulness. To acquire this benchmark of masculinity, men suppressed emotions, needs and 'feminine traits' (Kaufman, 1994), which researchers have posited set them up for difficult late-life experiences (Coston and Kimmel, 2013). Interestingly researchers have also suggested that rural men may subscribe to more traditional masculinities than their urban contemporaries and this can exacerbate health issues, as rural men are more likely to remain stoic, keep their problems private and avoid seeking assistance from others, particularly in relation to their health (Hammer et al, 2013; Levant and Habben, 2003).

These forms of masculinity would have occupied the hegemonic position while older men in today's modern society were growing up, thereby shaping their identity and the pattern of gender relations that they experience (Connell, 2005) as well as influencing behaviours including those associated with health (Sloan et al, 2015). Although these traditional masculinities may no longer predominate in modern society, as they are replaced by new ones particularly as 'protest masculinities' (such as those consisting of men from oppressed ethnic backgrounds, or with physical disabilities or stigmatised sexuality) become incorporated into the functioning gender order (Connell and Messerschmidt, 2005), they are still likely to have had substantial influence in the development of the identity and gender relations for the men in the current research (as highlighted in section 2.5.2 above) and are therefore important to acknowledge. As Coston and Kimmel (2013) posit, the current cohort of men either living with or caring for someone with dementia are likely to 'be born before the advent of the gender revolution of the 1960s' and so 'subscribe to more traditional gender identities, this is a generation that may be inhibited by the gender roles of the past' (Page 198).

Furthermore as Thompson and Langendoerfer (2016) discuss, there is currently no blue print that can be followed by older men for 'being a man.' As such they are likely to follow- and struggle to obtain- those of traditional masculinities that have followed them across their life span. During their review of the literature Thompson and Langendoerfer (2016) reported that older men drew on four master discourses when discussing their experiences and age-based bodily changes. These were: No Sissy Stuff (such as maintaining a stiff upper lip or masking self-doubt); The Big Wheel (be successful and garner respect in the eyes of other men); The Sturdy Oak (standing tall, enduring and supporting, it embodies resilience, self-sufficiency, robustness, independence and hardiness); and Give 'em Hell (risk taking and competitive practices). These practices of masculinity are consistent with traditional Western hegemonic masculinities.

Therefore it is pertinent that the traditional masculinities are drawn upon when attempting to understand how they may impact on the social inclusion of older men with dementia in this current study. Drawing on the aforementioned literature, the concept of hegemonic masculinity that will be used throughout this study will refer to the more traditional Westernised pattern of behaviour. This favours men who are white, middle class and heterosexual, and display masculine characteristics of independence, stoicism, resilience and self-sufficiency, strength, respect and competitiveness. These characteristics align well with the master discourses outlined by Thompson and Langendoerfer (2016). I will use this definition as one lens (in addition to my definition of social inclusion) through which to interpret and discuss my research findings in Chapter 7 of the thesis.

### 2.5.4 Limitations of a hegemonic masculinity lens

It is important to acknowledge at this juncture, that adopting a masculinity lens, could be viewed as a reductionist approach and might not offer the same benefits as using a wider lens such as 'intersectionality.' This takes into account the multiple facets of a person's identity, including race, education, wealth, social class, ethnicity, nationality, sexual orientation, religion and age as well as gender (Hulko, 2009). Intersectionality research has shown how these multiple structures are interwoven and can shape the experiences of social inclusion/exclusion for people with dementia and other disabilities (Hulko, 2009; Hunting et al, 2015; Moodley and Graham, 2015).

However, given recent research has highlighted the importance of understanding masculinity when promoting social inclusion in older men (Milligan et al, 2015), I felt that this was an important concept to focus on in its own right and to understand the distinct relationship it may have to the social inclusion of older men with dementia. This may be particularly pertinent in the population I was targeting during my research, where other facets of their identity such as age, social class, ethnicity, nationality and possibly sexual orientation (as outlined in Chapter 4) may not be vastly different. As such, these facets may not be as vital to incorporate into the lens through which I viewed and interpreted my findings. Furthermore, as there is a dearth of research within the dementia literature that has viewed people living with the condition as

anything other than a homogeneous, androgynous population (as will be discussed in section 2.5.5), understanding masculinity as a structure in its own right for promoting social inclusion would still add valuable knowledge to the field. Therefore, although I acknowledge the importance of being aware of the multiple facets of a person's identity, my primary focus for this research is to understand the interplay between masculinity and social inclusion. This is in accordance with Connell and Pearce (2015) who state:

"For many purposes we need to treat gender as a structure in its own right. We should not collapse gender into other categories, or treat it as the effect of some other reality...But we must also remember that gender relations always work in context, always interact with other dynamics in social life. And from those interactions come many of the forces for change" (page 86).

Having acknowledged this limitation within the current research, this section of the review will conclude by outlining the few existing studies that explore the role of gender and masculinity within the experiences of men living with dementia.

# 2.5.5 Experiences of men with dementia

Within the dementia discourse the influence of gender has rarely been addressed (Bartlett et al, 2016; Hulko, 2009; O'Connor et al, 2010). For instance, Caddell and Clare (2010) conducted a systematic review of the impact of dementia on self-image, yet made no mention of gender despite its importance in the development of self and identity. This is also the case with gender-related dementia studies with Phinney et al (2013) noting that predominantly studies remain gender-neutral even when they exclusively sample men with dementia. This is notable in a study by Carone et al (2014) who explored the experiences of men with early onset dementia and their perceptions of a community based sports group. Despite eliciting issues that these men faced-and having no female participants- the authors neglected to interpret and discuss the findings in the context of masculinity or in relation to theories of masculinity. This can result in a homogenised, androgynous experience of dementia. Whilst there are signs that the female gender is moving into the dementia care landscape (ADI, 2015b; Savitch et al, 2015) there is a risk that focussing on women leads to men with dementia and the relational aspects of gender being overlooked (Bartlett et al, 2016).

The majority of studies exploring men and dementia examine this within the context of male care partners (e.g. Robinson et al, 2014; Spendelow et al, 2016). There is a dearth of published academic literature that examines the experiences of older men with dementia and none with rural-dwelling men. Those that have been found during an extensive review of the literature will be discussed below.

Hulko (2009), although not focussing specifically on the male gender, showed that dementia tended to be perceived as more devastating to those participants who were categorised as more privileged in terms of class, gender, race and ethnicity. She suggested that for the most privileged participants, their socio-emotional preoccupations were more affected and they

required the involvement of others for fulfilment or alleviation whereas those who were less privileged saw dementia as 'no big deal' in the grander scheme of issues that they had to contend with in their daily lives. This is relevant for the present study as it suggests that the likely participants (white, older men) will have been accustomed to a relatively privileged social positioning and therefore may find the impact of dementia particularly distressing and require active involvement of others to alleviate these issues. However, they may find it difficult to come to terms with this if they hold strong traditional hegemonic masculine ideals that favour stoic, self-reliance.

Two studies located within care home settings demonstrated the interplay between masculinity and dementia and how this can impact on relationships and experiences of living with the condition (Bartlett, 2007; Campbell, 2012). Bartlett (2007) presented a case study of a man residing in a nursing home (Mr Brown). She found that Mr Brown demonstrated a traditional masculine working identity and this influenced his relationships with other men in the home. As there were so few other men in the care home for Mr Brown to relate to then this detrimentally impacted on his sense of social inclusion. Bartlett (2007; page 23) also noted a degree of manliness in the humour of Mr Brown when being bathed by a younger woman and suggested he used this masculine trait as a means to alleviate potentially embarrassing situations. This suggests that Mr Brown not only maintained a sense of his masculinity but sought relationships and interactions that help him to sustain these. When these could not be found it resulted in a sense of inhibited social inclusion.

Campbell (2012) explored embodiment and masculinity. Focussing on shaving, Campbell highlighted how this process was intimately linked with masculinity. She posited that this task was traditionally controlled by men and that relinquishing this power and independence to female care workers may result in a disintegration of masculinity. This is reminiscent of the relational process of gender and masculinities (Connell and Messerschmidt, 2005) and resonates with Coston and Kimmel (2013) who suggest that losses of autonomy and control might be felt more acutely by men as a consequence of the loss of traditional notions of masculinity. For example, the loss of their driving licence is not just a practical constraint particularly within a rural location but can also diminish a positive sense of their male identity and self.

Further work by Phinney et al (2013) explored the experiences of two community-dwelling men with dementia and their families residing in Canada. The themes elicited from the data were closely associated with traditional masculine roles. As the men became less active and less capable they expressed a sense of loss of their masculine identities and this resulted in periods of frustration. As a result they often opted to undertake work-related pursuits and masculine activities that had filled their lives in the past. These activities were encouraged by the men's care partners and families and offered the men an opportunity for on-going engagement with life and a sense of continuity that enabled them to feel connected and socially included. The men's families also discussed their desire to uphold the men's role as the 'boss' within the family

despite the challenges and tensions that this could result in within their relationships. Again this study provides support for the relational process of gender and the on-going influence of masculine identities in the experiences of living, and supporting men, with dementia.

Carone et al (2014) also sought to explore the experiences of five community-dwelling men with younger onset dementia and their care partners within England. They suggested the men found it difficult to adjust to the dementia diagnosis and the notion that they were not in control of the condition. The men experienced a sense of loss in terms of their work, their roles in the family and society and this resulted in financial implications and detrimental impacts to their emotional well-being. Although the authors neglected to discuss the findings in relation to masculinity theories, it is possible that the men experienced the adverse impacts of dementia more profoundly due to upholding masculinities that emphasised their role as provider for the family and one who retains a sense of autonomy and ensures financial stability. The study participants also expressed a desire for more services that were age appropriate and suited to their interests. This emphasises the need to better tailor community activity groups to the interests of men.

Regan (2016) presented a case study of the experiences of a Muslim male (Mr Q) with younger onset dementia accessing health and social care services in the UK. She reports on the predominantly negative experiences encountered by Mr Q that were a consequence of services ill-informed understandings of his younger onset dementia and culture. Whilst Regan (2016) reports that issues associated with gender were prevalent in the data it was suggested that Mr Q's ethnic diversity presented more of a challenge with care services. Mr Q felt that it would take time for a Muslim person to earn the trust of the services regardless of gender; emphasising the importance that ethnicity has in our understandings of the dementia experience (Hulko, 2009). Interestingly, Mr Q felt more comfortable receiving care from females than males as they were perceived to be more sympathetic and patient. Consequently this had impacted on his levels of trust and comfort with the services he accessed. This highlights the importance of providing an 'emotionally safe' (Phinney et al, 2016) environment for services aimed at men with dementia. This will be discussed again in section 2.6

Finally, Capstick and Clegg (2013) have posited that the onset of dementia may adversely impact on the cognitive control that men are able to display, resulting in a reduction of the 'stiff upper lip' mentality that is reminiscent of men born within the first half of the twentieth century. As such this can lead to more insightful narratives around their experiences and particularly those that may have been emotionally difficult (in this case the Second World War and post-war years). Again this demonstrates the impact that dementia may have on the masculinities of older men and in this case may in fact be beneficial for them in receiving support to address any unfulfilled needs.

These limited studies suggest that masculine identities are maintained throughout the lives of men and interact with their dementia to impact on the men's experiences of relationships and consequently their sense of social inclusion. As such it is important to consider these

masculinities when promoting social inclusion for this population of people. However as Bartlett et al (2016) posit it is still unclear how health and social care professionals can incorporate gender awareness into their work to achieve this. My current study will seek to highlight ways this can be achieved when promoting social inclusion in older men with dementia through the use of ecopsychosocial initiatives. It is to this issue that I will now turn.

## 2.6 Promoting social inclusion through ecopsychosocial initiatives

Before discussing the potential to promote social inclusion in rural-dwelling older men with dementia it is important to discuss the use of ecopsychosocial initiatives more generally. I have elected to use the term 'ecopsychosocial' in response to Zeisel et al (2016) call for new terminology (other than 'nonpharmacological' or 'psychosocial') that takes account of the ecological context or environment people within dementia operate within and encapsulates the full range of approaches, interventions and initiatives that seek to benefit them.

## 2.6.1 Why ecopsychosocial initiatives?

The changing conceptualisations of dementia as illustrated in section 2.3 have led to an understanding that it is possible to support people with dementia to maintain their social inclusion. This has resulted in policy directives calling for a reduction in pharmacological interventions for people with dementia (DH, 2009; NICE/SCIE, 2007) in favour of ecopsychosocial interventions or initiatives. This is a broad term used to describe different ways to support people with dementia through nonpharmacological means, including: changing the environment or contexts of people with dementia (Zeisel et al 2016); helping people to adjust to a dementia diagnosis; supporting people with dementia and their care partners and family with stress, anxiety or depression; enabling people to live independently; and the use of activities to support memory and cognitive functioning (Moniz-Cook and Manthorpe, 2009). Ecopsychosocial initiatives are now considered a core element of dementia care research (Moniz-Cook et al, 2011; Orrell, 2012) and have witnessed a rapid growth in their use, particularly since the inception in 1999 of INTERDEM; a pan-European network of researchers tasked with promoting methodologically and academically rigorous ecopsychosocial interventions (Orrell, 2012; Moniz-Cook et al, 2011). It has now been recognised that ecopsychosocial interventions can be effective treatments to support the well-being of people with dementia (Dugmore et al, 2015; Olazaran et al, 2010; Oyebode and Parveen, 2016) and can be cost effective when compared to pharmacological treatments through delaying admission to long term care (Aguirre et al, 2014). Consequently researchers (Dugmore et al, 2015; Kenigsberg et al. 2016; Oyebode and Parveen, 2016) have called for more ecopsychosocial initiatives that are individually tailored and seek to raise the well-being of people with dementia. Interestingly Dugmore et al (2015) have argued that research should elucidate all elements of an ecopsychosocial initiative including its implementation, its possible 'active mechanisms' and its impact; thereby enabling a fuller theoretical account of the processes. They suggest that qualitative research is well positioned to offer these more detailed insights than quantitative studies. To address this call, throughout the thesis I will provide details on the implementation process (Chapter 4), the 'active mechanisms' and the impact (both in Chapter 6 and Chapter 7).

2.6.2 Promoting the social inclusion of community-dwelling people with dementia Two thirds of people living with dementia in the UK reside in the community (Alzheimer's Society, 2013c) and so it is important to understand how ecopsychosocial initiatives can be used in this context to promote social inclusion. This is particularly pertinent given that people with dementia can feel removed from the community and consequently report poor well-being. For example the Alzheimer's Society (2013c) showed that 61% of community-dwelling people with dementia felt anxious or depressed, 40% felt lonely and 34% did not feel part of their community. Other research has also demonstrated a lack of opportunities for people with dementia to engage in social and recreational activities within their community (Miranda-Castillo et al, 2013; van der Roost et al, 2009); this is likely to be particularly keenly felt given their desire to remain connected and involved in activities that are meaningful to them (Han et al, 2015; Phinney et al, 2007, 2008). Innes et al (2015) reported on the barriers faced by community-dwelling people with dementia in accessing leisure activities and spaces in Dorset, England, such as inappropriate facilities to accommodate people with dementia and reduce the stress associated with social and physical obstacles. Other research has found that fear and embarrassment about making mistakes in public (Roland and Chappell, 2015) or the cognitive demands of social situations (Di Lauro et al, 2015) and an inability to fulfil previous social roles (Clarke and Bailey, 2016; Vikstrom et al, 2008) can cause both people with dementia and their care partners to withdraw from activities and social situations. This research highlights the interplay between the geo-socio-cultural environment and the psychological demands of dementia in hindering the social inclusion of community-dwelling people living with the condition. This provides further support for researchers who highlight the need for activities to be accessible both physically (by reducing environmental barriers) and conceptually by providing emotionally safe and communicative spaces (Bevan, 2013; Dupuis et al, 2012; Fortune and McKeown, 2016; Phinney et al., 2016; Wiersma et al., 2016).

Reducing access to social and leisure activities hinders the social inclusion of people with dementia and can lead to social isolation, insecurity and anxiety (Fortune and McKeown, 2016; Roland and Chappell, 2015; Topo, 2009). Conversely, research has shown that engaging in community activities can provide people with dementia a sense of hope (Genoe and Dupuis, 2011, 2014) and can promote feelings of pleasure and enjoyment, a sense of connection and belonging, an opportunity to grow and develop as well as retain a sense of autonomy and identity (Clare et al, 2008; Dupuis et al, 2012; Genoe and Dupuis, 2011; Innes et al, 2015; Keyes et al, 2016; Phinney et al, 2007, 2016; Phinney and Moody, 2011; Wiersma et al, 2016) and address important psychological needs (Nyman and Szymczynska, 2016). The importance of play has also been established as beneficial for the well-being of people with dementia (Astell, 2013; Killick, 2013; Kitwood, 1997). These facets are fundamental for fostering a sense of social inclusion. Interestingly, Fortune and McKeown (2016) have demonstrated how a leisure group called 'Memory Boosters' in Canada enables people with dementia to work in

alliance with the group facilitator to lead on the activities undertaken rather than have them proposed from a set, prescriptive agenda. They highlighted that those attending appreciated this opportunity and felt it was important for ensuring the people's interests and capabilities were taken into account as well as their limitations; thereby affording them a more meaningful activity. The authors posit that this approach is essential for ensuring social justice and social inclusion for people with dementia can be fully achieved, as their voices are promoted and respected. They also highlight the importance of making visible research that seeks to bring about social change to enhance the social inclusion agenda. This aspect will be discussed again in the following chapter when addressing the 'action' component of my research.

As well as providing beneficial outcomes for the mental, physical and social well-being of community-dwelling people with dementia, these activities may also assist the wider social inclusion agenda. Genoe (2010) has argued that people with dementia, by engaging in atypical activities (those not necessarily associated with people with dementia), can begin to resist negative assumptions and stereotypes of their capabilities as well negative discourses surrounding dementia and ageing more broadly. Genoe (2010) posits that by engaging in these types of activities, people with dementia can reinforce alternative identities and maintain desired identities as well as encourage people to focus on their abilities, interests and remaining capabilities. This is likely to enhance their social inclusion by challenging practitioners' and care partners' attitudes towards their capabilities. This will encourage them to engage people with dementia in alternative activities that may be more appealing and appropriate for their needs. Dupuis et al (2016) provides support for this argument through a community arts group that enabled people with dementia to challenge dominant negative assumptions of their abilities. Similar to Genoe (ibid) they argue that these findings can be used to bring about social change for people with dementia more generally.

Consequently, a range of ecopsychosocial initiatives have been designed aimed at providing beneficial social and recreational activities for community-dwelling people with dementia, including: social support groups (e.g. Leung et al, 2015; Hochgraeber et al, 2013); social recreation groups (eg. Phinney and Moody, 2011; Phinney et al, 2016); arts and singing programs (e.g. Camic et al, 2013, 2014, 2015; Dupuis et al, 2016; Young et al, 2016), day programmes (e.g. Weir and Fouche, 2015); cognitive stimulation therapy groups (e.g. Woods et al, 2012); Occupational therapy groups (e.g. McLaren et al, 2013); and physical exercise groups (e.g. Farina et al, 2014; McLaren et al, 2013). Weir and Fouche (2015) highlighted that community-based initiatives and activities that were particularly beneficial were those that encouraged the person with dementia to engage in social and physical activities that were tailored towards their interests and capabilities. This point will be addressed again in Section 3.3.2. Interestingly, very few of these have been situated within rural areas and looked specifically at enhancing the social inclusion of older men with dementia.

2.6.4 Enabling social inclusion for people with dementia in rural areas through ecopsychosocial initiatives

Most of the research highlighted above has employed ecopsychosocial initiatives and activities within urban communities. However researchers have determined the economic, social, cultural and political geographies within rural locations make it difficult to apply results ascertained from urban initiatives to their rural counterparts (Bascu et al, 2014; Blackstock et al, 2006; Menec et al, 2015). To date, the majority of initiatives implemented within a rural environment aim to improve diagnosis rates of people with dementia or ensure they can better manage the condition (Bowes et al, 2016; Dal Bello-Haas et al, 2014; Morgan et al, 2009; Szymczynska et al, 2011) or reduce 'carer burden' for those supporting people with dementia (O'Connell et al, 2014), rather than offer social and leisure activities for people with dementia.

Phinney and Moody (2011) explored the impact of a suburban community-based social recreation group in Canada for people with dementia, focusing on experiences and perceptions of the participants themselves (11 in total more than half of whom were men). The research identified many benefits for the participants, such as a 'place to be themselves,' to have fun and feel wanted and to meet other people and come alive. The authors suggested the informal groups appealed more to people with dementia than usual, more formal community groups that provide support on managing dementia. The authors called for future research to better understand the unique perspective that people with dementia have as service users, as well as exploring the socio-cultural context of people's lives outside of these groups, and how leaders of such groups can best create a beneficial environment for people with dementia. This study will address this call in Chapters 4, 5 and 7.

# 2.6.5 Enabling social inclusion in men with dementia through male-only community ecopsychosocial initiatives

Many of the community ecopsychosocial initiatives have sought to engage both men and women with dementia. However, Milligan et al (2015) have argued that these activities may fail to appeal to older men if they do not take into account the gendered aspects of the environment or the social activities. Typical activities such as dance, cooking, arts and crafts that are commonly used within the UK could be regarded as 'women's activities' and therefore rejected by the majority of older men (Ruxton, 2006). Consequently, Milligan et al (2015) have argued that a better understanding of the factors for promoting communal activities to older men is required. This is also applicable for older men with dementia who reside in rural communities.

Some of our understandings of supporting older men (predominantly without dementia) to live well in the community (and in particular rural communities) has come from the work on 'Men in Sheds.' This idea originated in Australia in the mid-1990's with much of the research being focussed on initiatives within that country (Cordier and Wilson, 2014; Misan and Oosterbroek, 2016; Waling and Fildes, 2016; Wilson and Cordier, 2013; Wilson et al, 2015). However, it is now becoming a growing activity within the UK, and a small body of research is beginning to develop within this context (Milligan et al, 2015, 2016) although the work is mostly concerned with older men with no reported cognitive impairments or dementia (Wilson and Cordier, 2013).

The 'sheds' are located in community spaces or residential care settings and are equipped with a range of workshop tools. They provide a space for older men to socialise, teach and learn new skills and participate in 'DIY' or other similar activities with other older men. Sheds tend to be tailored towards their local context rather than being standardised, and have members rather than service users. This is consistent with the call to use language that repositions people with dementia away from 'clients' or 'service users' who are passive recipients of care; thereby acknowledging the agency they retain (Bartlett and O'Connor, 2010; Innes, 2009; Phinney et al, 2016; Wiersma et al, 2016).

The 'Men in Sheds' literature has shown benefits for the mental, physical, social and emotional health and well-being of older men (Cordier and Wilson, 2014; Misan and Oosterbroek, 2016; Waling and Fildes, 2016; Wilson and Cordier, 2013). Milligan et al (2015) have also understood the importance of the 'Men in Sheds' literature from the perspective of a gendered space. They suggest that the initiative appeals to older men as it enables them to undertake an activity they have been accustomed to throughout their lives, in an informal, less pressurised setting as well as socially interact within a male-only environment (Milligan et al, 2015). This gendered space enables the men to maintain their perceived health and well-being as well as provide them an opportunity to perform and reaffirm their masculinities. This resonates with other research that has explored the leisure and social experiences of older men more generally (Genoe and Singleton, 2006; Wiersma and Chesser, 2011) as well as older men with dementia (Phinney et al, 2013). This has shown that men enjoyed engaging in activities that were reminiscent of their younger years and particularly when they did not require them to perform or compete as they may have done in their youth. However, Wiersma and Chesser (2011) also highlight that leisure activities can reinforce the identity of the 'old man' and may be detrimental to older men's wellbeing if they are unable to accomplish activities they were previously competent in. This demonstrates how the ageing male body as well as the social constructs of being perceived as 'an old man' can influence the masculinities of older men. Milligan et al (2015) also note that whilst men with dementia gained a sense of achievement and self-worth when engaging in these activities in mixed groups (those with and without dementia) they struggled to socially connect. The authors suggest that this was partly attributed to the reluctance of those without cognitive impairments (through discomfort or anxiety) to socialise with those members with dementia. This implies that whilst these environments may be appealing to older men more generally, mixed groups may not necessarily promote an environment where older men with dementia feel 'emotionally safe' (Phinney et al, 2016) and enabled to socially participate. Furthermore, whilst this emerging literature provides promise for the social inclusion of older men and those within rural areas, their scope may be limited due to cultural differences. For instance in countries where the concept of the shed is relatively unknown this may impede older men's willingness to engage with it. Therefore other initiatives that can apply the principles ascertained from the 'Men in Sheds' literature may be successful at engaging older men with dementia who have limited interest/knowledge of the 'Shed' or DIY activities.

There are only a limited number of ecopsychosocial initiatives that have sought specifically to engage community-dwelling men with dementia. Three notable studies were identified during an extensive review of the literature all of which used the medium of football (Carone et al, 2014; Solari and Solomons, 2012; Tolson and Schofield, 2012). Two studies (Solari and Solomons, 2012; Tolson and Schofield, 2012) examined the use of football reminiscence for men with dementia and found an increase in aspects of social inclusion and well-being including, increased sociability and confidence as well as stimulation, fun and laughter. This was particularly the case if the men were interested in football prior to their diagnosis (Solari and Solomons, 2012). Tolson and Schofield (2012) also highlighted the benefits to the men as they were repositioned as experts during the conversations. Tolson and Schofield (2012) noted that whilst the reminiscence sessions appeared to be a success they were unable to identify the underlying factors that were responsible for the positive outcomes as recommended by Dugmore et al (2015). Carone et al (2014) examined the benefits of a community-based football group for five men with early-onset dementia. They reported that the community group was welcomed and promoted improved mood and physical benefits as well as peer support and a sense of normality. The male-only environment, which encouraged a 'dementia-free' zone (no talk about dementia), as well as the reputation of the coaches was viewed as important for the success of the initiative. The former aspect resonates with the 'Men in Sheds' literature (Milligan et al 2015) although Carone et al (2014) do not engage in a discussion as to why this environment may be important to the appeal and beneficial outcomes of the initiative. As all of these initiatives rely on the participants having an interest in football, similarly to the 'Men in Sheds' initiatives, they may be limited in their scope. It is important that community initiatives offer a range of activities so that they can cater to the varied interests of older men with dementia.

Additionally, Manthorpe and Moniz-cook (2009) report on a support group for men with mild cognitive difficulties and dementia. The group consisted of four men with dementia and another with mild cognitive impairments. They met once a week in the member's homes and engaged in conversations and activities that appealed to their interests such as outings to a local transport museum and ten-pin bowling. The men's self-reports demonstrated no change in happiness or confidence although it was noted that in six to eight weeks this was unlikely to occur. Qualitative analysis however showed that the group provided a 'normalising' experience for many difficulties the men were experiencing, and insights into the everyday problems these can cause. The authors concluded that support groups for men may be beneficial in ensuring their social inclusion and enabling them to address behaviours, expectations and activities that are not currently meeting their needs. They suggest, however, that future research must consider the gender of the facilitator as well as the researcher and the ways men are able to design or influence studies that draw on their perspectives. This is something that will be addressed in this study in Chapters 4 and 7.

# 2.7 Technology as a ecopsychosocial initiative

### 2.7.1 Why use technology?

Technology can provide a means for supporting the well-being of community-dwelling people with dementia (Lauriks et al, 2007; Span et al, 2013) and those in rural areas (Bowes et al, 2016). Consequently, the Alzheimer's Society has released a Technology Charter (Alzheimer's Society, 2014b) in addition to guidance by the Social Care Institute for Excellence (Hicks and Miller, 2011) to encourage its use amongst people with dementia. To date, however, there is a dearth of research that explores its application with older people with dementia, possibly because the uptake and acceptance of technological devices in the older population is limited at present, rendering such research problematic (Heart and Kalderon, 2013). Many reasons for this have been posited including: a perceived lack of need for it, lack of interest in it or fear of it (Bowes et al. 2016; Heart and Kalderon, 2013; Peek et al. 2014); the perceived likely difficulty in using the technology (Bowes et al, 2016; Cahill et al, 2007) and a lack of appropriate support to enable older people to engage with it (Greenhalgh et al, 2013; Cahill et al, 2007; Engstrom et al, 2009). Heart and Kalderon (2013) found that the uptake of Information and Communication Technology (ICT) reduced with increasing age although health was found to moderate this effect; healthy older adults were more likely to use computers than their unhealthy counterparts. These issues are exacerbated due to a growing rural/urban digital divide within the UK (Townsend et al, 2013) and concerns that people with dementia are unable to interact with everyday technology and require dementia-specific technology (Astell, 2013). Consequently these factors are likely to mean that technology will be viewed as an atypical activity for ruraldwelling older men with dementia in England.

Literature reviews highlight a range of dementia-specific products developed to provide a sense of safety and security to people with dementia and their care partners as well as enhance communication (Lauriks et al, 2007; Riikonen et al, 2010, 2013; Span et al, 2013); thereby promoting their social inclusion. These include: electronic calendars and medication dispensers (Topo, 2009); monitoring systems such as Cogknow (Meiland et al, 2014); GPS systems (McCabe and Innes, 2013); video phones (O'Neill et al, 2011); and entertainment robots (Mordoch et al, 2013). Recent research by Bowes et al (2016) has shown the use of dementia-specific and off-the-shelf technologies (such as iPads) in rural areas of Europe is becoming more widespread and shows promise for effectively addressing challenges associated with remoteness including distance, communication and workforce deployment issues. However they reported problems amongst service providers associated with organisational difficulties, lack of clear information about their rural populations with dementia and a lack of knowledge of local communities. This demonstrates the importance of understanding rural environments and cultures (as highlighted in section 2.4) before introducing initiatives for people with dementia. This is acknowledged and addressed in the current study in Chapters 3 and 4.

Astell (2013) has argued that contemporary dementia-specific technology has focussed predominantly on the safety and security of people with dementia whilst paying less heed to supporting people with dementia to experience new opportunities and engage in activities that

are stimulating, enjoyable and fun. As a consequence, she has been party to developing dementia-specific technology known as Computer Interactive Reminiscence and Communication Aid (CIRCA) (Alm et al, 2009; Astell et al, 2010). This has demonstrated health benefits for people with dementia, including improved communication and heightened mood and sense of well-being through reminiscence activities. The system is also capable of engaging people with dementia in 'Living in the Moment' Games including 3D tours of botanic gardens, musical chimes or fairground games such as Duck Shooting (Astell, 2010). People with dementia could engage with the games independently of their care partner as well as learn new information and improve in their accuracy and speed depending on the demands of the games (Astell, 2010). This is coupled with 'serious games' research that has demonstrated digital games specifically adapted for purposes other than entertainment, can have positive effects on the well-being of people with dementia (McCallum and Boletsis, 2013; Robert et al, 2014).

This body of research has suggested that people with dementia are willing and able to engage with dementia-specific technology and this can have benefits for their well-being and social inclusion. The research has also highlighted the importance of working alongside people with dementia when designing the technology to ensure it is suitable and appealing for the intended users (Span et al, 2013). Engaging people with dementia in this design process is also beneficial for their well-being and sense of self-esteem as they are enabled to contribute meaningfully to the research process (Riikonen et al, 2010; Span et al, 2013). These are important aspects for fostering a sense of social inclusion. However, these technologies can be expensive and are not commercially available and so are unobtainable for many community-dwelling people with dementia. Additionally, by focusing solely on dementia-specific technology there is a danger that researchers and practitioners will assume this is the only type of technology suitable for promoting well-being in people with dementia (Astell, 2013). This has the potential to lead to a stigmatisation of the equipment (and potentially a reluctance to use it) as well as limit research that explores the benefits of off-the-shelf technologies that are more easily affordable and common place within modern society; and as such more socially inclusive.

# 2.7.2 Commercial off-the-shelf digital gaming technology

A range of commercial technologies exist that are available off-the-shelf and can be used to run various applications and games. Table 3 presents a description of the most up to date technologies that are available for purchase.

Table 3: Table of modern commercially available technologies

Technology	Description
Portable touchscreen tablets (e.g. iPad)  Nintendo Wii	Small portable computer that allows players to interact with it through touching the screen. Has the capacity to connect to the internet remotely through Wifi. A range of games and applications can be downloaded and played through the system.  Gaming system that uses sensors located within a Wii remote to detect the movement of players and transmit
Microsoft Kinect	their position.  Gaming system that uses a camera to capture the position and movement of players. This negates the need for a remote.
Nintendo Wii Fit Balance Board	A low tech force-plate platform that connects remotely through the sensor technology of the Nintendo Wii. The player stands on the board and controls their avatar by shifting their weight on the platform. Visual feedback is given by seeing the avatar move around in the desired direction.
Nintendo DS	Small hand-held portable gaming devices. Has some touch screen features although predominantly interact with it using a control panel. Cannot connect to the internet but has a varied range of games available for it.

Research has demonstrated that computer game technology and video games can have benefits for psychological therapy, physical therapy and physical activity across the age range of population groups (Primack et al, 2012). They have also been shown to be useful within a rehabilitation setting when supporting people with strokes (Saposnik et al, 2011) and multiple sclerosis (Taylor and Griffin, 2015). For older people, research has demonstrated that video games can be a safe intervention that can motivate people to engage with them through a variety of sound and sensory stimulations (Bleakley et al, 2015). The devices and range of games can promote a variety of health benefits including enhanced physical activity and balance (Bleakley et al, 2015; Clark et al, 2010; Kahlbaugh et al, 2011; Maillot et al, 2012), cognitive training (Ackerman et al, 2010; Boot et al, 2013; Bleakley et al, 2015) and hand-eye co-ordination in addition to preventing or reducing cognitive decline (Basak et al, 2008). Other

research has also highlighted the social benefits afforded older people when engaging with gaming technology such as a sense of social connection and enjoyment when participating in the activities (Kahlbaugh et al, 2011). These are important elements for the social inclusion and participation of older people.

2.7.3 Commercial off-the-shelf digital gaming technology and people with dementia

Studies have shown how activities on a computer can bring social benefits for people with dementia through using applications such as Google and YouTube to find and discuss images that are of interest to them (Capstick, 2011) or using Skype and social networking to keep in contact with friends and relatives (Savitch and Stokes, 2011). However, Smith and Mountain (2012) have argued that smaller touchscreen technologies such as tablets are a more appropriate device than desktop computers for providing social and leisure activities for people with dementia given their intuitive design and interface, portability, larger buttons and the fact they do not require a keyboard and mouse. Therefore it was decided to exclude the use of computers (desktop, laptop or netbook) from the Technological Initiative. The remainder of this section will outline other commercial off-the-shelf technologies for which there is research evidence supporting their use with, and benefits for, people with dementia.

A small body of literature is emerging that examines the use of touch screen tablets with people with dementia. These studies have been conducted both with people with dementia residing in care homes (Evans et al, 2015; Leng et al, 2014; Upton et al, 2012) and community settings (Cutler et al, 2016; Lim et al, 2013). All the studies used the technology to provide a range of activities tailored towards the interests of the participants. Cutler et al (2016) used iPads in conjunction with other gaming technologies such as the Nintendo Wii and Nintendo DS to deliver a 'Tech Club' to community-dwelling people with dementia. The studies to date have employed a range of methods to understand the impact of the technology, including: interviews (Upton et al, 2012), focus group discussion and/or observations (Cutler et al, 2016; Leng et al, 2014; Upton et al, 2012); questionnaires (Lim et al, 2013); and a mix of surveys, interviews and observations (Evans et al, 2015). The studies provide evidence that people with dementia are able and willing to engage with touchscreen technology, particularly if the activities are tailored towards their interests (Cutler et al, 2016; Evans et al, 2015; Lim et al, 2013). Engaging with the technology provided benefits for the participants including: increased levels of social interaction and engagement (Cutler et al, 2016; Evans et al, 2015; Upton et al, 2012); reduced agitation and increased enjoyment (Evans et al, 2015); increased range of exhibited behaviours (Leng et al, 2014) and opportunities for life-long learning (Cutler et al, 2016). The studies also posit that touchscreen technology could be used to foster and enhance relationships between care staff and people with dementia (Evans et al, 2015; Upton et al, 2015) as well as support intergenerational communication (Cutler et al, 2016; Evans et al, 2015; Upton et al, 2012). Although in its infancy, this research suggests that touchscreen technology can benefit the wellbeing and social inclusion of people with dementia and as such warrants further exploration, particularly in relation to older men with dementia. This assertion is further supported by recent research that seeks to identify dementia-appropriate apps that are available on touchscreen

devices (Joddrell et al, 2016). Although again, the danger is this may lead to a view that only certain apps are accessible for people with dementia.

Research has also been conducted using commercial digital gaming technology with people with dementia in care homes (Tobiasson, 2010; Ulbrecht et al, 2012) or Assisted Living settings (Chao et al, 2013; Padala et al, 2012; Weybright et al, 2010) as well as within the community (Cutler et al, 2016; Fenney and Lee, 2010; Leahey and Singleton, 2011). The technologies used within the studies varied between the Nintendo Wii, Nintendo DS and Nintendo Wii Balance Board although only Cutler et al (2016) used the technologies in conjunction with one other. Interestingly no research has explored the use of the Microsoft Kinect with people with dementia although Marston et al (2013) have suggested this may be a beneficial device in long-term care settings for older people. The current study is well placed to establish if this is the case for rural-dwelling older men with dementia.

The games selected within the existing research tended to be chosen by the researchers prior to the study. Only Cutler et al (2016) and Tobiasson (2010) adopted a participatory approach that encouraged the participants to select the games they wished to play (although Tobiasson (ibid) gave participants a choice from a limited number of games that are part of the Wii Sports package). The studies employed a range of methods to understand the impact on people with dementia. This included: pre and post questionnaires and measures (Chao et al, 2013; Padala et al, 2012; Ulbrecht et al, 2012; Weybright et al, 2010); observations (Fenney and Lee, 2010; Leahey and Singleton, 2011); and a mix of observations and focus group discussions (Cutler et al, 2016). Findings from these studies highlighted that people with dementia can engage with these technological devices although sufficient supervision may be required (Ulbrecht et al, 2012). Engaging with the technology afforded the participants both mental and physical stimulation (Cutler et al, 2016; Weybright et al, 2010) with some studies demonstrating a significant improvement in balance and mobility (Chao et al, 2013; Padala et al, 2012) as well as a reduction in the fear of falling (Chao et al, 2013). In addition to this, studies also noted improvements in participants scores and a reduction in the support required to engage with the games over time (Cutler et al, 2016; Fenney and Lee, 2010; Leahey and Singleton, 2011). As well as the cognitive and physical benefits, studies highlighted improvements in social aspects noting increased opportunities for social stimulation and fun (Cutler et al, 2016; Fenney and Lee, 2010; Leahey and Singleton, 2011; Tobiasson, 2010), as well as life-long learning and independence (Cutler et al, 2016). Studies also suggested that engaging with the technology provided people with new skills that could be transferred to other leisure activities (Leahey and Singleton, 2011) as well as the opportunity to challenge negative assumptions around their capabilities (Cutler et al, 2016). These findings illustrate the potential for commercial gaming technology to provide activities that will enhance the well-being and foster important facets of social inclusion for people with dementia as well as enable them to challenge negative public perceptions of their abilities; thereby offering benefits for the wider social inclusion agenda.

Having provided an extensive review of the literature I will now summarise my findings and highlight important oversights in the research that I will address within my study.

# 2.8 Summary of current research and areas for further consideration

Throughout this chapter I outlined the current knowledge pertaining to important facets of my study, namely: definitions and understandings of social inclusion more widely and within the context of disability and dementia; constructions of dementia and their impact on our understandings of supporting the social inclusion of people living with the condition; the impact of the geo-socio-cultural rural context and the multiple male identities on the social inclusion of people with dementia; the use of ecopsychosocial initiatives for enhancing social inclusion in community-dwelling people with dementia as well as rural-dwelling older men (and those with dementia) more specifically; and the use of dementia-specific and commercial off-the-shelf technologies as ecopsychosocial initiatives for fostering well-being and a sense of social inclusion. This final section highlights the oversights in this research and demonstrates how my study will address these gaps.

### 2.8.1 Social inclusion for rural-dwelling older men with dementia in England

Throughout section 2.2 I demonstrated that the term 'social inclusion' is popular within the political discourse (Taket et al. 2009, 2014), the disability literature and the current global (Pot and Petrea, 2013) and UK dementia policy directive (Alzheimer's Society, 2013; DH, 2015). Therefore it is a useful concept to draw upon for this applied, real world study (Robson, 2011) provided a broader, 'stronger' (Taket et al, 2009) understanding of 'social inclusion' is adhered to; repositioning the person with dementia as an active social agent and examining the economic, material, social, cultural and political facets that may challenge them to enact their social rights and feel included within their inter-personal relationships and wider society. In section 2.3 I outlined that over time multiple constructions of dementia have emerged within the literature (and subsequently the policy discourse) that demonstrated the possibility for people to live well with dementia (Wolverson et al. 2015) and to develop a sense of social inclusion (Bartlett and O'Connor, 2010; Cantley and Bowes, 2004; Cook, 2008) as long as they were enabled to do so through more positive inter-personal interactions (Kelly, 2010; Kitwood, 1997) and more inclusive communities/societies (Alzheimer's Society, 2013). However, whilst psychosocial constructions advanced our understandings of dementia and challenged the traditional biomedical discourses, they often neglected the wider socio-cultural context and social positioning (Hulko, 2009; Innes, 2009; O'Connor et al, 2010) of people with dementia that can impact on their experiences of living with the condition. Consequently this has the potential for resulting in a homogenised, androgenised account of living with dementia. In sections 2.4, I posited that the geo-socio-cultural rural environment is one context that is likely to impact on the social inclusion of people with dementia (Clarke and Bailey, 2016; Blackford et al, 2006; Forbes et al, 2011; Szymczynska et al, 2011) and must therefore be taken into account. It is particularly important to understand this context in future research given the persisting higher proportions of older people in rural areas (and therefore higher proportions likely to be diagnosed with dementia) when compared to their urban counterparts (Buckner et al, 2013; Innes et al, 2011).

Over the ensuing years, this context has been addressed in international and national qualitative research and continues to demonstrate both the positive and negative impacts of the rural environment on the social inclusion of people with dementia; however, the experiences of older men with dementia have been neglected within this setting. This is an important oversight to address, given that in section 2.5 I demonstrated that the multiple masculinities persisted in men (including older men) with dementia and impacted on their experiences of living with the condition (Bartlett, 2007; Carone et al, 2014; Coston and Kimmel, 2013; Phinney et al, 2013; Reagan, 2016). Therefore research is required to understand older men's experiences of living within rural areas of England, and explore how their masculinities interplay with the rural context to impact on their sense of social inclusion. The current research is well positioned to explore this gap in the literature by posing the question:

 How does the rural environment impact on the sense of social inclusion of older men with dementia?

2.8.2 Promoting social inclusion in rural-dwelling older men with dementia in England Within section 2.6 I demonstrated the ability to promote social inclusion in community-dwelling people with dementia through the use of ecopsychosocial (Ziesel, 2016) initiatives (Phinney et al, 2016; Oyebode and Parveen, 2016; Wiersma et al, 2016). However, globally research has shown a difficulty in promoting social inclusion in community-dwelling older men (White et al, 2011; Wilson and Cordier, 2013) including those with dementia (Milligan et al. 2015). Whilst emerging research has emphasised the importance of providing a gendered space (Milligan et al, 2015) for older men that includes activities tailored towards their interests and abilities as well as a male-only environment, these initiatives may not appeal to those who have no knowledge and/or interest in the 'shed' concept, DIY and/or football (the present initiatives that tend to be delivered for men with dementia). In section 2.7 I posited that initiatives using off-theshelf gaming technologies may be an affordable means to promote social inclusion in people with dementia (Cutler et al, 2016). However, to date no research exists that explores this medium with rural-dwelling older men with dementia or answers calls (Dugmore et al, 2015) to identify the factors necessary to promote social inclusion in this population. The current study is therefore well positioned to address these oversights in the literature by answering the exploratory research questions:

- What is the impact of a Technological Initiative on the men's sense of social inclusion?
- How does a Technological Initiative promote male social inclusion?

Additionally, the studies that exist on commercial gaming technology for people with dementia can be guilty of using exclusionary research practices. For instance, limited studies have explored the perceptions of people with dementia when engaging with the technology (Cutler et al, 2016; Upton et al, 2011) and only Cutler et al (2016) have ensured people with dementia are included in the certain aspects of the design of the initiative and been enabled to engage with a full range of games and technologies that might appeal to their interests and capabilities. Research practising social inclusion should seek to ensure the views of people with dementia

are paramount throughout the research (Cantley and Bowes, 2004; Phinney et al, 2016; Wiersma et al, 2016; Wilkinson, 2002). To date these principles have rarely been applied when designing leisure initiatives for people with dementia (for an exception see Fortune and McKeown, 2016). Furthermore only limited research within the technological field has sought to publicise the results of research in an accessible manner through the use of guidance documentation (Alzheimer's Society, 2014b; Hicks and Miller, 2012). If such initiatives are to be used to enhance the social inclusion of people with dementia and challenge assumptions of appropriate activities for this population of people (Genoe, 2010) then it is important the learning is made accessible to practitioners in the field (Fortune and McKeown, 2016). This is pertinent given research has highlighted the need for confident support staff when engaging people with dementia with gaming technology (Engstrom et al, 2009; Evans et al, 2015).

With this in mind I now turn to Chapter 3 to discuss my research design and demonstrate how the ethos of social inclusion is maintained throughout my research practice.

# Chapter 3: Research design

'Theory- the seeing of patterns, showing the forest as well as the trees- theory can be a dew that rises from the earth and collects in the rain cloud and returns to earth over and over. But if it doesn't smell of the earth, it isn't good for the earth.' (Rich 1987: pages 213-214)

In this chapter I outline the Participatory Action Research (PAR) approach that formed the framework for the conduct of my study. Taket et al (2009, 2014) have discussed the importance of PAR for advancing the social inclusion agenda and therefore this framework is applicable for the current study. I begin the chapter by defining and highlighting the principles of PAR and considering the benefits this afforded me when conducting the research. Following this, I briefly examine the findings from the Consultation Phase of the study and demonstrate how they informed the development of the Technological Initiative and the subsequent study design. I then address the qualitative research methods chosen for data collection. I conclude the chapter by discussing the analysis process.

### 3.1: Participatory Action research

# 3.1.1 Definition of a Participatory Action Research approach

Participatory Action Research (PAR) forms part of a wider 'family of approaches' (Reason and Bradbury, 2008) associated with Action Research (AR) that also include, among others, Action Science, Cooperative Inquiry, Developmental Action Inquiry and Living Theory Approach (Chevalier and Buckle, 2013). AR is seen as an 'orientation to knowledge creation that arises in a context of practice' (Bradbury-Huang, 2010; page 93) and has been defined as:

'A participatory process concerned with developing practical knowing in the pursuit of worthwhile human purposes. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities.' (Reason and Bradbury 2008; page 4).

AR and PAR are considered multidisciplinary and multiform (Swantz, 2008), drawing on and contributing to various movements such as civil rights, anti-racism, feminism and community development (Gustavsen, 2003) as well as theoretical and epistemological stances such as pragmatism, phenomenology, critical theory and social construction and practitioner-academic fields such as organisation development, teaching, health promotion, nursing and community development (Reason and Bradbury, 2008). For this reason, no one perspective can claim authority or authenticity (Swantz, 2008). AR has therefore become a generic term used to describe a variety of research approaches whose principle aim is to improve a practical situation (Chevalier and Buckles, 2013; Kemmis, 2008). Therefore, as suggested by the definition above, AR is said to describe a particular orientation and purpose to inquiry rather than a research methodology (Reason and Bradbury, 2008).

# 3.1.2 Situating the research within a PAR approach

PAR and AR are closely aligned in their values and practices, and often the terms are used interchangeably. However as Schneider (2012) highlights, they tend to be indicative of the aspects people consider most important within the approach. For instance the term 'Action Research' (Reason and Bradbury, 2008) places the focus on taking 'action' through collaborative research and using the results to promote social change. PAR places more emphasis on the approach to knowledge generation by the people who participate with the aim of bringing about change within their lives and the cultures and institutions where they live (Schneider, 2012). Within this approach, research is developed with and for these groups and they have varying degrees of control over the research design, goals and processes; taking their role above and beyond merely participating in an interview, focus group or survey. Through these means, PAR can be adopted as a means to promote social change (Lykes and Mallona, 2008).

In situating the current study, I have drawn on the work of Kemmis (2008, 2009) who in turn builds on the work of Habermas, to distinguish three broad approaches for AR; empirical-analytic (or positivist), hermeneutic (or interpretative) and critical (or emancipatory) approaches. Each of these aims to collect a particular type of knowledge and so adopts different methods to accomplish this. At one end of the AR spectrum is the empirical action research that is grounded within a positivist, scientific method of inquiry into social change. This research is usually carried out 'on' other people as opposed to 'with' or 'for' them. The role of the researcher is distinctive from that of the participants and although participants' expertise is acknowledged their influence is limited to providing feedback on a particular intervention.

Towards the mid-section of the action research spectrum is the hermeneutic or collaborative research approach. This seeks to work collaboratively with other people to identify common problems, seek solutions and monitor the progress of these solutions. Although this approach focusses on collaboration and a commitment to improvement of practice, Reason (1994) suggests the approach suits a group of people who view themselves as relatively empowered.

The third approach is critical action research. This seeks to help oppressed groups identify problems and take action to improve their conditions. Participant empowerment is crucial and PAR is one of the most recognised forms of critical action research (Kemmis 2008). The participants engage in cyclic activities to explore and improve aspects of their practice or their own role within practice, with the process of reflection being fundamental in both approaches (Reason, 1994). Critical research tends to focus on oppressed groups and there is a commitment to transforming practice.

I chose to situate my research within the critical action research of PAR (Kemmis, 2008). This approach sat well with the main aims of my study (outlined in Chapters 1 and 2) as it recognised that people with dementia can be classed as vulnerable individuals (MCA, 2005) who may be stigmatised (ADI, 2012; Innes et al, 2004; Milne, 2010). It sought to work in collaboration with the older men (rather than 'on' them as more empirical-analytical approaches) to learn and

evolve together while developing the Technological Initiative and the final guidance documentation produced. Through this means of dissemination, the research is also committed to transforming practice locally and potentially nationally. Although I was aware that this transformation was unlikely to occur during the period of the study, I hoped that it might stimulate the beginnings of social change in the rural areas. This is in accordance with other research (Dupuis et al, 2016; Fortune and McKeown, 2016) that has highlighted the importance of using accessible means to present research findings to a wider audience to begin the process of social change by challenging dominant discourses of dementia. This approach also allowed for a range of outcomes to be explored rather than testing certain hypotheses or theories as empirical-analytical approaches advocate. This sat well with the qualitative research methods I adopted for the study (discussed in section 3.4).

### 3.1.3 Principles and benefits of PAR

Although PAR is diverse and has been influenced by many fields and disciplines there are several key principles that a PAR study must adhere to. Schneider (2012) outlines these as:

- a commitment to the participation of ordinary people as co-researchers involved in every aspect of the research;
- respect for the knowledge of all participants;
- mutual learning among participants;
- attention to the needs of marginalised or disempowered groups and people; and
- action to promote social justice for those marginalised people and others like them.

PAR acknowledges these issues of power, politics and empowerment (Gaventa and Cornwall, 2008; Reason and Bradbury, 2008) and can be viewed as part of a political process that involves people making changes together that affect others (Chevalier and Buckle, 2013). This goes over and above traditional qualitative approaches and is in accordance with 'real world' studies (Robson, 2011) as there is not only the concern to explore, describe or explain but also the requirement to facilitate action to help change or make improvements, and/or influence policy or practice (Reason and Bradbury, 2008; Lykes and Mallona, 2008; Reason, 1994; Schneider, 2012). This is why PAR approaches are typically undertaken with marginalised or oppressed populations (Baum et al, 2006; Fenge, 2010; Chevalier and Buckle, 2013) as they have the ability to empower people and enable them to have increased control over their lives (Chevalier and Buckle, 2013; Gaventa and Cornwall, 2008). I felt it was important to acknowledge the potential social exclusion faced by the men with dementia and in doing so it would have been irresponsible, even unethical, to not attempt to address this. Situating my research within this critical PAR approach therefore enabled me to tackle these issues and go over and above just 'doing research for research's sake'.

PAR approaches ensure the knowledge and learning that is created between the researcher and the co-collaborators is understood within the environment where it took place. It is vital to integrate the knowledge within its cultural context so that it is holistic and related to the community and its capabilities (Swantz, 2008). Understanding the rural cultural context has

been highlighted as particularly important for successfully implementing technological initiatives for people with dementia (Bowes et al, 2016). The development of the Technological Initiative in this study was an on-going process of evolution, whereby knowledge and learning were mutually developed within the local rural environment, then reflected upon and used to inform subsequent sessions. This aligns well with the cycles of reflection and action that are an integral part of the PAR approach (Chevalier and Buckle, 2013).

Throughout the study I adopted multiple roles as both the researcher and the facilitator of the Technological Initiative, it was therefore important that this was acknowledged. PAR approaches recognise the political, moral and ideological issues of the researcher and encourage them to be embraced rather than suppressed as they provide a vital source of motivation for the study (Gergen and Gergen, 2008). This is in direct contrast to positivist researchers who couch their findings in value neutral or realist terms and so suppress their underlying agenda. As Swantz (2008) posits, PAR breaks from the false objectivism, of positivist social science and allows researchers to illustrate a degree of personal presence in their work. As such I have outlined my motivations as a researcher in Section 1.2 and continue throughout the thesis to provide a reflexive account of the research through my style of writing; openly discussing my decisions and my perceptions of their impact on the research and the data collected. Furthermore, in situating myself within the research process, I have also recognised by position as both an 'insider' and an 'outsider' in the research process (Becker, 1998; Bryce, 2012; Coghlan and Casey, 2001; Corbin Dwyer and Buckle, 2009). Although I was a researcher and external to the rural communities, thereby positioning me as an 'outsider,' I was also a member of the groups and in these respects could be viewed as an 'insider.' Bryce (2012) has discussed her attempts at navigating multiple roles during her research with people with mental health conditions. She posited that initially she positioned herself as an 'outsider' yet over time as she worked closely with the participants her position moved to one where she closely aligned with the 'insider' researcher position and this was beneficial for developing trust with the research participants and enhancing the data collected. In Chapter 4, I will reflect on this process demonstrating its implications for building and maintaining relationships with my cocollaborators through the duration of the research, as I moved from a position of 'outsider' to 'insider' researcher.

### 3.1.4 PAR in relation to current dementia discourse

These PAR principles are in accordance with the current dementia discourse (Cowdell, 2006, 2008; Dewing, 2008b; McKeown et al, 2010; Murphy et al, 2015; Wilkinson, 2002; Wiersma et al, 2016) that highlights the need to 'hear the voices' of people with dementia (Goldsmith, 1996). This can help to improve the systems, equipment (Lauriks et al, 2007; Span et al, 2013) and services designed to support people to live well with the condition as well as challenge the misconceptions that all people with dementia are unable to communicate their experiences and contribute meaningfully to their own lives (Bartlett and O'Connor, 2010).

More recently there has also been a call for interventions to build and mobilise equal and 'authentic partnerships' within dementia care (Dupuis et al, 2012, 2016) and to integrate PAR approaches to enable a change in culture for working with people with dementia (Dupuis et al, 2016; Wiersma et al, 2016). These approaches emphasise the need to 'actively involve the person with dementia in decision-making to the fullest of their abilities, and support their involvement using whatever means necessary' (Dupuis et al, 2012; page 431). More specifically they should:

- recognise how people with dementia have been silenced, excluded and oppressed while also recognising the collective capacity they have to empower themselves and others;
- seek to work in partnership with persons with dementia, their families and others to promote equality and social justice for all persons with dementia;
- view knowledge as power, and education and learning as important vehicles for social change, transformation and liberation;
- challenge the supremacy of higher order or expert knowledge and instrumental rationality by acknowledging, valuing and incorporating the lived experiential knowledge of the partners; and
- incorporate a systematic process of critical reflection and dialogue in community with others, as all partners work together collectively towards the realisation of new possibilities.

This approach aligns well with the processes and principals involved in PAR approaches (Bradbury and Reason, 2008; Schneider, 2012). It is also in accordance with concepts of social inclusion that highlight the need to promote the voices of people with dementia so they can contribute to their own support needs and can develop meaningful relationships (Cantley and Bowes, 2004; Cook, 2008; Bartlett and O'Connor, 2010).

Emerging research has suggested that PAR approaches can be used with people with dementia and may be particularly beneficial in rural and remote communities to enhance the overall quality, relevance, application and sustainability of the research produced (Kosteniuk et al, 2014; Morgan et al, 2014). However, McCabe and Bradley (2012) note that more work must be undertaken to include people with dementia in the development of research, practice and policy. Whilst these participatory approaches are beginning to be viewed as best practice for designing and evaluating dementia-specific technology (Godwin, 2012; Span et al, 2013) they are rare outside of this field. A noteworthy study is that by Wiersma et al (2016) who worked alongside people with dementia in 'advisory hubs' to develop and implement self-management programs. The authors commented that positioning people with dementia as 'experts' empowered them and was important for their sense of social citizenship and inclusion as they were able to express their opinions and have them acted upon. Furthermore, consulting people with dementia on the structure of the group prior to its implementation ensured the self-management programs met their needs. This demonstrates how the adoption of PAR

approaches can be empowering for people with dementia and beneficial for the design and delivery of ecopsychosocial initiatives intended for their use.

## 3.1.5 Using PAR with my co-collaborators

It is important to acknowledge at this juncture that this research is not a PAR study in its truest form. Typically PAR is seen on a continuum; at one end there are studies that adopt an outsider-led approach and at the other, are truly emancipatory user-led studies (Blair and Minkler, 2009; Chevalier and Buckle, 2013). The current research sat within a more outsider-led position on the PAR continuum. I chose to include the men as my co-collaborators in the design of the Technological Initiative (both during the Consultation Phase and the main Doctoral Study) as well as the data collection (through the methods adopted), analysis procedure (by seeking their input post analysis) and dissemination stages rather than the entire research cycle. I felt that adopting this approach ensured that the Technological Initiative was fit for purpose and took into account the social context of my co-collaborators.

As the study aimed to develop a new digital gaming Technological Initiative, I felt it was important to incorporate knowledge and expertise from both the researcher and the men when implementing it within the rural areas. The PAR approach enabled me to recognise the men as co-collaborators rather than 'subjects' of research (Reason and Bradbury, 2008), thereby addressing the balance of power (Gaventa and Cornwall, 2008) in the research process. By consulting the men throughout the Consultation Phase of the research as well as the delivery of the main Technological Initiative by enabling collaborators to have a voice and giving weight and value to their experiences; rather than revering the researcher as the sole expert. As Swantz (2008; page 38) states:

'PAR rejects science as the dominating knowledge and bases the problems on everyday knowledge; the researcher and the researched share their knowledge as equals. The researcher genuinely recognises that she does not know the life world, wisdom or meaning of central symbols of life of the co-researchers.'

Finally, a PAR approach enabled the men to take ownership of the groups and this was important for their sustained social inclusion after the completion of the research period. Research has shown that over-time PAR studies have the potential to bring about major social changes as people come to realise the discrimination they may face and seek to challenge it (Chevalier and Buckle, 2013; Kemmis, 2008; Schneider, 2012). Although it would be optimistic to think this could be achieved during the short period of the research, by encouraging the men and volunteers to take ownership of the groups and continue them after the conclusion of the research may lead to longer term benefits moving forward. It can also be considered ethical to ensure the groups continue beyond the research period as removing them (particularly if they have been successful) is likely to adversely impact on the well-being and social inclusion of the men.

In this instance, the use of digital gaming technology was selected by the funding body as were the rural areas where the initiative was to be implemented and the method of dissemination/action that sought to bring about a transformation in dementia care practice. This approach is consistent with many PAR studies, as reported by Blair and Minkler (2009) who illustrated that the majority of PAR studies with older people tended to have the topics identified by the researchers and then seek the involvement of elders through an advisory board or through co-researchers in interpreting findings and/or using the findings to bring about change. As Reason (1994) points out, many projects:

'...would not occur without the initiative of someone with time, skill, and commitment, someone who will almost inevitably be a member of a privileged and educated group' (page 334).

Having certain criteria enforced by the funding body had both advantages and disadvantages. Given the time and financial constraints of the three year Doctoral study it would have been difficult to successfully complete the research adopting a truly user-led approach. Identifying the rural areas to conduct the research as well as negotiating the aims between the men or between the project funders and participants can require considerable effort and resources (Fenge, 2010). I had to carefully manage this process throughout the duration of the research to ensure that the project achieved the aims of the funder but also accomplished my own personal aims of using a PAR approach and working in collaboration with the men. Furthermore, it is also likely that the men would not have selected digital gaming technology as an initiative for the study given the barriers to the uptake of technology amongst older people in rural areas, illustrated previously in section 2.7.1. Consequently, having the research aims imposed on them enables them to explore other more creative means that they might not have considered, yet could offer benefits to their social inclusion.

I will now discuss the Consultation Process undertaken with rural-dwelling older men with dementia as part of the PAR approach that informed the design and delivery of the Technological Initiative.

3.2 Preliminary development of the Technological Initiative: The Consultation Process In this section I discuss the Consultation Process that I undertook prior to conducting the main Doctoral study. This process formed the preliminary stage of the PAR approach that framed the delivery of the main Doctoral study. The information I ascertained from the consultations was used to understand the rural communities and examine the feasibility of engaging rural-dwelling older men with dementia with commercial digital gaming technology. This enabled me to ensure the successful implementation of the Technological Initiative for the main Doctoral study.

As part of the consultation process I delivered a briefing meeting with dementia stakeholders followed by one-off technology sessions within four rural areas of England. The following section reports on the findings from these consultations and their implications for the wider Doctoral study.

## 3.2.1 Briefing meeting with dementia stakeholders

During February 2013, I delivered a briefing meeting with thirteen dementia practitioners working in rural locations. The participants consisted of three Occupational Therapists; two older person's mental health practitioners; one Primary Care Dementia Facilitator; three managers of Day Services/Centres for older people and people with learning disabilities; one funder of local projects within the rural area including dementia projects; and five representatives from a local charitable organisation who were responsible for various initiatives for older people and people with dementia. The meeting aimed to obtain their buy-in to the research and support to promote it. This is in accordance with McKeown et al (2010) who have emphasised the need for researchers to identify and seek the input of influential community gatekeepers prior to engaging any person with dementia or their care partner. The meeting ran for 4.5 hours and during this time discussions took place regarding the feasibility of the Technological Initiative. A flip chart was used to collect the main points elicited from the discussions. Following the completion of the meeting a completed set of notes was emailed to all participants to ensure accuracy and to follow-up on any negotiated action points.

#### Outcomes

All participants agreed that the planned research would be welcomed in the rural locations. They felt that having an initiative specifically targeted at men would be useful, as at present predominantly only women with dementia attended the community activities they visited. The participants agreed to form an Advisory Group to comment on documentation produced throughout the research and ensure that it was applicable to the area. This is consistent with O'Sullivan et al (2012) who as part of their PAR approach sought the expert advice of dementia practitioners when producing reports and guidance. The practitioners also agreed to assist with the delivery of the one-off technology sessions by liaising with organisations and personnel that could support the recruitment of participants and provide appropriate venues to host the sessions. This would reduce the time and resources required to conduct the sessions; something that can hinder PAR approaches (Fenge et al, 2012).

There was a general discussion that the ecopsychosocial initiatives currently in use within the rural locations whilst successful were limited. Predominantly they were Carer's Forums and Memory Cafes. These groups provided opportunities for socialisation, particularly for care partners, and occasionally enabled activities for people with dementia such as Bingo. Only one rural location provided a 'Men in Sheds' initiative. Whilst this was viewed as successful in engaging men with dementia and various other mental health conditions, it was limited in the number of people it could take-on and hence restricted its numbers to those who had been referred via the local NHS Community Mental Health Team. Participants were also unaware of any community ecopsychosocial initiatives that were using gaming technology, highlighting the novelty of the activity for people with dementia within the rural locations.

The participants reported that the term 'dementia' was stigmatised throughout the county and evoked fear in people. This is consistent with the wider literature that reports on the global

stigma of dementia (ADI, 2012) that can serve as a barrier for rural-dwelling people with dementia to attend specialist services in the UK (Clarke and Bailey, 2016; Innes et al, 2006) and internationally (Morgan et al, 2002,2011). The participants therefore recommended promoting the one-off sessions as an activity group for 'men with memory problems' as this may encourage more men to attend. This is consistent with Helstrom et al (2007) who suggest this terminology can be used instead of 'dementia.'

3.2.2 One-off technology sessions with older men with dementia in rural areas

Working in line with guidance from the Advisory Group, I ran a series of four one-off 'technology sessions' lasting 90-150 minutes with older men with dementia within four rural areas of England. The Advisory Group selected the locations and supported the recruitment of the men. In addition to this, advertisements were placed in local newspapers and relevant websites.

Although the groups were advertised for people with 'memory problems' all those who attended had a diagnosis of dementia. The consultation sessions aimed to:

- 1. Explore the feasibility of using commercially available digital gaming technology with older men with dementia
- Understand the most beneficial means to implement the Doctoral Technological Initiative
- 3. Examine aspects that should be understood in the research design of the Technological Initiative

Table 4 provides a breakdown of the people that attended the consultation sessions. Only in Locations One and Four did some care partners choose to watch the sessions. Volunteers recruited through Bournemouth University Dementia Institute (BUDI) and who were already DBS approved, supported the delivery of the sessions. Volunteers accompanied all sessions except Location One where only three older men with dementia were present.

Table 4: The four one-off technology sessions

Rural Location	No. of men	Technologies	Applications/games used	Number of volunteers	Number of Care Partners
Location One	3	Nintendo DS, iPad	DS= Camera, Art game iPad= Chequers, hangman, YouTube for music	0	0
Location Two	5	Nintendo Wii, Nintendo DS, iPad and Balance Board	Wii= Tennis, golf DS= Art game, Pet School iPad= Google for poetry and music, Art game. Balance Board= Tightrope walking	3	2
Location Three	8	Xbox Kinect, Nintendo Wii, iPad, Wii Motion and Balance Board	Kinect= Darts, golf, tennis Wii= Bowling iPad= Google Earth, YouTube, Balance Board= Tightrope walking Wii Motion= ice cream catching	3	0
Location Four	7	Xbox Kinect, Nintendo Wii, iPad	Kinect= Golf, tennis Wii= Balance board for tightrope and Hula hoop iPad= Piano 2	2	1

At each session I enabled the men to engage with various pieces of technology: the Nintendo Wii; Nintendo DS; iPad; Microsoft Kinect; Nintendo Wii Balance Board; and Nintendo Wii Motion. These were chosen as they were the most up to date pieces of commercially available gaming technology. The technology and the games used at each of the four sessions varied as they were tailored towards the personal interests of the men, consistent with recommended best practice (Leng et al, 2013; Cohen-Mansfield et al, 2009; Kolanowski et al, 2011). Each of the iPads and Nintendo DS were placed on their own table. This provided a space where the men could sit down and engage with the technology. The Nintendo Wii and Microsoft Kinect were set up in their own space with a 42-inch television. Chairs were situated around the TV screen enabling people to spectate whilst others played. This lay-out aimed to provide a communicative space (Bevan, 2013) that was both physically and conceptually safe (Dupuis et al, 2012; Wiersma et al, 2016) and enabled the men to engage with the technology, and offer their opinions.

Although each session was different as a result of adopting a participant-led approach and using the learning from previous sessions to better inform subsequent session, two elements remained constant: the consent procedure and the feedback conversations. The consent procedure was undertaken at the beginning of each session following best practice guidelines outlined by Dewing (2008b). Throughout the delivery of the sessions I encouraged the men to feedback on their experiences of the technologies. At the end of the session I also undertook a more formal feedback conversation that lasted approximately thirty minutes. During this period the men provided their verbal feedback on the technology and games as well as their thoughts

for the delivery of the Technological Initiative. Additional data was collected from my personal reflexive field-notes.

## 3.2.3 Findings of the Consultation process

The findings noted from the technology sessions are reported in accordance with the objectives outlined in section 3.2.2.

1. The feasibility of using commercial gaming technology with older men with dementia

The sessions demonstrated that the men were able to engage with most of the commercial gaming technology, although the Nintendo DS proved particularly challenging for some due to the small screen size and difficulties operating the control stick. In this respect the iPad was preferred due to the larger screen and the more intuitive touch screen control system. Many of the men also found it easier to engage with the Microsoft Kinect than the Nintendo Wii due to the more intuitive nature of the system, plus the fact that it did not require the use of a controller. For instance, some of the men were unable to operate the Nintendo Wii Bowling game in the one-off session as they were required to undertake a bowling action whilst releasing a button at the appropriate time, and they struggled to master this combined action. However, the men showed no apparent issues engaging with the Microsoft Kinect and were able to successfully interact with the system on their first attempt; including those who required a walking stick for mobility.

Although some of the men were initially reluctant to engage with the technology there were always some applications or games that they would show an interest in and would engage with provided they were given the appropriate support. This emphasised the importance of understanding the interests of the men prior to the technology session and adopting a personcentred approach (Kolanowski et al, 2011). Predominantly, the experience of interacting with the technology was positive for the men and their feedback and actions suggested they enjoyed it. On one occasion however in Location Four, one man found it difficult to navigate the iPad due to tremors in his hands. The experience left him frustrated and he opted to leave the group. This highlighted the need for me to remain vigilant throughout the sessions to ensure that the technology did not cause the men any physical or psychological difficulties, or harm.

2. Understand the most beneficial means to implement the Doctoral Technological Initiative

The men provided limited input into ways that the Doctoral study could be advertised within the rural locations. However a particular point of note that was raised was their misunderstanding of the use of the term 'technology.' Men in Location Two felt that the term 'technology' could either evoke fear or confusion as to the activities that would be undertaken during the sessions. Consequently they reported that in advertising the main Technological Initiative the focus should not be on the technology but the potential benefits that might be afforded the attendees.

Providing a 'communicative space' (Bevan, 2013) or 'safe space' (Wiersma et al, 2016) where the men were able to sit, relax and speak freely away from their care partners but also engage with the technology and watch others do the same was important for the delivery of the sessions. Creating these safe spaces by enabling people with dementia to be separate from their care partners has also been shown to be beneficial in support programs for people with dementia (Wiersma et al, 2016). The set-up also encouraged some of the initially more reluctant men to engage with the games. The academic literature (Kahlbaugh et al, 2011) has noted the process of co-viewing as an important unifying process that can create a more relaxed social environment. As such I felt the lay-out of the room used during the one-off technology sessions would be appropriate for the main Technological Initiative.

The volunteers were important for supporting the delivery of the technology sessions. They enabled the men to engage with pieces of technology as I led other activities. This meant that many of the men could be engaged in a range of activities and this prevented them from becoming bored. The men reported that the gender of the volunteers was unimportant and more integral was the need for them to be supportive and enthusiastic.

Research design approaches to understanding the perceived impact of the Technological Initiative

The one-off technology sessions provided some important findings that shaped the development of the research for the main Doctoral study. The men discussed multiple benefits of engaging in the one-off session including: social interaction; physical activity; the opportunity to learn new skills and engage independently with fun activities on novel devices; and the ability to accomplish tasks and the sense of achievement this enabled them. Many of these benefits were important for their sense of social inclusion and therefore I felt the social inclusion/exclusion lens that I had chosen to frame the study within was appropriate as an analytical framework.

The one-off technology sessions also highlighted the importance of understanding and exploring the socio-cultural context of the men's lives. Even during brief conversations with the men I noted difficulties they suggested they faced living with dementia in their place of residence. I felt it was important for the Doctoral study to attempt to explore these rural environments as part of the research so that the perceived impact of the Technological Initiative could be situated within this context. Phinney and Moody (2011) have also advocated this approach to ensure a richer and deeper understanding of the perceived impact of rural ecopsychosocial initiatives for community-dwelling people with dementia.

Whilst I delivered the one-off technology sessions I also acknowledged the important dynamics created between myself and the men when interacting and supporting them to use the technology. Whilst some men were confident and willingly engaged with me from the start other men were more apprehensive. On these occasions it was essential that I looked at other ways to engage the men with the technology such as enabling them to work with other men they were

comfortable with in the group. I noted that during the Technological Initiative I would be required to adapt my approach for each of the men to ensure they felt comfortable engaging with the technology and contributing to the research. Again this highlights the importance of the PAR approach for acknowledging the role of the researcher in the data collection process.

### 3.2.4 Adjustments to the design of the Doctoral Study

Following the Consultation process, a number of adjustments were made to the Technological Initiative and the design of the main Doctoral study. These have been summarised below.

## 1. The technology used in the Technological Initiative

The Consultation suggested that the men struggled to engage with the Nintendo DS due to the small screen size. As such, I decided to remove it from the main Technological Initiative, as many of the activities that could be undertaken on this device could also be found on the iPad (something the men found easier to interact with).

Although some of the men found it difficult to interact with the Nintendo Wii, I chose to keep both types of motion sensor technology in the Technological Initiative. Previous research has suggested people with dementia can engage with the Nintendo Wii provided they are given enough time (Fenney and Lee, 2010; Leahey and Singleton, 2011; Tobiasson, 2010), which I felt would be likely to occur over the nine week period of the Technological Initiative. However, I decided to introduce the Microsoft Kinect earlier to enable the men to become accustomed to the sensor technology before moving on to some of the more complicated games and movements required on the Nintendo Wii.

### 2. The implementation of the Technological Initiative

Following feedback from the men, I chose to remove the word 'technology' from the recruitment flyers and used the terms 'gadgets' and 'gismos' instead. These terms were recommended by the Advisory Group, as more appropriate and less fear evoking. I also elected to promote the groups as 'social clubs' as this would likely move the focus away from the technology, thereby further reducing some of the anxiety that may be experienced by potential co-collaborators.

I decided to recruit only male volunteers to the Technological Initiative despite feedback from the men that the gender of the volunteer was not important. I drew on previous research that has highlighted the importance of the male-only environment when delivering ecopsychosocial initiatives to support the social inclusion of older men (Milligan et al, 2015) to support this decision.

During the Consultation, I became aware that I missed many of the interactions between the men as they engaged with the technology. Consequently I chose to use a video camera for the main Doctoral study to enhance the robustness of the data collected. This is in accordance with research by Phinney and Moody (2011) who commented on the utility of a video camera when exploring the perceived impact of a dementia support group in a suburban location in Canada.

### 3.3 The Technological Initiative

In this section I define and outline the Technological Initiative (TI) that was introduced within the rural areas. I identify the principles drawn upon when working in collaboration with the men to implement the initiative and understand its perceived impact.

#### 3.3.1 Definition

The TI consisted of three individual deliveries of a programme I devised (Table 5) in the three rural locations of England. Each individual programme ran for a total of nine weeks with one session per week lasting for two hours including breaks for refreshments and informal discussions. The three individual groups ran concurrently on three different days between August-October 2014. Dementia support workers from each of the rural areas were consulted on the most appropriate time and days to run the programmes. Following advice from the support workers, each session began around 10am-10.30am depending on the availability of the venue. The day on which each programme ran was selected so as to avoid clashing with other groups in the area for people with dementia whilst again also taking into account the availability of the venues. For the entirety of the nine weeks, each programme began and finished at the same time on the same day.

### 3.3.2 Using the technology with the men

In line with the approach undertaken during the Consultation process, I adopted a person-centred approach when engaging the men with any of the technology. This ensured that the activities were focussed on the men's personal history, personality, needs, capabilities and values and provided a positive social environment that valued them as an individual. This is in accordance with the best-practice academic literature (McCormack, 2004; Brooker, 2004; Cohen-Mansfield, 2013; Cohen-Mansfield et al, 2009, 2010; Kolanowski et al, 2011; Leng et al, 2014).

The technologies used during the TI were the Nintendo Wii, Microsoft Kinect, iPad, Nintendo Balance Board and Nintendo Motion. The academic literature (Chao et al, 2013; Fenney and Lee, 2010; Leahey and Singleton, 2011; Leng et al, 2013; Padala et al, 2012; Tobiasson, 2010; Ulbrecht et al, 2012; Upton et al, 2011) and the Consultation process supported the use of these technologies with people with dementia.

### 3.3.3 Creating a safe space for the Technological Initiative

During the facilitation of the TI my aims were to introduce and use the technological equipment with the men and enable them to provide feedback that would inform subsequent sessions. During the facilitation of each programme I drew from the principles of PAR research as well as current knowledge from the dementia research discourse to provide an appropriate environment to accomplish the aforementioned aims. I established 'communicative spaces' (Bevan 2013) or 'safe spaces' (Wiersma et al, 2016) to provide both conceptual and physical spaces that the men felt comfortable in. I also elected to refrain from focussing on the men's dementia. Phinney et al (2016) have highlighted this as important in their community-based activities group for

creating an 'emotionally safe' space whereby attendees are positioned as people rather than medicalised by their dementia. Linked to this, I also felt it was important that the men were able to name their own group, thereby enabling them to take ownership of it and remove any associations with being a support group for men with dementia.

I ensured each venue was spacious enough to safely run the activities, had Wi-Fi availability as well as kitchen facilities to provide refreshments. These criteria were also identified as important during the consultation phase of the research. In addition to this, each venue's location in the rural area was also considered. If the venues provided the aforementioned criteria but were situated on the fringes of the rural area then I looked for an alternative more central venue. I felt it was important that the initiatives were delivered in spaces that were located centrally within the rural areas to ensure the men felt socially included within their community. The rooms were set up similar to those set out during the Consultation, enabling men to interact with the technology but also have a quiet space to retreat to if they wished. Care partners were also given the option to stay and watch each session or leave. If they chose to stay, they were offered a table to sit at that was still in eyesight of the men but far enough away so they were out of earshot of any conversations. I felt it important to provide this option for care partners and the men as during the Consultation process some men expressed a desire for their partners to remain if possible. Wiersma et al (2016) have argued that the presence of care partners in a self-management program could restrict the voices of people with dementia and so hinder the creation of a 'safe space' as well as limit the sense of solidarity that was generated. Therefore it was important that during the TI they were at a safe distance from the men, thereby enabling them to speak openly.

Throughout the TI, I continually encouraged the men to feedback on their experiences either through informal discussions as they engaged with the technology or more formally at the end of each session during a longer focussed conversation. These discussions asked the men to reflect on the technology and games used as well as the structure and format of the sessions. During the final sessions, I asked the men to feedback on the whole experience of participating in the TI and their perception of its impact. These methods will be discussed in more detail in section 3.4.

During all conversations, I paid meticulous attention to ensuring that I included the voices of all the men. Lennie (2005) has demonstrated that a process of political disempowerment can occur within minority groups during PAR research, where certain participants take control of particular aspects thus oppressing others. By only focusing on these voices, PAR can assume conformity of experiences, thereby overlooking the variety of opinions that may emerge and consequently result in a presumption of unity (Healy, 2001). This can be particularly prevalent in groups of people with dementia where some people may struggle with communication and so have difficulty providing their opinions and experiences during group discussions. To avoid these 'untold truths' (Lundy and McGovern, 2006), I ensured each co-collaborator was given sufficient time to express themselves. As rapport and trust developed with the men, they

became more willing to engage in these conversations and offer opinions on improving the groups or other games they wished to engage with. Gustavsen et al (2008) have highlighted that trust is an important element for successful PAR and this is also seen as imperative when working with people with dementia (Dewing, 2008b). Over time as I developed a rapport with the men then they became more confident with their feedback. This aspect will be discussed in Chapter 4.

### 3.3.4 Facilitation of the digital gaming Technological Initiative

I was both the researcher and the facilitator of the TI. Throughout the TI, I worked in collaboration with the men to introduce and use the technological equipment whilst also enabling them space to feedback on their experiences. This ensured the TI developed and evolved over time in collaboration with the men. The learning from each session was used to inform subsequent sessions so consequently each of the three programmes differed to some extent. However there were certain aspects that I kept constant as they were central to, and beneficial for the development of the TI and the group relationships. Table 5 outlines these aspects.

Table 5: Summary of the Technological Initiative

Sessions	Technology	Applications
Introductory session	iPad, Microsoft Kinect	Camera; sports game
2	iPad	Game of Life
3-8	Range of Microsoft Kinect, Nintendo	Balance games; Sports
	Wii, iPad, Nintendo Balance Board	games; Google Earth; Motion
		Play games; Beatles Rock
		Band
Closing session	Varied	Groups favoured games and
		applications;
		Group discussion

### 3.3.5 Introductory session

The introductory session involved two main activities that aimed to promote light hearted dialogue between the men. The first was an 'ice-breaker' activity using the camera application on the iPad. The men were asked to take a photograph of another person around the table and once their picture had been taken they were invited to introduce themselves to the group. This activity engaged the men with the technology and provided valuable information that could be used to tailor subsequent activities towards their interests. The second activity encouraged the

participants to name their group. This name was used throughout the remainder of the research.

The Consultation highlighted the benefits of introducing the technology in a group setting at first. I chose to use the Microsoft Kinect first in accordance with the findings of the Consultation Process, and use games that required simple, basic movements. This was important as research has highlighted detrimental impacts on people with dementia's willingness to reengage with technology if they fail at their first attempt (Hicks and Miller, 2012).

### 3.3.6 Second session

I used a 'Game of Life' application during the second session of the TI. This is a board game that works in conjunction with the iPad. I felt this game would be a useful way to further introduce the iPad (beyond the camera application) to the men and also encourage discussions about the men's lives. Again this information was used to tailor future sessions and highlight any similar life histories or interests between the men.

### 3.3.7 Final group discussion

During the final session of the TI, I undertook an extended discussion with the men to explore their experiences of participating in the research and its perceived impact. Further details of the research study and methods are now discussed.

### 3.4 Study Design and Research Methods

In this section I discuss the rural locations chosen to host the TI and outline the research methods adopted to gather the data required to answer my research questions.

### 3.4.1 Locations for the Technological Initiative

Working in accordance with the project funder, I selected three rural locations to host the TI. The localised nature of a PAR approach can make it difficult to generalise the findings to a wider population (Chevalier and Buckle, 2013). Adopting a multi-site design allowed the findings to be compared across the different rural locations, thus improving the generalizability of the research. This was imperative to ensure that the guidance documentation could be applied more widely in other rural locations throughout England. Table 6 provides an outline of the demographic data for each of the three rural locations. This has been compiled using the most recent 2011 Census data. A more detailed understanding of the rural environments is ascertained from the perceptions of the older men and presented in chapter 5.

Table 6: Demographic data of the three rural locations

Demographic data	Location One	Location Two	Location Three
Population	4,013	5,496	7,314
•			
Males	2,254 (56%)	2,563 (47%)	3,488 (48%)
Population over 65	577 (14% with	1,504 (27% with	1,613 (22% with
	7% males)	11.5% males)	8.5% males)
Median age	40	50	43
Population density per	12	8.6	16.3
hectare			
Day to day activities	21.8%	21.5%	17.6%
limited			
Health very good/good	78.2%	78.9%	82.4%
Health very bad/bad	6.2%	6%	4.2%
Provide unpaid care	10.3%	12.9%	10%
White British	89.8%	96.3%	93.3%
Economically active	62.7%	67.9%	73.8%
(% of those aged 16-			
74)			
High skill occupation	28%	32.8%	32.9%
Low skill occupation	28.2%	21.6%	23.8%

The demographic data suggests the majority of the populations in these areas are White British. Location One has the smallest and youngest population with a mean age of 40 compared with Location Three (43) and Location Two (50) with the oldest population; however it also has the lowest percentage of people who are economically active with 62.7% when compared with 67.9% and 73.8% in Location Two and Three respectively. Location Two has the most dispersed population density with 8.6 people per hectare compared with Location One (12 per hectare) and Location Three (16.3 per hectare). Of the total populations in the three rural locations, Location One has the highest percentage of men (56%) yet the lowest percentage of males over the age of 65 (7%). The data suggests that the higher percentage of people in Location Three describe themselves as having good health (82.4%) compared to Location Two (78.9%) and Location One (78.2%). In Location Two, 12.9% of the population provide unpaid

care compared to 10.3% in Location One and 10% in Location Three. Location Three has the highest proportion of high skilled occupations of the three rural locations (32.9%) with Location One having the highest percentage of low skilled occupations (28.2%). Finally, the data suggests that Location Three has more day-to-day activities available in the area with only 17.6% describing limited activities when compared to Location Two (21.5%) and Location One (21.85).

### 3.4.2 Co-collaborators recruitment process

A purposive sample of older men (65 years +) with dementia living within or around the rural locations was selected (provided they were living within a rural area). The definition of older age was established in accordance with the World Health Organisation who accepts that the majority of developed world countries classify 65 years as 'older age' (WHO, 2016). The men were initially approached about the research through gatekeepers within each rural location. These included Memory Support Workers (MSWs), Activity Leads (ALs) who were running activities for people with dementia in and around the rural areas, and other personnel known by the funding organisation. The academic literature (Mason et al, 2005) advocates this as a beneficial approach to recruiting people with dementia for a number of reasons including: reducing the anxiety participants may feel when being approached by an unfamiliar researcher or feelings they are being coerced by the researcher to take part; reducing the amount of resources and time required to recruit participants as the gatekeepers are likely to know those who are eligible and potentially willing to participate; and providing the study with more credibility as it is being endorsed by people known within the local rural community. This latter benefit is particularly important in rural areas where 'community embeddedness' (Lauder et al, 2006) can lead to 'outsider' specialist service providers being viewed as untrustworthy (Hansen et al, 2005; Morgan et al, 2011).

I provided recruitment flyers and project information sheets to the gatekeepers during the recruitment process (see Appendix 3). The groups were advertised as 'social clubs' with activities using 'gadgets' and 'gismos.' Interested participants recruited via this means were encouraged to call me directly as the Doctoral researcher or provide their permission for the gatekeepers to forward their contact details to me so they could be contacted.

Multiple methods of recruitment were employed to ensure a wide spread of participants were recruited. I visited the rural locations and distributed advertisement flyers in local buildings where men with dementia were likely to attend (churches, pubs, libraries, halls) and in local newspapers. This approach allowed me to familiarise myself with the rural locations before the start of the TI and for potential co-collaborators to become familiar with me. Clarke and Bailey (2016) suggest this is important when setting up and delivering dementia services in rural areas of England. The advertisement flyers encouraged men or their care partners to call or email me to express their interest.

Once an initial interest had been expressed, I called to provide more information about the research and ascertain whether they were suitable participants. The inclusion criteria were:

- they had received a formal diagnosis of dementia
- they were aged 65 years or older
- they lived within the rural location or a rural location in close proximity

As I do not subscribe to biomedical constructions, I did not seek to ascertain the type and stages of dementia (Lyman, 1989). I felt for this research it was more important to elicit the lived realities of different older men with dementia within the area rather than focussing on a specific subset of the population. During the telephone conversation, additional health conditions and other issues (such as transport) that may impact on the men's ability to participate in the research were discussed. Following these discussions, none of the men were excluded due to other health conditions but three of the men from Location 1 expressed a concern about transport to and from the venue. This is consistent with the academic literature that has also highlighted transport as a barrier to accessing dementia services within rural areas (Blackstock et al, 2006; Innes et al, 2005, 2006; Morgan et al, 2011). Fortunately a community bus ran in Location 1 and two of the men were able to use this and I was able to pick up the third man on my journey to the venue. This was agreed with the man and their care partner after week two. Whilst none of the other men who expressed an interest in the research were excluded following this conversation six men decided not to attend the TI after expressing an initial interest. Their reasons for this were not ascertained.

The men were sent an additional information sheet alongside a pre-initiative questionnaire prior to the start of the TI (discussed below). At this point care partners were also invited to join the research if they wished. If they declined this did not exclude the men from taking part. However if the men declined to participate in the research at this stage, then their care partner was also prevented from taking part.

A few days prior to the start of the TI, the men were contacted again to ensure they were still willing to participate. This conversation also acted as a reminder for when and where the sessions were running.

#### 3.4.3 Volunteer recruitment

The Consultation Process suggested that volunteers were essential to the success of the TI. Volunteers were recruited through local dementia charity networks. This ensured that they had all undergone a Disclosure and Barring Service check (DBS). Information sheets were distributed throughout these networks outlining the research and highlighting the benefits of volunteering (see Appendix 4). These included: contributing to research; playing an active role in the community and; learning something new and fun. This is consistent with academic literature that highlights these as important reasons why people volunteer within their community (Allen et al, 2016). Those who were interested in volunteering for the research were asked to contact me. Given the numbers of men within the TI, I opted to recruit a maximum of

three male volunteers per location for the duration of the initiative. Unfortunately it proved difficult to recruit male volunteers and so my numbers were restricted with two male volunteers in Location 1, one volunteer in Location 2 and two volunteers in Location 3. More details on the volunteers are provided in Chapter 4. In addition to providing support for the TI, volunteers were also encouraged to provide data on their experiences of participating in the research and on the impact for the men with dementia. This will be discussed in more detail in section 3.4.4.

#### 3.4.4 Research methods

The research methods used to gather the necessary data sat within a qualitative paradigm and drew from a PAR approach. As the study was exploratory it required an investigation without explicit expectations (Flick, 2014; Robson, 2011). A qualitative paradigm allowed more scope to address the impact of the TI. This sits well with current recommendations for using qualitative research to offer greater insights into the processes and perceived impacts of ecopsychosocial initiatives (Dugmore et al, 2015). Adopting a positivist stance would have required me to have generated hypotheses beforehand so that they could be tested using value free objective measurements (Flick, 2014) and could limit the theory developed from the research (Dugmore et al, 2015). Furthermore, as Banerjee et al (2009) have highlighted, these standardised measures such as those used to assess Quality of Life can be problematic in detecting change particularly for people with dementia. For instance Camic et al (2014), when exploring an art gallery based intervention for people with dementia and their care partners, found that the quantitative measures of Quality of Life and care partner burden elicited limited significant differences yet they were able to ascertain information on the perceived benefits of the intervention through semi-structured interviews and field-notes. Consequently, Stewart-Archer et al (2015) have posited that qualitative approaches should at the very least be used alongside quantitative dimensions. Given the exploratory nature of the study, I felt it was more beneficial to elicit a broad range of outcomes and so develop a more detailed and refined theory from the research findings (Dugmore et al, 2015).

Multiple qualitative research methods were used flexibly to gather the required information from the participants. This approach is supported by literature on conducting real world research (Robson, 2011) and when undertaking research with people with dementia (Murphy et al, 2015). For instance Heggestad et al (2013) suggest that researchers should conduct their research in a morally sensitive way, ensuring research methods are appropriate for the participant with dementia and that they are willing to engage with them. This requires an element of flexibility. Consequently the research methods employed were flexibly adapted so as to ensure they remained morally sensitive (Heggestad et al, 2013) to the co-collaborators.

I situated the men as co-collaborators (McKenna et al, 2011; Robson, 2011) in my study, thereby acknowledging their position as experiential experts. As such, I sought to collect information from them via multiple research methods and used their voices as paramount in my understanding of the rural environments and the perceived impact of the TI. This will be discussed below. However I also collected information from their care partners and the

volunteers and used this in collaboration with my own reflexive field-notes as a form of data 'triangulation.' This refers to the practice of employing multiple research tools within the same research design (Flick, 2014; Robson, 2011). This approach enabled me to add further insights into the research topic. As Flick (2014) suggests, employing a method of data triangulation can: help to enrich the nature of the data collected; allow it to achieve a higher degree of validity, credibility and research utility and; enable the deficiencies associated with single method studies to be overcome. Table 7 provides a summary of the research methods, outlining the data gathered at each phase of the research process and its purpose within the wider study.

**Table 7: Summary of the Study Design** 

Phase	Timeline	Point in	Research method	Participants	Purpose
		research			
		process			
1	July 2014	Pre-initiative	Questionnaires	Men with	Ascertain men's
		planning		dementia	interests
					Explore
					preliminary
					perceptions of
					research
2	Sept-Nov	During the	Informal	Men with	Develop the TI
	2014	Technological	discussions,	dementia	and explore in-
		Initiative	'Photovoice' and	Volunteers	the-moment
			focus groups		perceived impacts
			Reflexive field-		
			notes		
3	Nov-Dec	Upon	Interviews	Men with	Further explore
	2014	completion of		dementia	impact of TI.
		the initiative			Ascertain an
					understanding of
				Care Partners	socio-cultural
				Volunteers	context.
				v Olullicel S	
4	July 2015	Post initiative	Focus groups	Men with	Feedback of
				dementia	preliminary
				Volunteers	findings
				VOIGITIOOIS	

#### Questionnaires

Short questionnaires consisting of open ended questions were distributed to the men during phase 1 (see Appendix 5). They were designed to elicit data on the men's hobbies, interests and current leisure activities as well as initial perceptions of the TI. This ensured the activities could be tailored towards the interests and capabilities of the men (Cohen-Mansfield et al, 2009; Cohen-Mansfield et al, 2013; Kolanowski et al, 2011). All the men were asked to fill out the questionnaire and return it in the attached stamped addressed envelope prior to the start of the TI. I realised that some men may be uncomfortable writing on the questionnaire and so if they were not returned it did not preclude them from attending the TI. This is consistent with ensuring I maintained a moral sensitivity to the participants (Heggestad et al, 2013).

#### Photovoice

Throughout the delivery of the TI the men were encouraged to take photographs of their experiences as part of the 'Photovoice' research method. This is a visual research method that draws on a PAR approach by enabling participants to decide what aspects of their lives they choose to depict (Genoe and Dupuis, 2013). Typically participants are given cameras and provided the opportunity to express, reflect and communicate their everyday lives by taking photographs and describing and reflecting upon them (Wang et al, 1998). This approach has been used previously in the context of dementia to elicit unique insights into people's experiences of living with the condition (Wiersma, 2011) and participating in leisure activities (Genoe and Dupuis, 2012, 2013). Within the present study, each week (beginning from week 4) two men were encouraged to either use a camera (supplied to them at the start of the session) or the camera application on the iPad to provide visual representations of their experiences of participating in the TI. These photographs were then discussed in a group at the end of each session. Unfortunately the majority of men were uninterested in the research method and so chose not to participate. This will be discussed further in Chapter 4.

#### Focus groups

Focus group discussions were undertaken with the men and the volunteers at each of the locations during the final session of the TI (phase 2 of the research). Although the volunteers were present and could contribute during the discussion they were encouraged to enable the men to provide the majority of the feedback. The aim of the focus group was to elicit the men's perceptions of the TI. The discussions focussed on the positive aspects of the TI and its limitations whilst also exploring the perceived impact for the men. The focus groups provided immediate feedback from the men on the TI whilst they were still within that environment but also allowed potential themes to be elicited that could be explored further in the subsequent one-to-one interviews (discussed below). Photographs taken by the men throughout the duration of the TI were also used as prompts to help with recall of the activities over the nine week period.

Focus group discussions were also conducted during phase 4 of the research with the men and the volunteers. These sought to provide feedback on the preliminary findings of the analysis and to refine the themes and ensure they were representative of the men's voice. Research has suggested the need to include participants where possible in their own analysis and interpretations of the data to avoid objectification of their experience (Cook, 2002; Wiersma et al, 2016) and this is emphasised within the PAR approach (Chevalier and Buckle, 2013). This is similar to O'Sullivan et al (2012) who used an action research approach and sought feedback on their findings from the participants with dementia.

The men were also encouraged to feedback on the guidance documentation. Co-production and collaborative partnerships are important within public policy and practice in the UK to improve the quality and relevance of services (Fenge et al, 2012) and to develop 'authentic partnerships' (Dupuis et al, 2012) with people with dementia. As Fenge et al (2012) highlight, this gives recognition of the personal voice as 'cultural capital' and can help promote new understandings of research areas and practice.

### Interviews

Face-to-face interviews were conducted with the men, their care partners and the volunteers immediately post- TI over a three week period during November and December 2014. The only exception to this was the interviews conducted with the men and their care partners who elected to drop out during the delivery of the TI. These were undertaken as soon as was feasibly possible, if the men were willing, after the decision had been made.

The aims of the interviews with the men with dementia were twofold. Firstly, to explore further any information that had been elicited during the focus group discussions. Secondly, to provide a more detailed understanding of how the men live within their rural community. Phinney and Moody (2011) have emphasised the need to provide the socio-cultural context when understanding the perceived impact of ecopsychosocial initiatives for people with dementia. Open interviews were conducted to enable the men to talk freely about aspects of their rural lives that were important to them.

Research has shown that qualitative interviews are a useful method to provide meaningful insights into the experiences of people with dementia (Cowdell, 2008; Goldsmith, 1996; Murphy et al, 2015; Wilkinson, 2002). I attempted to facilitate the interview process whilst also examining the rural geo-socio-cultural environment by undertaking 'walking interviews' or 'go-along' interviews (Phinney et al, 2016). This is a relatively novel method within dementia research (Capstick, 2015; Mapes and Hines, 2011; Phinney et al, 2016) and sits well with the PAR approach adopted throughout the study. It allows the researcher to walk alongside participants to observe, experience and make sense of their everyday practices. It enables them a greater detail of understanding and insight whilst also providing the participant the opportunity to dictate the aspects of the community they wish to reveal (Clark and Emmel, 2010; Mapes and Hines, 2011) as well as participate within their local community; thereby enhancing their sense

of social inclusion (Phinney et al, 2016). Unfortunately however the majority of men declined to participate in the walking interviews and this will be discussed further in Chapter 4.

I also undertook interviews with care partners and the volunteers. Semi structured interviews were used to elicit their perceptions of the TI and the perceived impact for the men as well as their opinions of living within the rural environment. This information was used as part of the data triangulation process (Flick, 2014; Robson, 2011). Volunteer interviews were conducted face-to-face whilst care partner interviews were conducted predominantly over the telephone. This approach was adopted as it was important that the care partners could talk openly. It also enabled care partners to choose an appropriate time to speak when the men were out or engaged in another activity. Although two different interview approaches (face-to-face and telephone) were undertaken, research has found little evidence to suggest they reveal substantial differences in the data collected (Sturges and Hanrahan, 2004).

### Reflexive field-notes

Reflexivity is about reflecting on a researcher's power to perceive, interpret and communicate about their research participants and the research process (Reid and Frisby, 2008). Throughout the research period and the development of the TI, I continued to make reflexive field-notes in my field journal. This process enabled me to engage in self-criticism and so learn from my failures and successes (Reid and Frisby, 2008) when developing the TI. It also ensured I was explicit about the decisions I made throughout the research. During the delivery of the TI, informal discussions with my co-collaborators were recorded as well as my observations. These notes described the implementation of the TI and provided interpretations of observations and informal discussions that would help to understand the impact of the TI for the men. Notes were also recorded immediately post interviews and written alongside the interview transcripts. These provided additional contextual details such as environmental aspects as well as non-verbal cues, and therefore enabled a deeper understanding and interpretation of the interview data.

Each session of the TI was video recorded, following verbal consent from the participants, and reviewed afterwards to support my reflexive field-notes. This approach is advocated by Phinney and Moody (2011).

#### 3.5 Ethics

This section will discuss the ethical issues that were present in the research and how these were considered when collecting and storing the data.

### 3.5.1 Ethical considerations during data collection

The research was conducted through the participation of individuals who have been considered vulnerable under the Mental Capacity Act (MCA 2005). Although the Act states that people with dementia should be considered able to provide informed consent, due care was taken to ensure the study was undertaken in an ethical, meaningful way that preserved participants' personhood at all times (Cowdell, 2006). As a voluntary sector organisation committed to undertaking the recruitment process then only internal ethical approval from Bournemouth University (BU) was

required rather than additional external ethics from the NHS. To adhere to Bournemouth University and the Social Care and Research Committee ethical guidelines, I had an enhanced DBS check carried out as did the volunteers. I also had prior experience of working with people with dementia that helped when collaborating with them.

A process consent approach (Dewing, 2008b) was used to ensure consent from people with dementia was obtained and maintained throughout the research process. This is considered best practice within the dementia care field. To enable this, an accessible information sheet outlining the proposed research was given to the men at the beginning of the study to ensure they could make an informed decision to participate. This initial information sheet outlined:

- the purpose of the research,
- why they had been selected,
- what their participation involved,
- · any benefits or disadvantages of taking part,
- confidentiality procedures,
- what happened to their information once provided and;
- further information such as complaints procedures and contact details for BU Ethics Committee.

In addition to this, prior to each phase of the research, additional information sheets were provided to the participants that summarised the phases of research to date and reiterated the purpose of the next phase. This is in accordance with Swantz (2008) who calls for transparency at all times for participants of PAR research so that they can trace the whole processes throughout the study.

Written consent was sought at the beginning of the research study from all men and verbal consent thereafter for the subsequent phases. Throughout the research, as advocated by the process consent procedure (Dewing, 2008b), careful attention was also paid to the men's body language to ensure that they understood the research and were participating of their own free will. If this appeared not to be the case then I would have been prepared to discuss this with them and emphasise that they would have been able leave the research irrespective of having given written consent. However, this did not occur throughout the duration of the study. For each of the five men who did elect to drop out of the research, a discussion was held with them to ascertain whether the information they had already provided could still be used in the analysis. All of the men agreed to this.

The men also gave their written consent at the start of the TI for it to be filmed. After this, prior to the start of each session, the men were informed that the session would be filmed. The reason for the use of the camera was again imparted to them and they were asked to provide their verbal consent. If any of the men did not provide their verbal consent then I was prepared to stop recording of the session, however this never became an issue, with all men freely consenting at the start of each session.

### 3.5.2 Data storage

Throughout the data collection process only the research team (my supervisors and I) had access to the data. It was stored in accordance to data protection laws and BU policy and held in a password protected folder. The focus groups and interviews were recorded using a Dictaphone. For the walking interviews a microphone was attached to the men (with their permission). The recordings were transcribed, anonymised and then uploaded on to Nvivo 10. This software was used to manage the data for analysis purposes. Data collected from the questionnaires was anonymised and stored within Excel. Reflexive field-notes were typed up, anonymised and also stored on Nvivo 10. During report writing, all information that could link the individual to the example was removed so as to maintain confidentiality and anonymity. The research participants were all given pseudonyms so as to preserve their identity. Any photographs or film clips used for dissemination purposes outside of the group received additional verbal consent from the participants.

#### 3.6 Analysis

3.6.1 Pre-analysis: Construction of data

This section provides an account of how I constructed the data sets from the multiple research methods I used throughout the study.

#### Reflexive Field-notes

My reflexive field-notes provided me with a thick description (Geertz, 1973) of the three rural locations and what I saw and heard during the nine-week delivery of the TI. They were written up as soon after I experienced, saw or heard something that was interesting. When this was not possible I would often record them into a Dictaphone on my car journeys back from the rural locations and then listen to them when at home. Alongside these notes I also recorded my interpretations, impressions and feelings. Every evening after I had visited a rural location or delivered a technology session, I reviewed the notes and typed them up into more detailed field-notes. My observations were written in text and were accompanied by comment boxes that recorded my feelings and impressions. If the notes were taken after a technological session, I also made a separate note of Action Points from the men that needed to be taken forward in the subsequent sessions or other notes for improving the set-up or delivery of the TI.

My focus for the field-notes was on the facets of social inclusion that were displayed or inhibited by the men. Focussing on my definition of social inclusion as set out in Chapter Two, I was able to add structure to my observations and notes, thereby enabling me to select appropriate data from my field-notes to incorporate into the analysis.

## Video

As I was both delivering the TI and recording detailed reflexive field-notes the use of the video recorder ensured I could maintain a more accurate record of the events that took place. This method was particularly useful for collecting information on interactions between the men that I may have missed when I was otherwise occupied.

Every evening, after video recording a technology session, I downloaded the video footage from the recorder into a file on my laptop. I reviewed the footage, stopping and starting frequently to write descriptions of what I observed during the sessions. These observations were used to support the field-notes that I wrote up prior to reviewing the video footage. I documented the interactions that occurred between the men or the men and the volunteers, transcribed any audible conversations and noted expressions and actions. The benefit of this method became apparent in the very first technology session in Location One. After I asked the men to engage in a discussion to name the group, I noted in my initial reflexive field-notes that it was likely to have been one of the more out-going men that suggested the name 'The Old Boys' (Keith, David or Joe). However on reviewing the video tape it became apparent that Bill, one of the more reserved men had in fact named it. This demonstrated the fallibility of the researcher's recall process and highlighted the benefits of video recording to triangulate data sources to mitigate these issues to some extent (Phinney and Moody, 2011).

### · Focus groups and open interviews

Data was constructed from the focus groups and interviews following repeated listening of the tapes and transcribing of the conversations verbatim. Transcriptions of verbatim text were created for all interviews and focus groups. During the construction of this data I also used comment boxes to record my own thoughts and feelings about the participants' responses. These textual accounts were analysed alongside the other datasets.

### Management of the data

In accordance with the ethical requirements, I stored signed consent forms and all the hard data such as video tapes, interview tapes and transcripts in a locked filing cabinet at Bournemouth University. My field-notes, downloaded video-footage and transcripts for analysis were stored on my password protected laptop to which only I had access.

## 3.6.2 Deciding on my analysis approach

Having constructed the various datasets I entered them into NVivo 10; the latest development in qualitative data-analysis and management. This enabled me to manage the vast quantities of qualitative data as well as interrogate it, and quickly access original text to support and challenge the development of concepts.

When analysing my data, I followed the 6-phase guide to conducting thematic analysis as outlined by Braun and Clarke (2006) to ensure that the process was academically robust. This analysis approach was used by Carone et al (2014) when exploring the qualitative benefits of a community-based football group for five men with early-onset dementia. Table 8 below outlines the six phases of the analysis. Thematic analysis is not associated with any theoretical or epistemological position (Braun and Clarke, 2006) and therefore is particularly apt for the PAR approach that framed the conduct of my research study. A thematic analysis is also flexible in how it can be applied, whether this is through an inductive process, where themes are identified

and data-driven or through a theoretical process whereby the themes are analyst-driven (Braun and Clarke, 2006).

When conducting the thematic analysis I adopted an inductive approach. This sought to ground the themes elicited from the data in the original words of the co-collaborators. Only once the themes had been constructed from the data, did I examine them through my chosen lenses of social inclusion and masculinity. As my research questions were exploratory in nature, I was keen to ensure that potentially prominent themes were not discarded in the early development phases of the analysis, as may have been the case if I employed a deductive approach where I coded directly to my higher order conceptual lenses. This process ensured that I could provide a rich overall thematic description of the dataset rooted in the voices of my co-collaborators to answer relatively broad, exploratory questions that focussed on the perceived impact of the socio-cultural rural context and that of the TI.

Throughout each phase of the analysis, I provided detailed reports to my supervisors to enable them to comment on the codes and themes I was generating and my interpretation of the data. This helped to add to the rigour and credibility of the analytical process.

Table 8: Braun and Clarke's (2006) Phases of Thematic Analysis

Phase	Description of the process
Familiarising yourself with your data	Transcribing the data, reading and re-reading
	the data, noting down initial ideas
2. Generating initial codes	Coding interesting features of the data in a
	systematic fashion across the entire dataset,
	collating data relevant to each code
3. Searching for themes	Collating codes into potential themes,
	gathering all data relevant to each potential
	theme
4. Reviewing themes	Checking themes work in relation to the coded
	extracts and the entire data set, generating a
	'thematic map' of the analysis
5. Defining and naming themes	On-going analysis to refine specifics of each
	theme and the overall story the analysis tells;
	generating clear definitions and names for
	each theme
6. Producing the report	Final opportunity for analysis. Selection of
	vivid, compelling extract examples, final
	analysis of selected extracts, relating back
	from the analysis to the research question and
	literature, producing a scholarly report of the
	analysis

## 3.6.3 The analysis process

As outlined above, I followed Braun and Clarke's six stage process when analysing my data. Below I provide a detailed account of the analysis process that I undertook during the six stages, which enabled me to construct my final themes.

# Phase 1: Familiarising myself with the data

As part of the process to familiarise myself with the data, I transcribed all of the focus group discussions as well as half of the interviews. The remaining interviews were transcribed by a specialist transcription company. In conducting the transcription I recorded all verbal utterances verbatim and on occasions also included some nonverbal utterances if I felt they would help to provide a more 'true' account of the conversation. This process helped me to gain a better

grasp of the data and begin the process of understanding and interpreting it. For the data that had been transcribed for me, I made sure I read the transcript whilst listening to the recordings. This enabled me to check the transcription for accuracy and ensured I became more familiar with the data. Once all of the data had been transcribed I read through the entire dataset (reflexive field-notes, focus groups and interviews) twice more so that I became accustomed to it and could begin the interpretative process.

### Phase 2: Generating initial codes

Although the interviews were conducted primarily to explore the rural lives of the older men with dementia, aspects of their rural living were also present in the field-notes through the discussions that took place during the TI. Therefore I opted to keep the field-notes, interviews and focus groups together and generate initial codes that concerned the men's lives within the rural areas from this dataset. Adopting an inductive approach, I coded data sentence by sentence, focussing on the information supplied by the men that appeared interesting and pertained to rural living. This ensured that their voices were paramount in the development of the themes and reflected their status as co-collaborators. I kept an open-mind throughout the coding process and as recommended by Braun and Clarke (2006) coded as many potential themes/patterns as possible, on occasions placing individual extracts of the data into numerous codes. For example the extract of text below was taken from an interview with Jess. I coded this into two initial codes: 'Residence-peaceful' and 'residence- friendly residents.'

'But it's quite nice living around here, it's quiet, and as I say everybody's very, very nice. You've got this nice, friendly feeling so it's alright.' (Jess, Marching On, Interview).

I also ensured I coded elements of the men's discussions that did not necessarily fit with the dominant story that was beginning to emerge from the analysis. For instance I created a code of 'Dementia adversely impact on well-being' despite the dominant story suggesting most men took a stoic, fighting or positive approach to living with dementia in their rural environment. Following the completion of this task, I then repeated the process generating initial codes of the data concerning the men's opinions of the TI and its perceived impact. For example the extract of text below taken from an interview with Kenneth, was coded into the three initial codes that focussed on the men's opinions of the TI: 'Male-only environment (MOE) promotes relaxation,' 'MOE: presence of women restrict men' and 'MOE familiar to men.'

'It's what you know. I don't really know. If you can swear which now and then you can do then you would feel offended with the women there. Then they would take over. And you would never get a word in edgeways and the woman always has the last word. I feel more relaxed with just men only.' (Kenneth, Old Boys, Interview)

Undertaking this process elicited a preliminary understanding of the perceptions of the men regarding their rural lives and the perceived impact of participating in the TI. Following this, as part of the data triangulation process, I undertook a similar task coding the care partners' and volunteers' opinions of their rural location and the perceived impact of the TI alongside the

reflexive field-notes that I had made. I coded all of the data at both a semantic level as well as a latent level. For instance, this extract of text taken during an interview with John's care partner, Angela, was coded at a latent level as: 'CP respects men's agency.'

'And the only trouble is I sometimes find that because you have to tell John so many times to do something it's easier to do it yourself, but that's not the point and I have to stop and say, no, let him do it; otherwise it makes him feel useless...But by helping him you're not helping him, do you understand?' (Angela, Marching On, interview)

## • Phase 3: Searching for themes

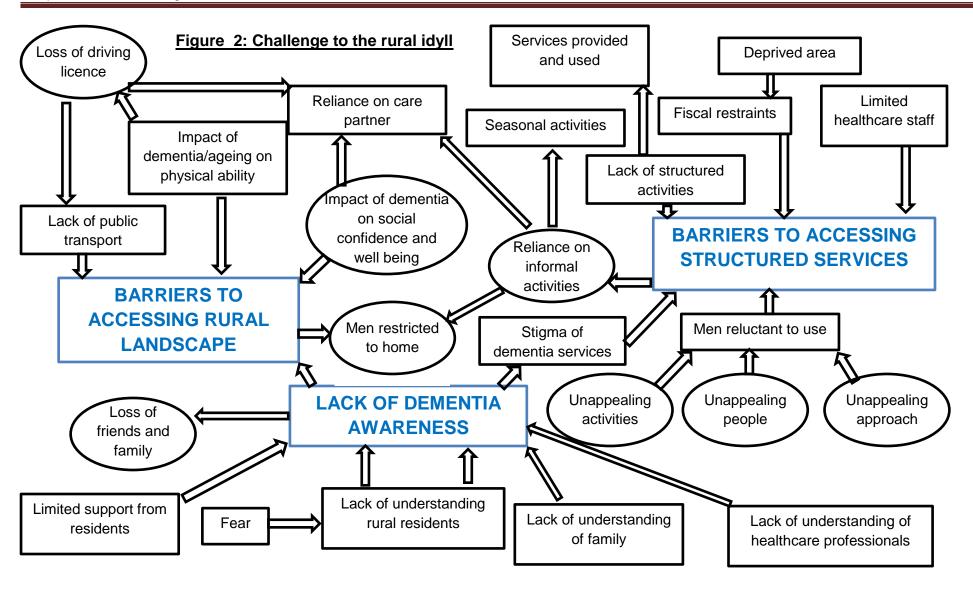
Braun and Clarke (2006) posit that this phase involves sorting the different codes into potential themes and collating all of the relevant coded data extracts within the identified themes. I labelled each code with a short description and then organised them into theme-piles. For instance I developed a theme of 'Lack of Dementia Awareness' that included the initial codes 'limited support from rural residents,' 'lack of understanding from rural residents,' 'lack of understanding from healthcare professionals' and 'stigma/fear of dementia.' At this stage, I found it useful to develop mind-maps that illustrated how the different codes could potentially combine to form an overarching theme. Through undertaking this process I began to think about the relationships between the themes and the different levels of themes. An example of a mind-map I created during this process is outlined below in Figure 2. My initial thoughts regarding these relationships were noted next to the themes within the NVivo folder. Any initial codes that did not seem to fit anywhere were labelled as 'miscellaneous' and put into a separate theme. These codes included benefits that the TI had for the men's care partners, which were not pertinent to the research questions I had set out to answer.

## Phase 4: Reviewing themes

This phase required me to refine the themes that had been created during Phase 3 of the analysis. Particular attention was paid to whether the themes sat together meaningfully and whether there was a clear and identifiable distinction between the themes (Braun and Clarke, 2006). As part of this process I read each of the themes to ensure they formed a coherent pattern. At this point I was able to remove certain data extracts and either apply them to another theme or discard them from the analysis. Once I was satisfied that I had developed a thematic map, I re-read the data set to ascertain whether the themes sat well with the rest of the data and to code any additional data within themes that had been missed in earlier coding stages. I also provided my supervisors a list of the codes and themes to enhance the rigour of my analysis. By the end of this inductive process I had developed a set of themes that seemed to sit together well and provided an overall story of the data.

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### Phase 5: Defining and naming themes

As part of the process of naming and defining the themes, I created sub-themes in order to provide a structure to the large and complex themes. At this point I was also able to carry out cross-case analysis on the final themes that had been elicited from the dataset to understand whether they differed between the three rural areas and between the men, their care partners and the volunteers. For instance I noted that the theme of 'Competition' was most prevalent in the Done Roaming group. The final names for the themes were also defined to accurately reflect a sense of what the theme was attempting to portray. A final table of the themes created from the inductive thematic analysis process can be seen in Appendix 6.

Following the creation of the final themes I wrote them up into an accessible document for the men so that they could comment on the findings for accuracy. This process will be discussed in the following chapter.

Once the themes had been defined and named I was able to interpret them using both a social inclusion framework as well as a masculinity lens, in accordance with my definitions of social inclusion and masculinity as outlined in sections 2.2.5 and 2.5.3 respectively. This enabled me to gain a deeper understanding of how my elicited themes could be understood more conceptually within the wider academic literature and allowed me to answer the questions that I posed at the start of the thesis. Understanding the data through these lenses was used as a way to frame my discussion of the findings in Chapter 7.

#### 3.6.4 Summary

Within this chapter I set out my research design by defining the PAR approach that I drew from whilst conducting the research and outlining the benefits that this framework offered me. Furthermore, I provided a brief overview of the Consultation Process that informed the development of the TI and the study design for the main Doctoral research. Having provided an overview of the Technological Initiative I discussed the multiple qualitative methods that I adopted. These enabled me to address the broad exploratory research questions that I posed at the beginning of the thesis. I concluded the chapter by discussing my approach to constructing the data set and analysing the multiple data sources. I will now discuss the co-collaborators that took part in my research and my reflections on working with them.

## Chapter 4: Introducing the men and reflecting on my experiences

This chapter draws on my reflexive field-notes as well as information supplied by the men, their care partners and the volunteers to provide a 'thick description' (Geertz, 1973) of those who collaborated in the research and offer a reflexive account of the processes of working with them. In doing so, I afford a better understanding of the overall research (Becker, 1998; Ponterotto, 2006).

## 4.1 Demographics

During each of the preliminary sessions the men decided upon a name for their group. These names were: Old Boys (Location One), Done Roaming (Location Two) and Marching On (Location Three). Throughout the remainder of this thesis the groups will be referred to by these names. All co-collaborators have been provided pseudonyms to preserve their identity.

The men were considered co-collaborators for the study and Tables 9, 10 and 11 outline their demographic details. This information was ascertained from the preliminary questionnaires. Further details on each of the men have been elicited from my reflexive field-notes and are supplied in Appendix 7. Care partners and the volunteers were considered secondary informants for the study and the information they provided was used to triangulate that supplied by the men. The men's relationship with their care partner (in addition to their pseudonym) has been provided in the tables below. Table 12 outlines demographic characteristics of the volunteers.

Table 9: Demographics of the Old Boys group

Men	Age	Years since diagnosis	Ethnicity	Years in residence	Attend other dementia groups	Main Care Partner	Interests	Expectations for research	Concerns for research	Previous exp with tech
Keith	74	3	White British	65	No	Wife (Linda)	Because of many health problems cannot do very much. Watching TV, driving, sitting in gardens	Make new friends. Gain a new interest. Help understand dementia better	None	None
David	68	2	White British	20	No	Wife (Anita)	Playing golf. Rugby	Technical knowledge	None	iPad
Joe	71	4	White British	25	No	Wife (Sheila)	I am secretary to housing group which takes quite a bit of time. I spend a lot of time on my computer and internet	That I am not as bad as I think I am. There is always someone worse off than you and maybe gain back my confidence.	None	iPad
Ken	78	8	White British	78	No	Wife (Iris)	N/A	N/A	N/A	None
Bill	87	2	White British	23	No	Wife (Barbara)	Walking, gardening, day outings	N/A	None	None
Bob	75	10	White British	75	Yes	Wife (Caroline)	Swimming.	N/A	None	None

Table 10: Demographics of the Done Roaming group

Men	Age	Years since diagnosis	Ethnicity	Years in residence	Attend other dementia groups	Main Care Partner	Interests	Expectations for research	Concerns for research	Previous exp with tech
Phil	77	7	White British	12	Yes	Wife (Maggie)	Playing music. Learning to read music. Listening to modern jazz and ballads.	Learning something new	None	iPad
Doug	90	1	White British	10	Yes	Wife (Alison)	Walking- twice a day	To laugh again and have a local interest. Give the wife a rest from absent minded irritable old man	None	None
Terry	82	2	White British	19	Yes	Wife (Jean)	Watching TV (sports if possible). Visiting friends, bus and coach and train travel	A better understandin g of what is happening to me. Receive feedback from a professional who has total understandin g of the	None	iPad and Nintendo Wii

								disease		
Norman	83	3	White British	83	Yes	Wife (Joan)	Walking when possible. Word search. Picnics. Going for long car rides with my wife driving. Watching television-World War 2 programmes	Meet new people and expand my memory I hope	Yes is there a toilet there?	None
Barry	84	3	White British	15	Yes	Wife (Betty)	Not answered	Not answered	Not answered	None

Table 11: Demographics of the Marching On group

Men	Age	Time since diagnosis	Ethnicity	Time in residence	Attend other dementia groups	Care Partner	Interests	Expectations	Concerns	Previous exp with tech
Jess	86	5	White British	52	Yes	Lives alone	I enjoy spending time on the computer, using programs to enable me to creatively produce pictures or documents.	Hope it will encourage others to explore this kind of group.	None	Computer
Gordon	76	2	White British	11	Yes	Wife (Shirley)	Gardening. Cycling occasionally	Some social activity	Not answered	None
Tel	81	3	White British	64	No	Lives alone	TV. Walking. Reading. Crosswords	More friends	Not really	iPad
Dick	90	7	White British	28	No	Wife (Rita)	Tasks in garden. Working in wood and metal in the	Understand dementia	None	None

							garage. Visiting other motor club events			
Colin	79	7	White British	32	Yes	Wife (Sue)	Reading. Listening to music- classical and big band. Watching some sports on TV (rugby, golf, tennis, cricket). Watching garden birds	Don't know	None	None
John	84	11	White British	7	Yes	Wife (Angela)	To take the dog for a walk. Gardening. Visit National Trust Houses. Drawing	Get out more. Friendship	None	None
Harry	70	7	White British	25	Yes	Wife (Veronica)	Walking and helping with outside tasks!	Fun	None	None
Chris	77	12	White British	20	Yes	Wife (Thomasina )	Gardening. Classical music. Word games.	Not answered	None	None
Simon	85	3	White British	11	Yes	Employed helpers (Maureen, Grace)	Not answered	Not answered	Not answered	None
Dave	86	3	White British	25	No	Lives alone	Not answered	Not answered	Not answered	None
Peter	87	4	White British	40	No	Wife (Doreen)	Not answered	Not answered	Not answered	None

**Table 12: Demographics of the volunteers** 

Group	Participant	Age	Ethnicity	Experience of dementia	Technology experience
Old Boys	Graham	66	White British	None	iPad
	Tom	63	White British	Had worked with old people but no experience of dementia	iPad and Nintendo Wii
Done Roaming	Greg	79	White British	Worked as a mental health nurse and volunteered at other groups for people with dementia in the rural community.	None
Marching On	Marching On Josh 84 White British Alzheim meetings		Personal experience caring for his wife with Alzheimer's Disease. Also attended other meetings for people with dementia and their care partners in the area.	None	
	Brian	78	White British	Was treasurer for a Memory Café for people with dementia and their care partners in the local rural area	iPad

## 4.1.1 Summary of the research participants

#### Men

Twenty two men participated in the research. On average, men in the Old Boys were younger than those in the other two groups, with a mean age of 76 years (range 68-87 years) compared to 83 years (range 77-90 years) and 82 years (76-90 years) in Done Roaming and Marching On respectively. All of the men attending the TI were White British. The length of time the men were diagnosed with dementia ranged from 1-12 years with a mean of five years. Those in Marching On had lived longer with a diagnosis of dementia with a mean of 5.8 years (range 2-12 years) compared to Old Boys (mean 4.8 years, range 2-10 years) and Done Roaming (mean 3.2 years, range 1-7 years). Predominantly, the men's care partner tended to be their wife although Simon (Marching On) had live-in paid support workers following his wife's death. Jess, Tel and Dave (all Marching On) had no care partners although Tel and Dave received a lot of support from the Day Centre they attended daily.

The men had resided in their rural location for varied amounts of time. On average, the Old Boys had lived in their rural location for longer (48 years, range 20-78 years) than Marching On (29 years, range 7-64 years) and Done Roaming (27 years, range 10-80 years) groups. The majority of men from Old Boys had resided in their rural location for almost the entirety of their lives (Keith, Joe and Bob) compared to only one man in Done Roaming (Norman) and one man in Marching On (Jess- although he moved there in his 20s).

All of the men in Done Roaming also attended other groups in their local rural area for people with dementia. This was similar for the men in Marching On, where seven of the 11 men attended other activities for people with dementia. Conversely, in Old Boys only Bob attended another local activity aimed specifically at people with dementia.

The men had a wide range of interests, with the most popular activity being walking. Other outdoor activities that some of the men engaged in included swimming and golf, day outings and going for drives. Predominantly however, the majority of men outlined interests that were primarily home based, including: listening to music; watching TV; gardening; and reading, drawing or tackling mind puzzles. The majority of the men had limited previous experience using the technological devices. David, Joe (Old Boys), Phil (Done Roaming) and Tel (Marching On) had experience using an iPad and Terry (Done Roaming) had previously played on an iPad as well as the Nintendo Wii. This would suggest that the technology was a novel device for the majority of the men and would be expected in older men residing in rural areas given the barriers outlined previously in section 2.7.1. Despite this though none of the men expressed any concerns with participating in the research.

The men reported a range of expectations and reasons for participating in the research. Some of these focussed on the need for more information regarding their dementia such as Terry (Done Roaming) however the vast majority were related to improving psychosocial aspects of their daily lives within their rural environment such as: socialising and making new friends;

learning something new; engaging in a fun activity; and regaining confidence. This provides further support for other research that has highlighted the willingness of people with dementia to be included in activities that enable them to feel connected and involved in their environment (Han et al, 2015; Phinney et al, 2007, 2008).

#### Volunteers

With the exception of Tom (Old Boys) all of the volunteers could be classed as older adults (aged over 65 years old) in accordance with the World Health Organisation's classification of old age in developed world countries (WHO 2016). Their ages ranged from 63 years to 84 years old with a mean of 74 years. The volunteers in Old Boys were of a slightly younger age (66 and 63 years) when compared to the Greg in Done Roaming (79 years) and those in Marching On (84 and 78 years). Across the three groups, all of the volunteers were White British. The volunteers' experience of dementia varied across the three groups. In Old Boys the volunteers had limited experience of the condition, whereas Greg in Done Roaming had previously worked as a mental health nurse and also volunteered as a support worker for other dementia groups within the rural environment. In Marching On, both Josh and Brian volunteered at another support group for people with dementia and Josh also had personal experience of caring for his wife who had died of Alzheimer's Disease two years previous. The majority of volunteers had limited experience of using the technology. Tom, the youngest of the volunteers owned an iPad and had also used the Nintendo Wii. Both Graham and Brian also owned an iPad but neither was accustomed to any of the other technologies used in the TI. Josh and Greg had no experience of using any of the technological devices.

# 4.2 Delivering the Technological Initiative

The following section discusses the delivery of the TI and reflects on my experiences of working with the men and developing the group relationships. This latter information was elicited from my reflexive field-notes as well as feedback provided by the men at the end of the TI.

#### 4.2.1 Attendance at the Technological Initiative

Table 13 outlines the number of men (M) and volunteers (V) that attended each session of the TI. The table shows that not all of the men attended all of the sessions. However within the Old Boys and the Done Roaming groups there was a mean of four men at the sessions and at the Marching On group there was a mean of nine men; although this mean was reduced to five men after session four when five men had left the TI.

Table 13: Attendance at the Technological Initiative

Group	Session Attendance								
	1	2	3	4	5	6	7	8	9
	7	6	7	6	6	4	5	7	4
Old Boys	(5M	(4M	(5M	(4M	(4M	(3M	(4M	(5M	(4M
	2V)	2V)	2V)	2V)	2V)	1V)	1V)	2V)	0V)
	5	6	3	5	4	6	5	4	4
Done Roaming	(4M	(5M	(2M	(4M	(3M	(5M	(4M	(3M	(3M
	1V)	1V)	1V)	1V)	1V)	1V)	1V)	1V)	1V)
	10	13	13	11	7	7	5	8	6
Marching On	(8M	(11M	(11M	(9M	(5M	(6M	(5M	(6M	(5M
	2V)	2V)	2V)	2V)	2V)	1V)	0V)	2V)	1V)

# 4.2.1 Delivery of the Technological Initiative

Throughout the nine week initiative I was responsible for facilitating group cohesion. To achieve this I established specific aims for each of the three phases of the group development: preliminary and early sessions (weeks 1-4), middle sessions (week 5-7) and closing sessions (weeks 8-9). These aims are outlined in Table 14.

Table 14: Aims of the three phases of group development

Sessions	Aims
Preliminary and	Developing initial relationships:
early sessions  Middle sessions	To encourage the members of the groups to become more accustomed to each other through exchanging personal information and highlighting commonalities  To establish an environment where the men felt relaxed and comfortable expressing themselves  To introduce the men to the new technologies and their possibilities  Maintaining relationships:  Solidify friendships and group cohesion  Encourage the men to take a more active role in the group  Introduce more difficult games that required more complex movements  Encourage more detailed feedback from the men on the evolution and development of the group
Closing sessions	Closing relationships:
	Acknowledge the research was coming to a close
	Understand and work towards ways to enable the groups to continue

My aims throughout the three phases of the TI were guided by my understanding of small group development as outlined by Tuckman (1965) and Tuckman and Jensen (1977). They posit that during the preliminary stages a group will enter a stage of 'Forming.' This is where the individual group members are brought together for the first time and the tasks are outlined to them. During this period Tuckman (1965) suggests that individuals tend to behave independently and look to test the boundaries of acceptable behaviours. The emphasis is therefore on the leader to bring the group together and outline these boundaries and responsibilities. Following this, groups can enter into periods of 'norming' and 'performing' (Tuckman 1965). Group norming refers to ingroup feeling and cohesiveness that develops and new roles that are adopted. The group members develop a stronger commitment to the group and its goals and feel more able to express their opinions even if they are not positive. Group performing is viewed as the stage when group members are confident and cohesive. They undertake tasks without supervision and the group members have roles that become supportive of the overall group performance. During these phases Tuckman (1965) has also suggested that a period of 'storming' can occur.

He posits that the group is characterised by conflict and polarisation and individuals can exhibit behaviours that challenge other group members, and the leader, and resist task requirements. If not managed correctly, it has the potential to be destructive to group formation and the overall success of the group performance. Conversely, if managed successfully the group can become stronger and more versatile as a consequence of moving through this stage. The final stage is that of 'adjourning' whereby group members reflect on the group and what has been achieved (Tuckman and Jensen 1977).

Throughout the nine week period I used a range of technological activities to enable me to achieve these aims. A summary of the activities undertaken is outlined in Table 15.

Table 15: The activities undertaken throughout the Technological Initiative

Activity	Groups	Description of activity		
,	(session)	· · ·		
1. iPad photography	All groups (1)	Men were supported to take a photograph of someone else in the group. Once your photograph had been taken you introduced yourself and your interests/hobbies.		
2. Naming of the group	All groups (1)	Men were encouraged to pick a name for their group. No technology was used to support this.		
3. Microsoft Kinect Golf	OB (1, 3) DR (1, 6) MO (1, 5, 8)	Each of the men played one hole of golf against a computer opponent. To engage with the game the men imitated a golf swing which is then replicated on the screen.		
4. iPad YouTube songs	All groups (all sessions)	Men were encouraged to use the iPad to play a song of their choice. Activity proved successful and so continued for all sessions.		
5. iPad Game of Life board game	All groups (2)	Board game which works in conjunction with the iPad. An electronic counter on the iPad is spun and then the game piece is moved the required spaces the appropriate amount of spaces on the board. The aim is to accumulate points and money as you move through the board. The person with the most points at the end is declared the winner. Throughout the game you are required to make choices (such as whether to go to college or straight out into the world of work) and to engage with a series of mini games on the iPad. Successfully engaging with these games increases the amount of points received.		
6. Google Earth	OB (3) DR (3, 4) MO (3, 5)	The iPad and Google Earth application was used to find places of interest to the men such as previous places of residence and past/future holidays. The iPad was linked to the TV to allow all group members to view the application and participate in the discussions.		
7. Microsoft Kinect Tennis	OB (3)	The men played three games of tennis against a computer opponent. This included serving for two games and		

	MO (3, 5)	returning for one.
8. iPad backgammon, chess, bongo drum and piano application. Also use Google to find photographs and videos.	OB (4, 5, 8) DR (3, 5, 6, 7, 8) MO (3, 8)	Men played against the computer at the various games which pertained to their interests or used the musical applications to play along with one another.  Photographs and videos were found by either me or the men using Google or YouTube applications.
9. Nintendo Wii, Mii Character development	OB (4) MO (3)	Work together as a group to create a Mii Character. Each man was responsible for picking a feature of the character (hair, eyes, nose, face etc). Once completed the group named the character.
10. Nintendo Wii Boxing	OB (4) MO (3)	Use the Wii remote and nunchuck to fight a computer opponent.
11. Nintendo Wii Mario Kart	OB (7) DR (4) MO (4)	Use the Nintendo Wii Steering Wheel to navigate the track and compete against a computer opponent. Relatively difficult activity due to the fast moving nature of the game.
12. Microsoft Kinect Bowling	OB (5, 7, 9) DR (5, 7, 9) MO (4, 6, 9)	Play in teams and compete against each other over ten rounds of ten pin bowling.  To engage with the game the player must imitate a bowling action which is then replicated on the screen.
13. Microsoft Kinect Darts	OB (7) MO (6)	Play on your own against the computer to score 501. Players imitate throwing a dart which is then replicated on the screen. The men were placed in pairs as they competed against the computer.
14. Microsoft Kinect Fishing	OB (5)	Play on your own to successfully catch a fish from the lake. To engage with the game the players must imitate a fishing action and then move their hands to the left and right once they have caught the fish to prevent it from swimming away.
15. Nintendo Wii Motion	OB (6) DR (6) MO (6)	The Wii remote is sensitive to the finer motor actions in the player's wrist. The various games require the player to balance ice cream on their cones as it falls from the sky, or use the controller as a hammer to hit moles as they appear out of their holes.
16. Nintendo Wii Bowling	OB (6) MO (7)	Compete against one another in a game of bowling. The game differed from the Kinect version as it required you to undertake the bowling action in conjunction with pushing and releasing the appropriate buttons on the controller.
17. Nintendo Wii Balance Board	OB (8) DR (7) MO (7)	Standing on a balance board the players are required to shift their weight between their feet to engage with the game. The games included balancing on a tight rope, ski jumping, moving their character to head footballs and avoid hitting football boots and hula hooping.

18. Nintendo Wii, Beatles Rock band	OB (8)	Players could engage with the drums, guitar or sing. The aim was to push the appropriate button at the appropriate time when it appeared on screen. The actions were in time with well-known Beatles Songs.
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Key: OB= Old Boys, DR= Done Roaming, MO= Marching On

### 4.3 Reflections on working with the men

The following section provides my reflexive account of working with the men over the nine week period of the TI. The information has been taken from my reflexive field-notes and is complemented with information and feedback provided by the men.

### 4.3.1 Preliminary and early stages: Developing the initial relationships

The size of the group and the interests of the men participating influenced the relationship building process. The Done Roaming group consisted of men who were accustomed to one another (with the exception of Doug) from other groups they attended in their local rural area for people with dementia. Although there were instances of anger from Doug, which were directed towards the other men and threatened the cohesiveness of the group, in the main it was evident that the group had already surpassed the 'forming' stage (Tuckman 1965). This was notable by the manner in which they supported and gently poked fun at one other when they played games such as Golf (task 3) and in their willingness to discuss very personal yet obviously salient issues from the outset, such as Norman's prostate cancer or Phil's epilepsy. This contradicts academic research that suggests older men remain stoic and closed about their health concerns (Sloan et al, 2015; Tannenbaum & Frank, 2011) and supports suggestions that the impact of dementia may reduce the 'stiff upper lip' mentality of men thereby enabling them to open up more about emotionally difficult experiences (Capstick and Clegg, 2013). These conversations also highlighted the co-morbidity of health conditions that the men lived with in addition to dementia (Bunn et al, 2014).

In contrast however both the Old Boys and Marching On were typical of newly forming groups. Conversations during the introductory sessions were laboured and the men required a lot of prompting before speaking. In the case of the Old Boys the preliminary activities were useful in encouraging the men to divulge information about their lives and highlight commonalities such as their love of the sea and fishing. This in turn encouraged some of the quieter men such as Bill and Bob to open up more about their lives and this was facilitated by the friendly environment that developed very quickly over the first few sessions. For instance during the Game of Life (task 5), Bill began to engage in longer conversations, discussing his life at university studying physics and maths. Consequently he opted to take the education route on the board game. When he won the game the men applauded him and joked at having lost all of their money to him. Whilst he laughed along with them, his wife (the only care partner to stay and watch throughout the nine weeks) was joyous in his triumph.

These initial relationships were more difficult to establish with the Marching On group primarily due to the higher numbers of men and their varying interests. During the preliminary activities men began to disengage with the group as they were forced to wait for extended periods of time before taking their turn. For instance during the Game of Life (task 5), Jess fell asleep and Tel took numerous trips to the toilet (something I later found out he did when he was bored). These issues were exacerbated by the differing interests of some of the men as well as their negative attitudes towards other members in the group. For instance Harry lived in the outskirts of the rural location in a small, wealthy rural settlement. During the introductory talks he discussed his love of sailing and tennis and divulged that he once owned a boat and had tennis courts at his home. In response one man retorted 'oh very posh, I can't afford that' whilst another commented 'you couldn't find them (tennis courts) where I grew up.' These responses soured the atmosphere and shut down the conversations. On another occasion Chris offered to play the piano for the group. As he played some of the men scoffed at him and another exclaimed: 'I like most music but none of that rubbish (pointing to the piano).' Again, these comments restricted Chris's willingness to engage with the group and stifled the subsequent conversations. The tense atmosphere impacted on the support the men were willing to provide one another when engaging with the technology and made it difficult for me to engage in conversations for fear of the responses of others. Furthermore, other men were reluctant to engage in conversations with me (such as Dave, Peter and Colin) or were antagonistic when I spoke to them and this ensured it was difficult to bond with them. For instance when I asked Colin what name he would suggest for the group he exclaimed: "'shower of shit' cause that's what it is!" It is likely that these difficulties were partly due to my position as an 'outsider' researcher (Bryce, 2012; Corbyn Dwyer and Buckle, 2009) within the men's rural community. These experiences also emphasised the importance of acknowledging the socio-cultural positioning of the men (Hulko, 2009) and provided a steep learning curve for me to overcome.

The issues in the Marching On group were exacerbated by the reluctance of the volunteers to engage with the group. Unlike in the Old Boys and Done Roaming groups, Brian and Josh were keen to distance themselves from those with dementia both physically and conceptually. This was a surprise given their previous experience supporting groups for people with dementia in the rural location. Both volunteers sat away from the men when they entered the venue and made it clear during the group discussions that they were volunteers rather than men with dementia (unlike the other volunteers). They also required constant prompting to help with the refreshments. There is potential that Josh's previous personal involvement with dementia made him more aware of the stigma associated with the condition (McParland, 2014; Zeilig, 2014) and so keen to 'other' the men (McParland, 2014) and distance himself from the 'fourth age' (Gilleard and Higgs, 2015). Consequently, this resulted in a disjointed group atmosphere over the preliminary weeks of the Marching On group and I found it difficult to develop a relationship with many of the men. My unconscious abstention from referring to the group by their name was indicative of the lack of group cohesion during the preliminary weeks. Although I opted to change tact over the subsequent weeks (splitting the group into two to spend longer time on the

activities), it was only once five of the men (Tel, Dave, Peter, Chris and Harry) chose to leave the group that the period of 'storming' (Tuckman 1965) was resolved and I could begin to develop relationships with a smaller, more cohesive group of men.

#### 4.3.2 Middle sessions: Maintaining the relationships

During the middle sessions of the TI, the relationships between the men began to develop as the groups passed through the 'norming' and 'performing' (Tuckman 1965) phases of development. I noted the men became more cohesive and friendships began to develop in the groups. This was most apparent in the Marching On group where the preliminary sessions demonstrated a lack of initial cohesion. For instance Gordon and Simon would choose to play together in the golf (task 3) and bowling games (task 12) and Gordon would support Simon with his walking stick as he navigated the venue. The men also began to converse about the activities and games rather than watching in silence. Consequently, the atmosphere softened as indicated by the men's actions and comments whilst playing the games. For instance Jess and Gordon would make stretching motions to limber up before their turn on the bowling and Jess would comment on his female avatar, 'Oh she's got a lovely bum!' These instances suggested that the group had passed through the 'storming' phase (Tuckman 1965) and were slowly developing more cohesion. During this time, I began to refer to them by their name, suggesting I was also beginning to recognise them as a cohesive unit and starting to develop a stronger sense of connection with them.

During this period, men in all three groups contributed towards the development of their group and took a more active role. For instance in the Old Boys, Ken and his care partner brought in tins of biscuits for the group and David began to make the drinks whilst the equipment was being set-up. The volunteers also began to take a more active role in the groups (although Greg in Done Roaming was always very actively involved). Tom gave a presentation and practical demonstration on fishing (accompanied by photographs and films on the iPad) and Graham used Google Earth to give a talk on his planned trip to South America. Josh brought in his paintings to discuss with the men and Brian started to make the refreshments unprompted. This sense of group cohesion was important when the men were tasked with engaging with more complicated games as the positive, jovial atmosphere helped to make light of the difficulties they encountered; thereby enabling an emotionally safe atmosphere (Phinney et al, 2016). For instance, during Mario Kart (task 7), Joe struggled to successfully engage with the game, crashing into a bollard and racing the wrong way around the track. As he played he exclaimed 'Anyone want a lift home?!' This was greeted with huge amounts of laughter and helped to ease some of the awkwardness he may have been experiencing.

During this period the power dynamics between the researcher and the participants began to shift as expected within PAR research approaches (Chevalier and Buckle, 2013; Gaventa and Cornwall, 2008). On numerous occasions the men invited me to participate in the games and I facilitated this by pairing up with them. This encouraged them to comment on my performances and make jokes at my expense and I would actively encourage this. Other instances also

demonstrated this shift in the power dynamics. For example, Simon took me aside to discuss an intimate story of him and a woman on a Greek Island and Doug began to refer to me as 'mate.' This latter instance was particularly rewarding given some of the difficulties I encountered with Doug in the preliminary stages of the Done Roaming group. The dissipation of these power dynamics was beneficial for the relationships that I developed with the men (Dewing, 2008b; Murphy et al, 2015; Wilkinson, 2002) and led to more honest feedback. For instance, the Old Boys were more confident in providing feedback even if it might offend me; stating the balance board games (task 14) that included skiing and tight rope walking were too difficult, not a great deal of fun and possibly better suited for a younger audience. I noted that I now felt 'one of the lads' in all three groups and such data suggested that I was moving into a more 'insider' researcher position as discussed by Bryce (2012). This was important for the research process.

#### 4.3.3 Closing sessions: Closing the relationships

As advocated by other research (Hellstrom et al, 2007), I used the final two sessions of the TI to celebrate the positive contributions the men provided to the research process as well as highlight the groups' achievements and the relationships that had been developed; thereby facilitating the 'adjourning process' (Tuckman and Jensen, 1977). Photographs that had been taken by the men throughout the TI were displayed on the tables to support the feedback they provided as well as give a sense of closure. A particularly touching moment took place during the final group discussion with the Marching On group when the conversation ended and unprompted Gordon accompanied by the rest of the group began to sing 'We'll meet again, don't know where, don't know when...' This had been a particularly difficult group to manage and witnessing the group finish in this way provided me with a real sense of achievement, highlighting the rewards that working closely with people with dementia can bring the researcher.

Throughout this period I also worked with the men to develop a funding application for a local external funding body that could support the continuation of the initiative post-research. This formed part of the co-collaboration process of the PAR approach (Fenge et al, 2012). The men were encouraged to provide short quotes and choose photographs that could be used to publicise the research. All three of the funding applications were successful and this enabled the TI to continue within the rural locations post-research.

#### 4.3.4 Feedback on the delivery of the Technological Initiative

Feedback following the delivery of the TI also suggested that my approach in situating the men as co-collaborators (Fenge et al, 2012) and 'active contributors' (Bartlett and O'Connor, 2010) in the research process was beneficial to them and something that 'people I don't think are used to, especially that sort of age group and those with dementia' (Graham, Old Boys, volunteer, interview).

'You gave us a choice and it was so relaxing. You didn't say, you've got to do this or that. You gave us all a choice of, would you like to do this or would you like to do that? It was just a nice, relaxed atmosphere.' (Joe, Old Boys, Interview)

'Yeah what I like about this (the TI) and what I have always liked every day I have come to this is the fact that we move into a mould for that day which is 'what do you think boys?' and it is coming from you. 'Should we try this?' You're the leader in other words without being bossy.' (Phil, Done Roaming, Focus group)

As Maureen suggested, the approach helped Simon to take ownership of the club; contributing to his feeling of self-worth and subsequently his well-being.

'He thoroughly enjoyed it and every time you praised him or asked his opinion, he came away glowing! Really pleased he'd done so well with it. And he was always in a good mood afterwards and felt he had helped you with the club. He had big plans for it! (Maureen, Marching On, Care partner, interview)

Although my position of researcher and my expertise within the groups was acknowledged by the men, I was also perceived as *'a friend of the circle'* (David, Old Boys, Interview), thereby highlighting the position I occupied between an 'outsider' and 'insider' researcher (Bryce, 2012; Corbin Dwyer and Buckle, 2009). This enabled me to develop close relationships with the men through the research process.

'Your success is in the fact that really none of us are aware of you as being in charge or a tutor, which is so important. If you think you've got a governor then you'll be more wary. But you've been part of it.' (Doug, Done Roaming, Focus Group)

Jean, a care partner who stayed to watch the sessions, suggested that this approach was particularly important when working with men.

'And I think your personality is important, if you'd been bossy, it wouldn't have worked at all, because men don't take to being told what to do or bossed around, but the way you handled it was brilliant!' (Jean, Done Roaming, Interview)

Furthermore, the men and their care partners also suggested that removing the focus of the TI away from dementia was beneficial and different from some of the other groups that they might attend in the rural locations.

'I suppose because you know you've got a problem. But everything is alright yeah. It helps not focussing on the problem.' (Bill, Old Boys, Interview)

'Absolutely you don't focus on dementia and that is good. The atmosphere in the other one (group for people with dementia) is quite harrowing...So I would say that this is a bit of fun that relaxes you and you enjoy it, the other one is almost serious, serious medical

and so very quickly you get grr (make angry noise).' (Doug, Done Roaming, Focus group)

'I mean he enjoys it...he considered your one...well, no I shouldn't say this, he prefers yours because he feels better about going there, because he doesn't associate it as being part of the Dementia Club that kind of Club.' (Grace, Marching On, Interview)

This data demonstrates that my approach was welcomed by the men and was important for their sense of well-being and social inclusion. It was also an important factor in ensuring that I could develop a close and respectful relationship with the men; thereby enabling them to provide more open and honest feedback. This facilitated the data gathering process.

4.3.5 Summarising my achievements when running the Technological Initiative

Table 16 summarises my aims for each of the three phases of the group development and my reflections on whether they were achieved during this phase of the research.

Table 16: Summary of my achievements

Phase of TI	Aim	Old Boys	Done Roaming	Marching On
Preliminary and early sessions	Encourage members to become more accustomed to one another	<b>✓</b>	<b>✓</b>	×
	Establish a relaxed and comfortable environment	<b>√</b>	<b>√</b>	×
	Introduce the technologies	<b>√</b>	<b>√</b>	<b>√</b>
Middle sessions	Solidify friendships and group cohesion	<b>✓</b>	<b>✓</b>	<b>✓</b>
	Encourage the men to take an active role in the group	<b>✓</b>	✓	<b>√</b>
	Introduce more difficult games	<b>√</b>	<b>√</b>	<b>✓</b>
	Encourage more detailed feedback	<b>✓</b>	×	×
Closing sessions	Acknowledge the research was coming to a close	<b>✓</b>	<b>√</b>	<b>✓</b>
	Work towards enabling the groups to continue	<b>√</b>	<b>√</b>	<b>√</b>

### 4.4 Reflections on using the research methods

This final section discusses my reflections on the research methods that I used to gather data for the study. It focusses specifically on the use of Photovoice, the focus group discussions and

the walking interviews. Table 17 provides a summary of the research methods that each of the men participated in.

Table 17: Summary of the men participating in each research method

Group	Men	Research Method			
		Photovoice	Focus Group	Interview	
Old Boys	Keith	×	×	*	
	David	<b>√</b>	✓	<b>√</b>	
	Kenneth	×	<b>√</b>	<b>√</b>	
	Ken	×	<b>√</b>	*	
	Bill	×	*	<b>√</b>	
	Bob	×	✓	<b>√</b>	
Done Roaming	Phil	×	✓	<b>✓</b>	
	Doug	<b>√</b>	✓	<b>√</b>	
	Terry	×	×	✓	
	Norman	×	✓	<b>√</b>	
	Barry	*	*	<b>√</b>	
Marching On	Jess	<b>✓</b>	<b>√</b>	<b>✓</b>	
	Gordon	×	✓	<b>√</b>	
	Tel	×	×	<b>√</b>	
	Dick	*	✓	<b>√</b>	
	Colin	×	×	<b>√</b>	
	John H	×	<b>√</b>	<b>✓</b>	
	Harry	<b>✓</b>	×	<b>✓</b>	
	Chris	<b>√</b>	×	<b>√</b>	
	Simon	×	<b>√</b>	<b>✓</b>	
	Dave	×	×	<b>✓</b>	
	Peter	×	*	*	

The table demonstrates that not all of the men participated in all of the research methods. As Keith left the TI after session one due to health issues he did not participate in any of the research methods. The interviews were the most popular method with 19 men choosing to take part in them. 'Photovoice' was the least popular method as only five men elected to participate. A more detailed reflection on the research methods is provided below.

#### 4.4.1 Photovoice

Initially I aimed to use Photovoice as a process to encourage the men to take an active role in the collection of data as advocated by the PAR approach. Unfortunately during the introduction of the method I found that many of the men were unwilling to engage with it. I noted that they appeared apprehensive of using the camera and were unsure what was required of them. This was particularly the case with Chris and Harry in the Marching On group. Consequently to maintain a 'moral sensitivity' (Heggestad et al, 2013) to the men I opted against encouraging them all to participate. Fortunately in each group there was one man who was comfortable using the camera and willing to take photographs on behalf of the group. These were David (Old Boys), Doug (Done Roaming) and Jess (Marching On). All three of the men were accustomed to using cameras as part of their previous occupations and/or interests. David had been an engineer and regularly took photographs of the structures he designed and built. Doug used a camera to document his work when restoring classic cars and Jess regularly took photographs as part of his daily routine to aid with memory recall at the end of the day. Therefore the research method sat well with the interests of the men and as such they embraced the task. The Photovoice approach was particularly useful for Doug as it enabled him to remain a part of the group on the occasions he did not wish to participate in the activities with the other men. This highlights the importance of adopting a flexible research approach (Kemmis, 2009; Robson, 2011) and ensuring that the methods are suitable for the participants (Murphy et al, 2015).

Although the men provided limited feedback on the photographs they took, they were useful in using as prompts during the final focus group discussions and interviews. A similar process of photo elicitation was used by Phinney et al (2016) to enable more detailed discussions with people with younger on-set dementia in their community-based activity group. The photographs taken by David, Doug and Jess were also used at the end of the research as evidence when applying for funding to continue with the groups. As part of the co-collaboration process (Fenge et al, 2012) the men were encouraged to select the photographs they felt best reflected the group and these were provided as supporting documentation for the funding request.

#### 4.4.2 Focus groups

The focus groups were conducted as part of the final session of the TI and were a successful method of enabling the men to provide feedback. Unfortunately some of the men were unable to attend this session and so this feedback was sought from them during the interviews. All of the focus group discussions lasted for longer than an hour and the men were comfortable discussing the research. The photographs were particularly useful as prompts for the

discussions. I noted that all of the men were willing to contribute to the discussions and were respectful of one another; allowing each other time to speak and express their opinions. This was particularly important for men such as Bob, Ken (Old Boys) and Gordon (Marching On) who sometimes struggled with their words and was indicative of the close relationships they had developed during the nine week initiative.

#### 4.4.3 Interviews

Face-to-face interviews were conducted with the men with dementia, their care partners and the volunteers immediately post the TI in a three week period during November and December 2014. The only exceptions were when the men chose to leave the group and then the interview was conducted soon after this decision, provided they agreed to participate. Only two of the men elected not to undertake an interview. Ken was unable to as immediately post the TI he became ill and was hospitalised and Peter declined as he felt it was not for him. This latter instance was indicative of the difficulties I had faced during the TI to develop a relationship with Peter before he left (after session four).

Although I initially anticipated undertaking 'walking interviews' with the men, unfortunately the majority of men opted against them citing their unappealing nature due to the cold winter weather and/or difficulties walking unaided in the rural environment. As such, to be 'morally sensitive' (Heggestad et al, 2013) to the men, the method was flexibly adapted and most of the interviews with the exception of two were conducted in the men's homes.

Two of the men (Bill and Chris) decided to participate in the walking interviews and these approaches were successful in enhancing our discussions. The walking interview sat well with Bill's evening routine when he would walk independently around his rural area and so he was happy to participate. The interview encouraged Bill to talk about his rural environment and I noted he was more willing to initiate conversations than when we had sat talking in his home. The interview with Chris was conducted as we walked around his expansive garden. Chris was an avid gardener and so the interview enabled him to show-off his gardening prowess and the beautiful array of flowers and plants that he had cultivated. Both of these interviews were very open and whilst I did not stick specifically to a script, I was able to glean valuable information from the men regarding their daily lives within their rural environment.

For the majority of interviews the men chose to conduct them in their living room or for Doug in his 'Man Cave.' All of the men welcomed me into their home and provided me with biscuits and drinks (John and Angela cooked a full lunch for me) and some offered to give me a tour. This was indicative of the positive relationships I had developed with the men and supported my decision to undertake the interviews at the end of the TI. All the interviews lasted from between 45-100 minutes and appeared to be an enjoyable experience for the men. For instance Bob commented:

'I thought that was quite good actually. I enjoyed chatting. I don't very often do it. I'm usually on my own! (laugh)' (Bob, Old Boys, Interview)

Five men also chose to have their care partner present as they spoke about their lives, although I encouraged them not to participate. In the majority of cases this did not seem to impact on the interview experience although I did note that in the presence of his care partner Joe changed his view from advocating male-only environments (stated during the focus group discussions).

'I never think of what people look like. You know, if I get on with them and they talk to me okay, I respect them, you know. Whether it's a man or a woman, it doesn't matter. I would go (to the TI) whether it was men or women, you know.' (Joe, Old Boys, Interview)

On other occasions I noted that having care partners present during the interviews appeared to be an enlightening experience for them. For instance during Terry's interview he spoke using a boxing metaphor to describe his experiences of living with dementia and the need for 'a good second in your corner, when you're fighting him (dementia)' (Terry, Done Roaming, Interview). Upon conclusion of the interview his wife, Jean commented:

'I've never heard you speak like that before. It was quite eye opening. I'm amazed!' (Jean, Location Two, Interview)

Similar to research by Wiersma et al (2016), this highlights the potential benefits and challenges associated with having care partners present in discussions with people about their experiences of living with dementia.

# 4.4.4 Post-TI: Reviewing the findings with the men

Consistent with the PAR approach I sought to deliver the findings back to the men to ensure they accurately reflected their views. This was undertaken ten months post the conclusion of the TI and was due to take place as part of the groups that continued to run within the rural areas. To ensure this was carried out in an accessible manner, I produced a simplified short report detailing the findings and sent it to the men two weeks prior to the planned meeting. I encouraged them to read the report and provided them space to note down their thoughts and opinions of the preliminary findings. I asked them to bring the report along to the meeting so that we could discuss the findings together.

Unfortunately in contacting the three locations I was informed that although the Old Boys and Marching On continued to run it was no longer attended by any of the men who participated in the study. Furthermore, two of the men in the Old Boys had been placed in a care home, another two had elected to leave the rural locations to be closer to family members and in the Marching On group two of the men had died. Consequently, I sought feedback from the remaining men in the Old Boys and Marching On via post but unfortunately none of them responded to my request. This highlights the difficulties in conducting longitudinal research with older people with deteriorating health conditions.

Furthermore, whilst the Done Roaming group had continued for a few months post TI, it was forced to stop when Greg (the volunteer) moved away from the rural location and another volunteer could not be found to support its delivery. Fortunately however I was able to deliver a feedback session at the same venue used for the TI and three of the men attended (Phil, Terry and Norman). During the discussions the men struggled to remember the TI and were therefore reluctant to provide any feedback, suggesting only that 'we had a really good time' (Phil). Consequently, I chose to focus the feedback discussions on the aspects of the rural location. I noted during these discussions that:

'The men appeared to agree with everything I found. Although I was giving them the option to challenge the findings they chose not to. This may be because they felt they accurately reflected their views but could be because they didn't want to offend me.' (RFN, Done Roaming, Post-Analysis feedback session)

One interesting point of note however involved Terry. As I fed back some of the difficulties that faced the men in their rural location, Terry commented:

'I never get bored. How can I...I'm alive.' (RFN, Done Roaming, Post-Analysis feedback session)

This was particularly interesting given that in his individual interview, Terry talked for sustained periods of the boredom he sometimes felt at home and how this caused him to sleep more often than he used to. Delivering the feedback within a group environment potentially hindered the feedback process as men such as Terry may have been keen to maintain a stoic and strong masculine image of themselves in front of other men. This is consistent with Genoe and Singleton (2006) who posit that masculinity is portrayed for the benefit of other men. This highlights the impact that the group environment may have on the responses of the men and has implications for the delivery of feedback to older men with dementia; particularly if it has the potential to threaten their masculinities.

# 4.5 Summary

In this chapter I have provided an overview of the men and the volunteers who participated in my study as well as presented a reflexive account of my role working with the men during the research process. I had a range of successes achieving my aims (particularly with the Old Boys) over the nine week period of the TI and I was able to develop a strong relationship with many of the men. This enabled me to transition from a position of 'outside' researcher to 'inside' researcher and consistent with other research (Bryce, 2012; Corbyn Dwyer and Buckle, 2009) this ensured I was trusted by the men and so received detailed and honest feedback from them. This research process also highlighted the importance of promoting the social inclusion of the men by positioning them as active contributors rather than passive recipients (Bartlett and O'Connor, 2010). This may be particularly beneficial when working with older men with dementia whose masculine identities can be shaped by characteristics such as autonomy and independence (Kilmartin, 2000; Kimmel, 1996). These ideas will be revisited in Chapter 7.

Furthermore, whilst my planned research methods weren't always successful, I was able to use them flexibly and in a morally sensitive manner (Heggestad et al, 2013) to gather the required data. The feedback sessions post-TI emphasised the difficulties of conducting longitudinal research with older people with dementia and highlighted important implications for delivering group feedback to older men with dementia, particularly if it poses threats to their masculinities. In the next chapter I will discuss the rural locations drawing on the perspectives of the men as well as the care partners, the volunteers and my own.

### **Chapter 5: Introducing the rural locations**

#### 5.1 Introduction

This chapter details the three rural locations chosen to host the Technological Initiative (TI). It provides an overview of each of the locations and venues drawing from my reflexive field-notes. Following this, it explores the men's perceptions of living with dementia within their rural environment, ascertained from the thematic analysis. This information is supplemented with data provided by the care partners and volunteers as secondary informants. These experiential accounts provide a social construction of the rural environments (Hennessey et al, 2014) and are important for enabling a deeper understanding of the research locations (Becker, 1998) as well as contextualising the perceived impact of community initiatives for people with dementia (Phinney and Moody, 2011), as will be discussed in Chapter 6.

#### 5.2 Perceptions of the rural locations and the venues

The following section provides a reflexive account of my perceptions of the rural locations and the venues chosen to host the TI.

### 5.2.1 Location One: The Old Boys

The demographic data presented in Section 3.4.1 are indicative of a poor, declining rural community and this was confirmed during my numerous visits whilst advertising and setting up the TI. I felt the rural area reflected a 'bypassed' (Keating et al, 2013) community and this was reinforced by the Memory Support Worker (Nicola) when she described how the high-street had once 'buzzed' yet over time the shops were closed and turned into flats or left abandoned as the resources were re-directed to other nearby more attractive villages. The rural population were now forced to take the bus into the main urban settlement to buy their shopping or visit essential amenities. This ran every 30 minutes unless the main road was flooded and then the island where the Old Boys resided became disconnected from the mainland. As the shops closed so did the other services and consequently people were left with very few activities to undertake in the village. This was particularly the case for older people and those with dementia who had access to a day centre or a 'Singing for the Brain' group that ran sporadically but was witnessing a decline in numbers. Speaking to the Activity Co-Ordinator running this latter group she felt the low numbers were a consequence of the stigma attached to attending the group coupled with the limited resources they had to promote the group around the village and neighbouring areas. She noted that they used to run the group weekly but had now opted for fortnightly because of the attendance rates.

Despite the noticeable poverty in the area, consistent with concepts of 'bypassed' communities (Keating et al, 2013), I also noted the friendly, close-knit and supportive nature of the residents. As I walked with Nicola she stopped on numerous occasions to speak with passers-by and introduce the 'exotic' foreigner from Brighton who was coming to set up 'some research' in their village. During our journey we met Nicola's mum and they both discussed how their family had lived in the village for numerous generations. As highlighted in section 2.4.4 this close-knit culture or "community embeddedness" (Lauder et al, 2006) could potentially be beneficial for the social inclusion of people with dementia by alleviating issues associated with a lack of

formal services. However on leaving the village for the first time, I reflected that I was very apprehensive about whether the TI would be a success or whether attendance would be limited.

I chose to host the TI in the only suitable venue within the rural location. This was a community hall attached to the local church. It was situated in the centre of the village and hosted other meetings within the community such as Cubs and Scouts. As such it was well equipped with a large television, wifi, kitchen and projector. Feedback from the men during our discussions suggested that the venue selected was suitable for the research and added to the appeal of the TI.

'No, I think it was a good venue actually. It is a nice hall, nice surroundings, as much as tea as you want, as many biscuits as you want.' (Joe, Old Boys, Focus Group)

### 5.2.2 Location Two: Done Roaming

This is an historic market town situated close to a large urban settlement. As I walked around the town publicising my research I noticed a more affluent feel to the place when compared to Location One. I was later made aware that recently a number of luxurious houses had been built in the area but never publicised in the local estate agents. Instead they were advertised in London as second homes for wealthy city workers. Speaking to some of the residents it was clear that they were less than enamoured by these propositions and felt that part of their community was being dismantled for a 'tidy profit'. This resonates with research on the 'bucolic' communities (Keating et al, 2013) that highlights the changing rural landscapes and communities as wealthy city dwellers are attracted to the 'Rural Idyll' (Cloke and Milbourne, 1992). As I wandered through the town centre, I noted the numerous churches and meandering canal. Although there was no pedestrianized areas (due to a main road running through the town centre) in the town centre there were typical high street stores and supermarkets interspersed with local butchers, coffee shops and other random gift shops. This was noticeably very different to Location One.

On the advice of a Memory Support Worker I chose to host the TI in an old church that was now used as a community café. The building overlooked the canal and greeted visitors with a beautiful glass door. Inside there was a large communal area, with wooden floors, lofty church ceilings and high windows that gave the space a bright and airy feel. The room had a community vibe to it with numerous posters littering the walls advertising local events and volunteering opportunities around the community. Speaking to the café owner, she agreed to open the café earlier one day a week for the sole purpose of running the groups and even agreed to hand bake us cakes. I was ecstatic at how relatively straight forward it had been to secure such a beautiful venue in the middle of the community and the enthusiastic buy-in of the local café owner. I wondered whether this may have been a consequence of some residents feeling they were losing a part of their community spirit and so gratefully welcoming initiatives that looked to solidify this spirit and support local residents, even if it was proposed by 'an outsider' (Becker, 1998; Corbin Dwyer and Buckle, 2009).

Feedback from the men suggested the venue was well received although the light that entered the building through the large church windows could make it difficult for Barry to see the television screen on occasions. This often resulted in comedy 'to me- to you' routines at the start of each session as we worked together to find the optimum spot for the television.

'It was nice. It was very, very comfortable and very pleasant surroundings I thought. The acoustics weren't terribly good and the sunshine was a bit of a pain, but other than that it was good.' (Doug, Done Roaming, Focus Group)

### 5.2.3 Location Three: Marching On

Location Three is a town that is relatively disconnected from any other major urban conurbations. As I drove towards the location for the first time, traversing the narrow countryside roads, I noted the remote and beautiful nature of the surrounding landscape, interspersed with small settlements consisting of luxurious country manners and rustic cottages. Upon entering the town, I felt an 'oldie worlde' presence, with narrow cobbled streets leading to a large open, pedestrianised town centre, where once a week a market was set up to cater for the local residents. This clearly wealthy quintessential English town reminded me of my home town in Lincolnshire and I was instantly drawn to it. In the town centre, accompanying the grand Town Hall were quaint charity shops and independent coffee houses as well as pubs, all located alongside typical high street stores. As I spoke to various shop keepers and residents, I noted that they were all enthusiastic about my research and were keen to help. They were clearly used to tourists and did not seem in the least bit suspicious about my intentions. The local Day Centre was also keen to be involved (something that had not occurred in either of the other two locations) and agreed to accompany some of their men along to the group if they desired. In addition to this, the local newspaper contacted me to find out more about the project and advertise it. I was amazed at how receptive people were to the research I was planning and this left me in a positive spirit prior to embarking on the study.

I chose to host the TI in an old Freemasons building that was situated in the middle of the community. Although other venues were available they were either too expensive for my limited budget or were situated on the outskirts of the rural location. Although the building had no outdoor light entering in (the windows had been bricked up for sound proofing) it was very spacious and contained all the required resources. It also had a small bar at the back of the venue as well as a piano at the front. I felt that the presence of the bar may help the men to relax as it could be reminiscent of their younger days. Feedback from the men generally suggested they enjoyed the venue although some of the care partners did comment that it was a 'convenient location' but a little 'dreary' (Sue, Marching On, Interview) and this had prevented them from staying to watch the activities.

'I think the venue is actually excellent because it gives a feeling of being in a club or a pub really. I like the bar in the corner.' (Simon, Marching On, Focus Group)

# 5.3 Daily living within the rural locations

This section explores the men's perceptions of living within the rural locations. This data has been obtained from the thematic analysis. The information provided by the men has been triangulated with that ascertained from their care partners, the volunteers and my reflexive field-notes to offer further insights. Differences elicited between the three rural areas during cross-case analysis have been reported where appropriate.

## 5.3.1 Cracking on with life in a 'Rural Idyll'

In the main, the men spoke of living well in their rural environment and many perceived a diagnosis of dementia had made little noticeable difference to their lives. Harry's response was typical of the majority of men who stoically spoke about continuing to 'crack on with life' (Harry, Marching On, Interview) or 'making the most of your life' (David, Old Boys, Interview) despite a diagnosis of dementia.

'Well it's (dementia) there so you just crack on with it. Got to crack on, there's no question...You may forget things every now and again...Yes that happens from time to time. But I always think whatever you do keep going. The whole thing is keep going. Whatever it is yesterday, leave it, forget it, it's done. Keep going up.' (Harry, Marching On, interview)

'It can be depressing...because of course it's a known fact that it's a no win, it's irreparable at the moment. There's no cure...but there is no need to worry because when your number's up, it's up. So just enjoy life while you've got it, the best you can. So that's it.' (Phil, Done Roaming, Interview)

These stoic responses resonate well with the concept of the 'stiff upper lip' (Capstick and Clegg, 2013) and may be somewhat expected in rural-dwelling older men (Levant and Habben, 2003).

For men such as Terry, whilst he acknowledged that dementia had detrimentally impacted on aspects of his life, he spoke eloquently of how he would not relinquish hope and would continue to fight it.

'It's a battle that you can't bloody well win, but you've still got to keep fighting. That's the nasty bit about it. You're on a loser. First time in my life I've been on a loser...I don't know why nature dealt it out. She don't need it as a weapon. She don't need Alzheimer's Disease, and she's got it and she uses it. But that's life and you got to keep fighting it.' (Terry, Done Roaming, Interview)

This is reminiscent of the 'fighting spirit' that Clare (2002, 2008) refers to when exploring the perceived impact of a diagnosis of dementia on a person's identity.

Only Doug discussed difficulties coming to terms with his diagnosis of dementia and on occasions it could be harrowing listening to him speak as he described his sense of loss and the 'burden' he perceived he placed on his wife.

"...But you can't believe all the things you took for granted have just evaporated. And no doubt about it...but I feel sorry myself because I never expect it would happen to me...I really don't know, sometimes I walk up on the moor and I think if only I could just fall on my face, the kids would stop fretting about it, Alison would get a better life and I'm out of it. Because it's taking...my life...it was all around activity and sport and running motorcycles and swimming, in one swoop you've lost it all without complaint.' (Doug, Done Roaming, Interview)

As Doug had recently been diagnosed with dementia, it is likely that he was still in a period of adjustment unlike most of the other men that participated in the TI.

When describing their rural environment, many of the men drew from the narrative of the 'Rural Idyll' (Cloke and Milbourne 1992), focussing on the natural, pleasant rural environment and the friendly, supportive informal networks to highlight the positive facets of their rural location. These themes were present across all three rural locations and enabled the men a familiar and safe environment where they could live positively.

### • The pleasant rural environment

Across all three locations the men indicated that they enjoyed the remote and pleasant surroundings of the rural settings and the tranquillity that accompanied this.

'It's quiet. Most of the time it's quiet. We don't have a bloody great road coming through the place and it's still a bit of an old fashioned place.' (Chris, Marching On, Interview)

'It's got more life. It's...when I look out there there's a herd of deer out there feeding, and looking at me, just the other side of the fence...this is the life... All the birds, we get a terrific variety of birds, and the open space. I like that big wide open space out there.' (Terry, Done Roaming, Interview)

In Location One, the sea was a particular attraction for men such as Bob who used to be a professional diver and would still regularly go swimming when the weather was warm enough.

These pleasant rural surroundings encouraged the men to go out for walks and consistent with information ascertained through the preliminary questionnaires (Section 4.1), for many this was a favourite activity they spoke of engaging in with their care partner. This activity enabled them to leave the house, to positively interact with the local rural environment and provided them an opportunity for gentle physical exercise.

'Well you can just walk out the house down the road or up over the hills. You don't have to be confined to roads... You can go up just climb over gates and go into the countryside.' (David, Old Boys, Interview)

Bob, Bill and Doug discussed going for walks independently of their care partner as they enjoyed the chance to spend time alone. As these were familiar and relatively confined settings

for the men they were able to confidently navigate around with ease. This provided a sense of comfort to both them and their care partners who were happy for the men to walk unaccompanied through the rural environment. These periods of independence were important for their mood, as highlighted by Doug, who felt the activity helped to lift his spirits when he was despondent about having dementia.

'Sometimes I say for god's sake...you're nearly 90 and you're still active and you can still get about. Snap out of it!...So I go for a walk; I sometimes go for a walk three times a day.' (Doug, Done Roaming, Interview)

This finding echoes other literature that demonstrates the potentially therapeutic benefit of the outdoor environment and natural landscapes for people with dementia (Gilliard and Marshall, 2012; Mapes and Hines, 2011). The familiarity of the rural location also provided the men and their care partners a sense of security, thus enhancing its appeal and their sense of social inclusion.

### Supportive informal networks

Informal networks are those that provide unpaid support and care for the men during their daily rural lives. The majority of men reported that this informal support was provided by their wives who were their primary care partners, and consequently the men came to rely on them or 'worship' (Barry, Done Roaming, Interview) them. They afforded the men practical support such as driving them to attend activities in the rural location and surrounding areas, as well as emotional support during times when they experienced anger, frustration, and despondency. As Bob highlighted:

'I get ratty sometimes...but Caroline's the one that keeps everything right...She's the best support I could've had.' (Bob, Old Boys, Interview)

Some care partners also highlighted the lengths they went to so as to ensure the men could retain some sense of agency, particularly whilst they were at home. For instance Sheila would support Joe with the maintenance accounts for the housing block where they lived. This meant he could retain his role as housing secretary. Joan and Norman discussed their night time routine where Norman would go up to the bedroom first to ensure the electric blanket was turned on before they both retired to bed. These activities provided the men with a role and sense of purpose around their homes and as suggested by other research (Cook, 2008), this was important for their social inclusion. As the men's physical and mental conditions deteriorated, these care partners highlighted how difficult and frustrating it could be to support the men's agency yet understood the value of doing so. As Angela stated:

"...and the only trouble is I sometimes find that because you have to tell John so many times to do something it's easier to do it yourself, but that's not the point and I have to stop and say, no, let John do it; otherwise it makes him feel useless...by helping him you're not helping him, do you understand?' (Angela, Marching On, Interview)

Ensuring people with dementia retain a sense of agency is important for their self-worth and social inclusion (Bartlett and O'Connor, 2010; Cantley and Bowes, 2004; Cook, 2008) and may be particularly beneficial for older men who are keen to retain traditional hegemonic masculine characteristics such as autonomy and independence (Kilmartin, 2000; Kimmel, 1994).

Contrary to many of the other men, Bob and Caroline discussed having the majority of their large family still living within Location One. They would often provide informal support and during the summer months the large family barbeques that were held by their beach huts were a major source of enjoyment for Bob.

Caroline: '...Sometimes there are twenty five of us eating down there (at the beach huts). All the children. We do proper food.

Bob: 'Yeah they're great, usually! (laugh) We see them quite a bit.' (Bob, Old Boys, Interview)

This resonates with the concept of a 'bypassed' rural community where strong family networks can persist and provide important sources of informal support (Keating et al, 2013). These were beneficial for ensuring Bob's sense of social inclusion.

The data also demonstrated that the friendly and supportive close-knit networks worked in tandem with the pleasant rural landscape to provide an appealing environment.

'Well it's a nice area, nice people. Things can chop and change normally but it's always very nice to be in this kind of area.' (David, Old Boys, Interview)

'But it's quite nice living around here, and as I say everybody's very, very nice. I mean I think I'm quite nice and tidy to them anyway, but you've got this nice, friendly feeling so it's alright.' (Jess, Marching On, Interview)

These informal support networks were appreciated by the men and their care partners and ensured they felt safe and were enabled to engage in various social and cultural activities within the rural location. This was particularly the case when the men were known to people in their area prior to their diagnosis 'because they know the person you were...and it's quite hard to get to know the person you may become' (Caroline, Old Boys, Interview). For instance, David spoke of playing golf with his wife, Anita and some of the local residents and then going for drinks in the pub afterwards. This was something he enjoyed and was a major part of his rural life. Both he and Anita were appreciative of people for continuing to include them in these activities. Caroline also discussed how Bob had lived his whole life in Location One and was well respected among the community. People would cut their lawn and taxi drivers would offer them free rides. She therefore felt safe when Bob was out independently in the rural location as she knew he would be supported.

"...and so he goes for a little walk, people chat to him, maybe give him a cup of tea or something, and he can do that independently, because everyone knows him...! know

that sometimes people will say to him,' where's Caroline?' He says,' I don't know,' and they say,' well come and have a cup of tea and wait for her,' which is quite nice. And, they'll talk about when he was young...and if he goes on the beach they will check that he hasn't left anything behind. It just makes it easier doesn't it?' (Caroline, Old Boys, Interview)

For Jess, who lived alone since the death of his wife and had no family close-by, these close-knit informal rural support networks were essential in ensuring he could live well independently and was able to socially participate within the area. His friends and ex-work colleagues whom he had lived near for many years would often drop in to see him or transport him to various activities when he was unable to drive himself. These informal rural support networks continued to ensure he remained socially connected within his rural environment despite dwindling familial networks; thereby alleviating some of the threat of social isolation.

The informal rural networks also supported Harry to remain economically active and hence socially included within his rural environment. Veronica described how a resident in the area provided Harry with a job as a delivery driver when he was first diagnosed with dementia and opted to no longer continue with his current employment. This work ensured he could remain economically active and so maintain 'material' (Ward, 2009) facets of social inclusion as well as ensure he was socially connected within the rural area. This was beneficial for his well-being and sense of self-worth.

'By then...he gave that up (job) and then he did parcel deliveries for one of the lorry drivers...one became a friend and he used to meet my husband in a little van and he load all his parcels into the van – do you remember that darling? And then he (Harry) used to do all the funny, little villages that the big lorries found difficult, it was a huge plus for (my friend the driver) and also it was the most fantastic thing for him because he had to remember where everybody was, and once he'd been there and done it, of course then he knew. They all knew him and he used to do the same people practically every day and that was really good for him.' (Veronica, Marching On, Interview)

This finding resonates with research that highlights the benefits of informal rural networks for ensuring people with dementia can remain socially included (Blackstock et al, 2006; Forbes et al, 2011; Innes et al, 2011), particularly if they have been known to them prior to their diagnosis of dementia (Innes et al 2005); as was the case with all the men except John.

Interestingly, Bob and Phil and their care partners suggested they preferred living in a rural environment against an urban one due to the strong informal rural support networks that they perceived as lacking in an urban area. Although Phil and Maggie had only moved to the area 12 years previous (as opposed to Bob who had lived in the area his whole life) they still demonstrated a sense of connection to the place.

'I think the community itself is brilliant in every way, we are lucky to live where we do, if we lived in the centre of Birmingham we'd probably wouldn't have the support we have here, but I think it's good we know the people who were there, so that when you walk in you see familiar faces.... I said to my kids if you get dementia move to a small community. It's the best place.' (Maggie, Done Roaming, Interview)

This was also a current topic of debate for David and Anita. Although their daughter was encouraging them to move closer to her in the city, they were hesitant to do so as they felt they would miss the informal support they received from the rural community. This finding is consistent with Blackstock et al (2006) who suggest their participants in rural Scotland drew on the rural/urban binary; believing their experiences of living with dementia would be inferior in an urban environment.

The data ascertained from the men and their care partners suggested that rural living was perceived positively. The benefits focused primarily on the pleasant and familiar rural environment and the informal support that they received from within the communities. These worked independently and in tandem to provide the men with a sense of security and opportunities to positively engage socially (and on occasions economically) within the rural communities. They also enabled a few of the men to maintain a level of independence and agency, which is likely to be important for their sense of masculinity.

However, during discussions it also became apparent that the 'Rural Idyll' (Cloke and Milbourne, 1992) was an incomplete account and certain aspects of the rural environment also provided challenges for the social inclusion of the men and their care partners.

## 5.3.2 Challenging the 'Rural Idyll'

Although the men and the care partners predominantly reported the positive aspects of living within their rural area, they also highlighted challenges they faced. This suggests that similar to both Blackstock et al (2006) and Forbes et al (2011), the research participants were not 'romanticists' and were able to perceive the difficulties they encountered. These focussed on the limited structured activities available, the lack of dementia awareness in the rural locations and the difficulties they faced to overcome the physical barriers of rural living and the emotional struggles of dementia. Each of these aspects will be discussed in turn.

#### Lack of structured activities

This refers to services and activities that are specifically designed for people with dementia. They are delivered by trained professionals who have knowledge and understanding of working with people with dementia. The lack of structured activities or material (Ward, 2009) opportunities for social connection was most pertinent in Location One where the only service was a Day Centre. This was attributed to a lack of funding within the area. As Caroline stated:

'Yeah there isn't a huge amount on in (Location One), it's quite deprived isn't it?' (Caroline, Old Boys, Interview)

The situation was more positive in the other two locations, with men and their care partners citing structured activities such as Day Centres, Coffee mornings, Melodies for Memories/Singing for the Brain, care farms and lunch clubs. Predominantly the men and their care partners accessed these services and they provided a welcome break within their day-to-day routines. However there were suggestions in both locations that fiscal constraints were detrimentally impacting on the services offered. Brian, a volunteer living in Location Three who also supported a Memory Café in the area, suggested that limited resources had resulted in fewer trained support staff in the area who were burdened by high workloads. Consequently, over time this had detrimentally impacted on the Memory Café's links with the local healthcare providers, who no longer had the time to visit the group to offer their trained support or gain an understanding of the service so they could refer people to it. He spoke of his concern that over time this had the potential to lead to a reduction in the numbers of people with dementia using the formal services as well as the quality of the service provided.

"...when we started (Memory Cafe) we did get some of them (trained support workers) coming along and they would refer or bring along people who they felt it would be useful to. But I think money restrictions and the lack of staff, I get the feeling that that sort of stops...because we never see any of the Mental Health team attending the cafes now...don't see anybody from Alzheimer's...but I think probably the same reasons sort of staff restrictions, they're thinner on the ground than they used to be.' (Brian, Marching On, Interview)

Even when there were structured activities available in the rural location, the men did not necessarily access them. On occasions they chose not to engage due to a range of factors including: the people running or participating in them; the approach used during the activities; or the activities on offer.

'Well, you sit in two long rows and you have three balls to roll along and try to get some score. And then they take you into the library afterwards and they ask questions which might require an answer. It doesn't do much for me. Plus the fact there's a guy there that fancies himself as the ironman, he insists I feel his biceps and he puts his fist right in my face and tells me what he's going to do.' (Doug, Done Roaming, Interview)

I: Why didn't you like that one (music group)? What was it about it that you didn't like?

Phil: the music. Not my sort of music. My old man's a dustman and all that. (Phil, Done Roaming, Interview)

This demonstrates the men's position as 'active social agents' (Bartlett and O'Connor, 2010; Bell, 2004) who decided to engage in activities within the rural environment only if they appealed to them. This highlights the importance of implementing structured activities that will appeal to the men and so ensure their social participation.

Where there was a lack of structured activities (particularly in Location One), the men were reliant on this being off-set by the unstructured day to day interactions and activities. Whilst in the warmer summer months this did not appear to be a problem as the men could take day trips out with their care partners or as David discussed, play golf with their friends, this became more difficult in the winter months. During this time, the cold inclement weather meant that the men rarely ventured outside and this could detrimentally impact their mood.

'Well, if there was something else going on, or if it was a nice day and he could have a little walk, it would probably keep going (his good mood). The problem is he's been very...active and now, on the days when the weather is not all that nice, he just sits, and that's just horrible for his mood.' (Caroline, Old Boys, Interview)

During these periods, the men's care partners were placed under a lot of pressure to provide mental, physical or social stimulation for the men. As Caroline exclaimed:

'I get desperate to think what can he do, and you kind of run out of things that you can do.' (Caroline, Old Boys, interview)

As a result of these limited activities (despite the best efforts of their care partners) and opportunities for social interaction with people other than their care partner, men spoke about sleeping a lot, 'mainly due to boredom' (Terry, Done Roaming, Interview).

The key findings emerging from the data suggest that although there were structured social activities particularly in Locations Two and Three, they were facing challenges to sustain themselves due to funding restrictions and a lack of awareness from healthcare professionals. In addition to this, those on offer did not always appeal to the men and so they chose not to attend. A lack of appealing structured activities (particularly in Location One) could be detrimental to the men's well-being and efforts to socially connect with their rural environment, thereby restricting their social inclusion. This was particularly evident in the winter months when opportunities for the men to participate in their favoured outdoor social activities such as swimming and walking were limited.

## Barriers of rural living

The men also spoke of difficulties they faced when navigating the rural landscape and accessing activities that they once enjoyed and were central to their masculinities. This was particularly evident as they aged and their physical capabilities and health deteriorated. For instance, during informal discussions, Keith spoke of difficulties he experienced accessing services and social opportunities within the rural environment due to his mobility issues. He was dependent on his wheelchair to move around but as Location One was situated on a hilly terrain this made it difficult to navigate and access buildings. Joe also discussed how the on-set of diabetes had impeded his ability to walk and negotiate the stairs in his tower block. Consequently he spent most of the time in his flat, thereby socially isolating himself from the rural community. Other men also discussed activities and interests that they used to enjoy

participating in within their rural environment but felt they could no longer do due to the adverse impact of ageing and/or dementia. Even when the men were physically able to access the rural environments, on occasions they opted not to as they no longer felt the desire or motivation to do so. This sense of apathy could be partly attributed to the difficulties they faced living with dementia.

'I've found my motivation has deteriorated a lot. Like I used to want to get on...but I can't do it...it's because you're getting older and therefore your joints don't work so well. That's one thing, and that bugs you. But the other is of course that...you've got to have that real get up and go to get on with it, and at the moment I just don't feel like that. (Phil, Done Roaming, Interview)

Terry also acknowledged how his lust for life had deteriorated since his diagnosis, stating how he had lived two lives; the first was prior to dementia and the second he was currently living.

'I suppose the capacity for life has changed. It's got a lot smaller. Yeah the capacity for life is a lot smaller...Things were bigger before, more things going on. Life was bigger...And a lot more humorous (before dementia). Was in my first life.' (Terry, Done Roaming, Interview)

This finding resonates with other academic literature that reports on the sense of apathy that accompanies dementia (Manera et al, 2015) and supports other research that highlights how the rural environment can become a frightening and difficult landscape to traverse as people age, particularly if they experience disorientation and navigational difficulties associated with dementia (Blackstock et al, 2006).

These issues of physical accessibility were exacerbated by the lack of transport options available within the rural environments. With the onset of dementia all of the men with the exception of Joe and Jess, had their driving licence revoked and for some this was still a very sore point. They spoke at great length about the sense of injustice they felt at losing their licence.

'Yeah I had a bit of a bump...and they just rang up and said you can't have that anymore (driving licence)...I was really annoyed...I'm going to speak to someone about that!' (Harry, Marching On, Interview)

Consequently they were predominantly reliant on their care partners to drive them to any activities or opportunities to participate within the rural environment. This placed a lot of pressure on care partners, as Angela explained:

'Well he goes singing tomorrow, we've got the Christmas party. And he goes all day (location three) on Thursday, he goes to the farm on a Friday, but these things are fine...and you have to seek them out, they obviously don't come to your doorstep. But it means that I spend an awful lot of time going backwards and forwards now...In fact one Thursday I went up to (location three) four times, it doesn't give you much time,

between going up, coming back, going back.....you know you don't have a lot of time to do other things. (Angela, Marching On, Interview)

Although buses were available in the rural areas and some men spoke of using them, only Gordon discussed travelling independently. Again this meant the men had difficulties accessing the rural environment independently and regularly required care partners to accompany them. As Norman stated:

'No I don't go anywhere on my own do I?' (Norman, Done Roaming, Interview)

The combination of the adverse impact of dementia and the men's 'total dependency' (Barbara, Old Boys, Interview) on their care partner to enable them to access the rural environments resulted in damaging effects to the men's social confidence. This sentiment was outlined by Jean:

'...he is very dependent on me, I know he's a grown man but he is very, very dependent on me. He doesn't go out on his own at all, he has lost all of his confidence. If I'm there he knows he is safe...You go shopping, and I'm like, where is he? And he is immediately behind me and you think, well why are you walking behind, but it's because he hasn't got to make a decision whether he's got to turn left or right, he just follows you.' (Jean, Done Roaming, Interview)

These issues resulted in some men rarely accessing social opportunities within the rural environment independently and often electing to undertake activities that were housebound, as outlined in the pre-initiative questionnaires. Although the home environment provided a comfort to the men, and for some this was an environment they preferred, there was an acknowledgment by Doug that this was likely to detrimentally impact on their well-being in the long-term:

'Because you're familiar with this (the home environment), this is all good times. This wasn't a worry, this was fun, and you're inclined to closet yourself, and of course that's not good. You should go out and face what's coming along and see if you can deal with it.' (Doug, Done Roaming, Interview)

A key finding emerging from the data is the detrimental impact that the rural landscape can impose on the men's ability to independently connect with their rural community particularly as their health conditions deteriorate. This can result in an adverse impact on their social confidence. Furthermore, the data also suggested that the men were active contributors to their experience of social inclusion; on occasions choosing not to socially connect with their rural environment or those that reside there and instead remain within their homes where they felt comfort and a sense of inclusion.

#### Lack of dementia awareness

Despite a predominantly friendly atmosphere from people within the rural communities, there were instances described by men in all three locations that suggested they found it difficult to gain support from the local community. A particularly pertinent discussion with Joe suggested he felt most people in the block 'kept themselves to themselves' and this seemed to be part of a 'modern trend.' He reminisced with 'nostalgia-tinted glasses' (Bell, 2004, page 22) how he felt social relationships had been more meaningful when he was growing up and people were more willing to support you.

'I would see people in and out all the time, like when I was a kid, it was terraced houses and everybody was in everybody else's house, and everybody knew everybody's business. But then everybody was on the same level, you'd no money. And they did help people out, and people did help you out, you know...they were good neighbours them in them days...But now you wouldn't...They're always friendly and chatty when you're outside but if you knock...they won't open the door.' (Joe, Old Boys, Interview)

This is reminiscent of arguments that everyone in society is now 'bowling alone' (Bell 2004, page 27) resulting in 'the end of the social' (Winlow and Hall, 2013) and making it difficult to form meaningful community ties and relationships, particularly for those people who may be socially excluded (Cantley and Bowes, 2004).

The data also demonstrated that a lack of dementia awareness from neighbours, service providers and family members meant some men and their care partners found it difficult to receive support and feel socially included. The men described a 'fear' (Terry, Done Roaming, Interview) surrounding dementia that was attributed to its 'unseen' nature (Dick, Marching On, Interview). This perception was supported by the men's care partners.

'A lot of people don't understand and they'll be quite honest with you. When people are walking around, you wouldn't look at Joe and say, oh, he's got dementia...I mean, if you've got a broken arm, leg or something like that people can see there's something the matter with you, but with dementia they don't.' (Sheila, Old Boys, Interview)

Consequently this fear had detrimentally impacted on people's friendliness towards the men and their willingness to engage them or include them in social and cultural activities.

'As regards to neighbours...I think they are scared that they are going to catch something, so they just keep well away...The couple that used to be...she used to pop in occasionally and see how we were because we are older than her, but since Terry was diagnosed we haven't seen hide nor hair of us. It's obviously they are scared stiff of it' (Jean, Done Roaming, Interview)

'I'm not finding so many as I used to (people to talk to), but that's just the way it rather goes...Yes, and they stay away for a bit, then they come back, and then you see them,

oh, hello, how are you? Well, I must go, because...you know, fat lot of good talking to him, he's gone.'(Simon, Marching On, Interview)

Care partners including Caroline, Angela and Joan spoke of close friends they had lost since their husband's diagnosis of dementia as 'people don't kind of understand do they?' (Caroline, Old Boys, Interview). Care partners also reported instances where they had been excluded or denied access to local events and opportunities to socialise because of these misunderstandings of dementia. For instance Colin's wife, Sue spoke of attending a film event with Colin in the local area that ran once a month during the autumn and winter. However, she felt she had been forced to abandon this activity as Colin started to shout out and make witty comments 'and the general public didn't really understand that' (Sue, Marching On, Interview). This highlights how a diagnosis of dementia can also adversely impact on the social inclusion of care partners as well as those living with the condition.

The men and their care partners also described instances where their relatives and family members no longer visited them since the on-set of dementia, thereby reducing their numbers of meaningful relationships. As Barry stated:

'Never see her (his daughter). No time for Dad now!' (Barry, Done Roaming, Interview)

Harry's wife stated that when their family members did visit on intermittent occasions, they would exclaim Harry 'seemed fine' (Veronica, Marching On, Interview) and begin to question the diagnosis of dementia. This would unintentionally belittle or undermine the adversity they were facing, as they did not appear to be conforming to the normative ways of progressing through dementia that people expected. This was particularly the case when friends and family had no previous knowledge or experience of dementia. For Doug the combination of growing older and his children's lack of dementia awareness had left him feeling as though he had lost an important connection with them. Losing this status as a father figure amongst his children was particularly difficult for him to come to terms with.

Doug: I'm going down to see my son soon... But that's the only time I can see him, they don't visit.

I: Why's that do you think?

Doug: Well, I think they probably think I'm a bit of a pain in the arse now. I've got another son...I guess he's visited once here...But the truth is obviously that I'm not much company and they probably remember me as I was when I was teaching them to ride bikes and chasing them across the moor. I used to go in and out of the woods and they would keep up with me...My daughter hasn't spoken to me as far as I can remember for at least four years. (Doug, Done Roaming, interview)

Interestingly, this quote highlights how Doug viewed his role as a father to be linked with the traditional hegemonic masculine ideals. He perceived the respect he earned from his children was associated with the masculine characteristics he was able to display in his youth such as

strength, agility and authority. As a consequence of ageing and the onset of dementia, he felt his abilities to undertake these activities diminished and along with this the respect he received from his children. This highlights the gendered experience of dementia (Bartlett et al, 2016; Hulko, 2009; Phinney et al, 2013) and the difficultly people can face when seeking to maintain their 'third-self' (Sabat, 2001).

Some of the men reported that the lack of dementia awareness displayed by members of the rural community and their friends and family, manifested itself in a questioning of the men's opinions and capabilities. For instance, Joe discussed how he had chosen not to reveal his diagnosis of dementia to those who lived in his housing block as he believed their misunderstandings of the condition may result in him losing his role as the volunteer maintenance accountant. This is something he enjoyed doing and it enabled him to contribute to his local environment. Instead he opted to only tell his family members, although this had not been without its complications.

'I get the feeling that people think you're a nutter...Like... sometimes, my son, I think he's a bit...he, kind of, not looks down on me but I don't think he values my opinion on things, you know?' (Joe, Old Boys, interview)

Jess also described instances where he felt his son questioned his capabilities and consequently excluded him from decisions. For instance he spoke of professionals visiting his house to fix appliances without informing him that they were attending. Jess explained that his son had taken it upon himself to arrange the visits without consulting him, as he did not feel he was capable of doing this. Although he had come to terms with this, he still expressed his annoyance at not having an input into these decisions.

A lack of dementia awareness was also displayed by health professionals within the rural areas. For instance, Angela discussed how John had walked out of the doctor surgery as he felt he was being spoken to like a child. David also discussed a difficult visit to a psychologist where he felt they didn't understand him as a person, choosing only to focus on the biomedical aspects of his condition.

'...that was more a chat with a psychologist. He didn't do me any good at all...some people don't get it do they? They study, study and study but they never get to understand the people they are dealing with a lot of the time.' (David, Old Boys, interview)

This was also highlighted by Joe who felt he had to 'pester' his doctor to fill out the appropriate forms that would enable him to maintain his driving licence and so remain connected to the rural environment. Although Joe felt the doctor was friendly, it was evident that he did not understand the importance that the driving licence held for his independence, well-being and social inclusion. As such Joe was forced to drive illegally on outdated papers until the doctor had completed the necessary paperwork. In Location Three, Brian the volunteer also discussed a lack of dementia awareness by healthcare providers. He reported that they were unaware of the

formal services that were offered in the rural location and the benefits that they could provide for people with dementia. Consequently healthcare providers were reluctant to promote them or refer people whom it may benefit. He described his attempts to make doctors' surgeries aware of the Memory Café he was affiliated with, so they could refer people. This had been difficult at first, although he now noted that these attitudes were slowly beginning to change.

'...but it's hard going (setting up a group for people with dementia) because some of the surgeries don't seem to really want to be bothered because they might not understand...you don't know if Drs get it, I mean there's more emphasis now on this sort of condition Dementia...in the past, I used to find getting our local surgery to put a notice up was a no-goer...Now...in a couple of the surgeries where they did seem to be...more aware, they put notices up to say there was a Memory Café and it was at such a place on the day.' (Brian, Marching On, Interview)

This finding resonates with other literature that has described a lack of dementia awareness amongst health professionals working in rural locations (Morgan et al, 2011) and a lack of understanding of the benefits that non-biomedically focussed activities can provide for the social inclusion of people with dementia (Clarke and Bailey, 2016). These findings also demonstrate that even when services are available to the men they may not promote their social inclusion due to their actions that de-value the men's sense of identity and autonomy.

Men reported that these ill-informed community perceptions of dementia also resulted in a stigma relating to the formal structured services provided for people with dementia. Care partners discussed how men such as Bob, Doug and Joe were initially reluctant to attend the TI or other services such as the Memory Café due to 'the name, it's a stigma isn't it?' (Sheila, Old Boys, Interview) that would have 'labelled them as someone with dementia or Alzheimer's' (Caroline, Old Boys, Interview). Terry explained during interview that he refused to tell people he visited the TI as he felt the lack of understanding his neighbours had of these services would detrimentally impact on the way they treated him.

'No. I think it would have an adverse effect (telling people about the TI)...They would then know that I'm having a brain wallah to check me out... they'd think, oh Christ, he's got one of them with him. You know?...They'd think I've gone screwball...Which of course is far from the truth.' (Terry, Done Roaming, Interview)

The key finding emerging from the data demonstrated a lack of dementia awareness within the rural communities from friends, family members and health professionals. This detrimentally impacted on the men's relationships and the sense of value and self-worth that they felt as well as their ability to engage with the rural environment and structured services that could support their social inclusion.

## 5.4 Summary

In this chapter I provided a detailed understanding of the rural locations and venues that were chosen to host the TI. I have supplemented the Census data relating to each location

(presented in Chapter 3) with my own reflections on the area as well as the perceptions of the men, their care partners and the volunteers, thereby providing a more detailed understanding of the rural locations. The data suggested that although the men predominantly lived well in their rural environment they did encounter challenges including: a lack of formal structured services to enable social connection; barriers to accessing the rural environment due to issues associated with their health conditions as well as transport limitations; and a general lack of dementia awareness amongst the rural community. Adopting a social inclusion lens demonstrates how this results in the reduction of certain facets of the men's social inclusion including their ability: to connect with the rural environment; to develop and sustain meaningful relationships; and retain autonomy and respect. This will be discussed in more detail in Chapter 7. These findings also provide an important context for situating the men's perceptions of the impact of the TI. This will now be explored in the following chapter.

### Chapter 6: Exploring the perceived impact of the TI

#### **6.1 Introduction**

Engaging with the Technological Initiative (TI) was reported as a positive experience for the majority of men with only five men choosing to leave before its conclusion (all from Marching On group). This chapter sets out my key findings based on my thematic analysis of the data. It demonstrates that the TI provided an opportunity for the men to come together in the rural environment. Through the use of technology and the male-only environment the TI offered an activity that was appealing to and important for the men's masculinities and enabled them a sense of social inclusion. Throughout the chapter, issues concerning the implementation of the TI as well as differences between the three rural locations are also examined.

### 6.2 An opportunity to engage within the rural environment

As outlined in the previous findings chapter (section 5.3), facets of the rural environment prevented men from engaging in enjoyable activities and socially connecting with others within their local rural area. The data suggested that the introduction of the TI enabled these important aspects to be promoted within the rural areas.

#### 6.2.1 Enjoyable participation in the rural environment

The men predominantly reported enjoying the TI and consequently this ensured their continued participation. As Phil exclaimed:

'Excellent! Each one of them has been superb and as good as the previous one.' (Phil, Done Roaming, Focus Group)

For two of the men, their enjoyment of the TI came as a surprise to them.

'I never thought of it as research. No, I just thought it was a club...I didn't think I was going to like it but I did in the end...If I didn't want to go I wouldn't have.' (Joe, Old Boys, Interview)

'Yeah it was good. I was surprised I enjoyed it.' (Doug, Done Roaming, Interview)

Joe's assertion that he viewed the TI as a 'club' resonates with Graham the volunteer at the Old Boys, who stated:

'I don't think you should, whether you've got dementia or not, I don't think you should undervalue that the fact that Monday is the day you go to the Old Boys Club...you're part of a club that you can get involved in.' (Graham, Old Boys, Interview)

This is reminiscent of Phinney et al (2016) who report on the importance of removing biomedical associations from dementia support services (such as not referring to people as 'clients' or 'service users') and supports my decision to enable the men to name their club and take ownership of it.

Section 5.3 highlighted that within the rural areas (particularly Location One) the men were rarely afforded opportunities to engage in formal structured activities. Unsurprisingly therefore a consistently reported benefit of the TI across all three locations, was *'the mere fact it exists'* (Dick, Marching On, Interview) as an enjoyable activity that could be accessed locally within their rural area. Within Location One, where there were so few formal services, then David felt having this local activity was:

'...good for the community... and well for one thing it is pretty close. You know you haven't got to go 50 miles to attend.' (David, Old Boys, Focus group)

This comment resonates with the idea that enabling more socially inclusive societies that support people with dementia is beneficial for them as well as the wider community as a whole (Phinney et al, 2016). Only in the Marching On group did some care partners discuss issues with the time it took to transport the men to the TI. These care partners resided on the outskirts of the rural location and consequently spent considerable time driving the men to the TI.

The introduction of the TI to the rural environments, added a 'bit of variety in their (the men) lives, that otherwise isn't there' (Brian, Marching On, Interview) and enabled the men to leave their house and engage with their local community. As highlighted in section 5.3, many of the men were often restricted to house-bound activities in their day-to-day lives, therefore the TI was a welcomed and liberating experience for them and offered them an 'escape' (Dick, Marching On, Interview) from the mundane routines associated with spending a lot of time at home.

'Well it's an outlet for everybody otherwise you just sit there and mope in your room or in your front room or something at home.' (Phil, Done Roaming, Focus group)

Even Tel, who left the TI after session four, appreciated the change it brought to his usual daily routine.

'Like I say, not the most exciting day I've ever spent but it's different one and anything different is a plus. I mean we see this (the day centre) and we see our flats or our houses and that's it' (Tel, Marching On, Interview)

Leaving the house also provided the men a period of respite away from their care partners and this was seen to be important for both parties.

'Yeah getting out of the house and getting away from your siblings or your wife or whatever is going on at home (is a benefit).' (David, Old Boys, Focus group)

'Yes, I think it's beneficial...it gives them time away from their carer, which...must...get on their nerves at times always being perhaps told...try not to do this, or, don't do that. Yeah, I should think it's very difficult.' (Shirley, Old Boys, Interview)

As many of the men had highlighted a day-to-day dependency on their care partner for practical and emotional support, then these periods of independence were important for them. These interludes of respite were also essential for care partners' sense of well-being with many care partners highlighting this as the predominant benefit of the TI for them. Cross case analysis demonstrated that this theme was not as prevalent at Location Two, however, where the care partners opted to stay and watch the TI (except Betty who rarely remained and chose to use the time to go for long walks around location two). Care partners at this location did not view the TI as an activity they undertook separately from one another but enjoyed the fact it was 'something we could do together' (Jean, Done Roaming, Interview).

Engaging with the TI enabled the men periods of enjoyment where they could relax and have fun, and the men perceived this to be important and beneficial for them.

'...you know you can have a crack and can have a laugh. That's the salient thing...I think that is wonderful.' (Simon, Marching On, Interview)

'This I will tell you is a cracker!...there's so much harmonies and laughs and jokes and you know, and it's good.' (Gordon, Marching On, Interview)

The volunteers also supported this sentiment with Greg viewing this aspect as integral to the success of the TI.

'Yes, it's a lot of fun. I think that's an important word, the word 'fun'; it was fun for them (the men). Not just for them but for us all. Taking part is one thing but when it's fun it's been successful.' (Greg, Done Roaming, Interview)

As highlighted by Jess, the jovial atmosphere of the TI was important for its success and made it a more enjoyable and appealing community activity to attend than others in the rural environment.

'I prefer this (the TI)...you know I got told off for laughing, in some group. My raucous laughter was..(makes finger wagging motion) and I got told off. You know that did me for several days after and I thought how on earth can anyone complain about that?' (Jess, Marching On, Focus group)

This finding resonates with the wider literature that emphasises the importance of fun activities for supporting well-being and a sense of social inclusion in people with dementia (Astell, 2013; Dugmore et al, 2015; Dupuis et al, 2016; Killick, 2013).

#### 6.2.2 Social participation

Section 5.3.2 demonstrated that the men faced difficulties socially participating and connecting in their rural environment. Data suggested that the TI provided a welcomed opportunity for the men to socially participate with others in their community. As Bill and other men across all three locations highlighted:

'Well it (the TI) helped to sort of meet other people. I don't socialise that much.' (Bill, Old Boys, Interview)

Both the volunteers and the care partners also agreed with this sentiment, discussing how the TI provided the men with a much needed opportunity to socially connect within their relatively isolated day-to-day lives.

'...something which was highlighted right from the outset, as a lot of people seemed to be quite isolated. So them being able to go someplace and get involved with something else and other people, was a good thing.' (Tom, Old Boys, Interview)

Men reported that the TI enabled them to socially participate and connect with people outside of their immediate local environment. Expanding their social network and developing more meaningful relationships, ensured they could discuss 'slightly different conversations and different subjects' that 'neighbours are not at all interested in' (Doug, Done Roaming, Interview) and was this perceived as beneficial by both the men and their care partners.

'I think it's the social aspect; being able to talk to other people. Because obviously we're quite isolated where we are. He doesn't go very far because of the health conditions he has. And it does actually make him go, and he finds that he can talk to people about things that he doesn't talk to me about; that I've not got any interest in. So, yeah, I think it's been a big help to him.' (Sheila, Old Boys, Interview)

Tom, the Old Boys volunteer, also discussed how the TI enabled the men to develop a social support network that he felt was often lacking in the lives of older men as opposed to older women.

'I think that was a good thing...women seem to be so much aware and so much more organised at that stage of life, if you like, that they seem to have support around them through their groups of friends and things. Whereas I think men don't have that, so, to me, I think that was a good thing.' (Tom, Old Boys, Interview)

These findings demonstrated that the TI filled an important unmet need within the rural locations; providing the men with an opportunity to engage in an enjoyable activity within their local community and socialise with other people outside of their immediate home environment. As such, it provided them an opportunity for social inclusion in ways that had not been available in formal service structures or informal arrangements and day-to-day activities.

#### 6.3 Technology as an enabler

The data demonstrated that the commercial gaming technology was an important and novel facet of the TI. It supported the appeal of the TI and afforded the men important perceived beneficial outcomes by acting as an enabler for them to: engage in a meaningful activity; continue life-long learning; socialise; and resist negative assumptions associated with a diagnosis of dementia.

## 6.3.1 Meaningful activity

The data showed that the technology enabled the TI to provide activities that were meaningful to the men, thus enhancing its appeal. Literature exploring the concept of 'meaningful activities' has highlighted the need for people with dementia to engage in activities that are enjoyable, maintain their interests and physical abilities as well as address psychological needs (Phinney et al, 2007; Harmer and Orrell, 2008; Nyman and Szymczynska, 2016; Roland and Chappell, 2015). The data demonstrated that the technology engaged the men in an enjoyable, fun activity that could be tailored towards their interests and capabilities, and provided them with stimulation and friendly competition.

#### Person-centred activities

The use of the technology ensured the activities could be tailored towards the men's previous interests and this enhanced the appeal of the TI. As highlighted by John, there were numerous examples of the technology enabling the men to reconnect with previous interests that had once been integral to their identity, thereby ensuring the activities were more meaningful and enjoyable.

'Yes I used to do that when I was much younger (boxing) and liked it (playing the game)...When you are in your mid 80s like me it is something you think twice about now!' (John, Marching On, RFN session six)

'I loved the golf game... I can't play it in reality...I can't go out and play on a course anymore. I don't have the money or equipment and... I'm not physically able to now but I love it...and I played it and I hit a good shot occasionally. About once every three weeks!' (Tel, Marching On, Interview)

This latter discussion with Tel showed how the technology provided him with an opportunity for social inclusion by enabling him to re-engage with an activity he used to play as well as overcome the physical limitations associated with his age. Brian, the volunteer for Marching On also agreed that this was an important feature of the technology.

'Some of the things that people were good at, they were good at when they were active people. So it (technology) brought it out of them, "Oh I'm not too bad at this, I may not be able to do it physically now, getting on the golf range, or ten pin bowling, but on a game I can still do it, once I've got used to the features of doing it on a game console" (Brian, Marching On, Interview)

The iPad was particularly beneficial for enabling the men to re-engage with previous activities as it could be connected to the internet and therefore respond to the men's interests as and when they became apparent. For instance when I became aware of Bill's interest in chess and Joe's interest in backgammon (Old Boys, RFN session 4) I was able to download these applications and play them with the men during one-to-one interactions. This finding is

consistent with other research that discusses the immediateness of the iPad for enabling person-centred activities (Cutler et al, 2016; Upton et al, 2011).

Enhancing the men's social inclusion through providing opportunities to engage in activities that were individually tailored towards their interests was important for the appeal of the TI and was valuable for the men's well-being. This was highlighted during my discussions with Maureen when she came to pick Simon up.

'Yes he really enjoys it. He used to play golf and fly fishing. He misses his golf and was in his element the other day when you played golf. I was driving him back the other day and he just said: "I feel so elevated." And I said: "You mean like happy." And he said: "Yeah. We played golf today and I haven't played in ages!" (Maureen, Marching On, RFN session six)

Using a range of technological devices ensured the TI 'did not become stale' (Gordon, Marching On, Focus group) and could cater for the various interests in the groups; thereby enhancing its potential for social inclusion. For instance in the Marching On group, I was able to split the group up to enable some of the men to engage in the boxing game (as John, Tel, Peter and Dave highlighted this as an important interest in their life) whilst others who were less interested used the Google Earth application. This adds further support for the need to use multiple technological devices in tandem, to ensure the activities remain appealing and meaningful to the group members (Cutler et al, 2016).

However, despite the use of multiple technological devices, data elicited from my reflexive field-notes suggested that when the activities could not be tailored towards the men's interests they declined to participate. In two extreme cases, care partners of men in the Marching On group felt their husbands, Chris and Harry, decided to leave the TI as the technology and/or games did not align with their previous interests. However it should be noted that as the care partners never watched the TI, they could only speculate. Unfortunately when interviewed both men were unable to remember the TI in great detail.

'He actually came twice when he said he didn't want to...I think, all I can imagine is that he never really played boxing or golf very much...For him you'll need to get sailing on it...I don't think he was interested (in the other games).' (Veronica, Marching On, Interview)

Furthermore, using a range of technologies, applications and games with varying difficulty settings also ensured the activities could be tailored to the men's capabilities thereby enabling them to successfully participate. For instance, I purchased a steering wheel for Mario Kart racing on the Nintendo Wii as the men were better able to engage with the game using this device than the standard controller. When introducing this game within the Done Roaming group, I found Doug to be particularly adept on it (due to his previous experience as a motor car racer) and therefore I challenged him with more difficult levels whilst the other men played on

the beginner levels. Furthermore, the intuitive nature of the actions required to engage with games on the Nintendo Wii and Microsoft Kinect meant that men who had previously played these games in reality would often automatically adopt the appropriate actions/stance with little prompting. In the case of Colin who regularly used to play golf in Scotland and now required a walking stick to move about, the Microsoft Kinect was forgiving enough to enable him to use the stick as he played the game.

'Once Colin got to the screen and saw the golf game he immediately adopted the correct golfing stance without prompting. He seemed to be recalling this from his past days when he regularly played golf...it was fortunate that the game enabled him to swing his walking stick in a similar manner to a golf club...ensuring that he could keep it on him whilst he interacted with the game.' (RFN, Location Three, Session 5)

Data elicited from my reflexive field-notes suggested that where the games were viewed by the men as beyond their capabilities then they were reluctant to engage with them. Fortunately these instances were rare and often the men would participate if I provided them with a little encouragement or they witnessed other men successfully engaging with the game. This latter aspect highlights the benefits of co-viewing when introducing gaming technology to people with dementia.

Consistent with the wider academic literature (Cohen-Mansfield et al, 2006, 2009, 2010; Kolanowski et al, 2011) a key finding emerging from the data is the importance of ensuring the activities are tailored towards the interests and capabilities of the intended users; thereby ensuring their ability to participate and so enhancing their sense of social inclusion. This former aspect may be particularly pertinent for older men who often favour activities that are consistent with their previous interests and occupations (Genoe and Singleton, 2006; Milligan et al, 2015; Phinney et al, 2013).

## Fun and relaxed atmosphere

The games' light hearted music and colourful graphics along with the actions required to engage with the Microsoft Kinect and Nintendo Wii (such as hitting moles around the head with a mallet, catching ice cream as it falls from the sky or hula hooping) provided an element of humour to the activities that made them appealing. As Terry and Simon discussed:

'All of them (the games). They were just sort of amusing you know. They were something to run your mind round.' (Terry, Done Roaming, Interview)

'I think a lot of it is very good...and you find, good lord alone, what a funny game this is. And, it's great fun, and you can see it, and all of them respond (the men), I respond if I can, I don't always win but it's great!'(Simon, Marching On, Interview)

Two of the volunteers also concurred with this sentiment with Greg suggesting, similar to Simon, that the 'fun' nature of the games was important for encouraging the men to participate in the TI.

'Those games were really good and the golf one we had a lot of fun with...Yeah that bloody golf game, we had a lot of fun that day. It's a great method of getting a laugh as well as encouraging them (the men) to be interested in and part of a group and everything like that.' (Greg, Done Roaming, Interview)

The humorous games ensured the men experienced little pressure when engaging in the activities and this was appealing to them. Indeed on the rare occasions when the men did feel a pressure to perform then the games lost their appeal and I noted a detrimental impact on the men's sense of well-being. These instances usually occurred when the games were linked to aspects of the men's younger masculinities and as such they perceived a requirement to perform to a certain standard. For example David was a keen sportsman in his younger years and consequently enjoyed playing on the sports games, usually engaging with them very successfully. However I noted one occasion when he struggled to interact with a tennis game.

'David was trying to hit the ball but kept mistiming it. Each time he did he became frustrated and shouted at his female avatar: 'You're worse than my wife!' After a few unsuccessful attempts he decided to sit down and watch others play the game.

Although I asked him if he wanted to play again he refused saying he would let others have a go. During feedback he suggested that the tennis was 'ok but she wasn't very good.' (David, Old Boys, RFN session 3)

A similar instance occurred in the Marching On group when some of the men who had previously been boxing coaches attempted to engage with the boxing game on the Nintendo Wii. As they failed to hit their opponent, they became increasingly frustrated with their performance as well as the volunteer supporting them, with one man shouting: 'what would you know? How many fights have you been in?' (Marching On, RFN session three). During feedback, Tel suggested he hadn't liked the game as it was 'too unrealistic' (Tel, Marching On, RFN, session three). However, Gordon, who was part of the group but had no previous boxing experience noticeably enjoyed the game, swinging his arms around and laughing. Interestingly, in both these instances, to diffuse the potential detrimental impact on their masculinities, the men sought to blame factors external to their own control; the female avatar and the unrealistic mechanisms of the game. Although these instances were rare, they needed to be carefully managed.

A key finding emerging from the data demonstrated the importance of creating a fun activity and supportive atmosphere that did not place pressure on the abilities of the men. This is consistent with other community-based research (Milligan et al, 2015; Phinney et al, 2016).

## Provides stimulation

The data suggested that the technology enabled the men to engage in an activity that was mentally stimulating and consistent with the academic literature (Harmer and Orrell, 2008) this was perceived by the men as important for them. Men such as Gordon commented on the

'value' of the TI to 'help keep your brain working' (Gordon, Marching On, Interview). For Doug, this mental stimulation was perceived as important to 'liven things up' as he felt he was rarely afforded these opportunities whilst at home.

'Anything that makes your mind work which it doesn't do at home a lot of the time is worthwhile. It livens things up for you. It carries on a little further into the week afterwards. You have got some of the rust off and that's very important.' (Doug, Done Roaming, Focus group)

Care partners, particularly those that stayed to watch the sessions, also supported the view that mental stimulation was an important component of the TI and provided health benefits for the men.

'He (Phil) was absolutely...exhausted (when he got home), but he'd had the stimulation and anything that stimulates his brain is good.' (Jean, Done Roaming, Interview)

Although Angela did not attend the TI sessions she felt her husband, John, 'slept much better at night' after being encouraged 'to use his brain' (Angela, Marching On, Interview). This resonates with research that highlights the health benefits for people with dementia when engaging in activities that promote mental stimulation (Hall et al, 2009; Wang et al, 2012, 2013).

Furthermore, although the men did not report on the technology enabling opportunities for physical activity, data elicited from my reflexive field-notes highlighted these instances. This was particularly the case with games on the Nintendo Wii and the Microsoft Kinect such as boxing, tennis and hula hooping. When engaging with these games the men became animated and the exercise itself, in addition to any pleasure gained in completing the task, appeared to contribute to a positive sense of well-being. One example from my reflexive field-notes is outlined below.

Bob was able to interact with the boxing game quite easily and became very active and animated as he was hitting the opponent. On a number of occasions he moved right up next to the screen and I had to ask him to move back for fear he would take the TV off the table. He only played two rounds as I think he became quite exhausted with all the exercise. Although he commented that he wasn't sure what he was doing, he certainly seemed to be enjoying it and was laughing about it to the other men afterwards.' (Old Boys, RFN, session four)

Interestingly other research has suggested that care staff and care partners often perceive physical activity as an important component of meaningful activities, yet this is something that is overlooked by people with dementia (Harmer and Orrell, 2008). The data suggests this may also be a similar finding in the present study.

### Friendly competition

The technology enabled the men to engage in activities that promoted friendly competition such as bowling or golf. The data suggested that the competitive aspect was relatively absent in the Old Boys and the Marching On group but was particularly pronounced in the Done Roaming group. Here the men were more accustomed to one another from the beginning of the TI and seemed to relish the competition that the games afforded them. Consequently this appeared to enhance the enjoyment of the TI as well as the men's sense of achievement as they sought to be crowned 'champion of the group' (Phil, Done Roaming, RFN session six). As Phil commented:

'The competition was good...it was a healthy one and everybody's really...they could feel the progress they were making inside themselves.' (Phil, Done Roaming, Interview)

Data from my reflexive field-notes suggested that this competitive aspect was reinforced by the care partners, many of whom stayed and supported the men as they engaged with the games. This included shouting words of encouragement as the men competed and singing their praises when they were successful. As Jean exclaimed after Phil had won the bowling:

'Well done love! We're going to struggle to get your head through the exit now aren't we?!' (Marching On, RFN session 7)

The data demonstrated that the technology enabled the men to express their competitive characteristics; however this competitiveness was most prevalent when they were competing for the affection of their care partners. This finding provides further support for the relational concept of gender, where both men and women 'perform' their gender characteristics in relation to one another, (Connell and Messerschmidt, 2005) and highlights how the social environment can promote certain aspects of the men's masculinities.

The key findings emerging from the data demonstrated that the technology was an important factor in providing fun, 'meaningful activities' (Roland and Chappell, 2015) that were tailored towards the interests and capabilities of the men, thereby enhancing the inclusivity of the TI. By engaging with the activities, the men were afforded both mental and physical stimulation as well as an opportunity to participate in friendly competition. This was important for their well-being and sense of social inclusion. Offering fun activities that are tailored towards the past interests of the intended users may be particularly appealing and beneficial to the masculinities of older men (Milligan et al, 2015), thereby supporting their sense of social inclusion.

# 6.3.2 Life-long learning

The data demonstrated that the technology encouraged the men to develop and learn new skills and this was welcomed by them. The majority of men were unfamiliar with the commercial gaming technology, yet demonstrated a desire and competence to engage with it. Men reported an aspiration to feel socially included within modern society, and viewed the technology as

providing them an important means 'to clobber along with the rest of them' (Jess, Marching On, Focus group). Phil emphasised the importance of being involved in a modern and progressing society and continuing his learning despite a diagnosis of dementia.

'But seriously it's progress. Everybody wants to be involved in progress don't you? No matter what you do. It opens a new chapter in your mind doesn't it? You would think it would never work but it does...But what you've proved is that things like that machine have opened our education.' (Phil, Done Roaming, Focus group)

Data from my reflexive field-notes highlighted occasions where the men were keen to advance their knowledge of the technology and improve their skills. This included seeking information on how to improve their performances and testing various tactics, as well as enquiring about other apps and games that could be used on the technology.

'You're having a go after this! (on the ski slalom game) I think I was a little bit early that time. I did that on the red line, so will try it before the red line this time. That was too late that time.' (Joe, Old Boys, RFN session eight)

'On the second go the men were also keen on finding out how to get the green arrow up on the screen so that they could adjust where they stood before they bowled the ball. I encouraged Phil to do this and he did this on all his subsequent goes. Terry also listened and lined himself up for his second ball. When he didn't quite hit the pin he laughed at the screen and gestured his hand towards it.' (Done Roaming, RFN session five)

For Jess, his main enjoyment of the TI came through learning more about the technology. During the final feedback session he advocated personalised learning agendas so that he could advance his skills on the technology that appealed to him. This provides support for Cutler et al (2016) who promote individualised learning agendas when engaging people with dementia with commercial gaming technology.

Learning how to engage with the technology and master the games provided the men with a sense of achievement that contributed to their heightened mood. This was evident in the way the men would perform celebratory dances when bowling a strike or putting the golf ball. This sense of achievement was reinforced by the other men and their care partners (if they were present) who would congratulate and praise them after successfully engaging with the technology. This enhanced the men's sense of social inclusion and connection within the group.

Bill: 'I thought the iPad was good and I was really pleased I was able to use it. I thought the golf game was really good too and I managed to get it in the hole.'

Joe: Yeah he's practically professional! (laughs)(Old Boys, RFN Session Three)

'And, people who would not know how to do all these things. But, you can do it...and when they've got to know how to do this and what it's all about I think they will quite happily say, right, well this is fun, this is good, I've got it all 100 per cent. And, I think they will feel chuffed at that.' (Simon, Marching On, Interview)

Care partners also agreed that the sense of achievement when the men mastered the technology and games contributed to their enhanced mood and well-being.

'I think the social benefits were brilliant, and I think he felt he had achieved something, I noticed all the men were very competitive, they all wanted to win, and that's good, that's healthy coz you know, most people are, aren't they?' (Jean, Done Roaming, Interview)

'Well it made him do a little bit of exercise, but it also boosted his morale, in as much as he felt he was achieving, he felt that he was you know winning the game' (Angela, Marching On, Interview)

Upon completion of the TI, Joe, David and Jess were keen to purchase some of the technology to enable them to continue their learning outside of the initiative and advance their skills.

'It (the TI) sets you up to use it (technology) at home as well doesn't it? So that you don't just use it there but when you come home you can look back on what you did and then continue where you left off.' (David, Old Boys, Interview)

For Joe, his interest in buying the technology stemmed from his desire to play the Microsoft Kinect bowling with his granddaughter. He arranged for her to bring her device along over the Christmas period so that they could play together and he could share his new found learning. This provides further support for research that highlights the desire and abilities of people with dementia to transfer learned technological skills to other activities outside of the initiative (Cutler et al, 2016; Leahey and Singleton, 2011) and suggests a potential for commercial gaming technology to be used to promote inter-generational communication (Cutler et al, 2016; Upton et al, 2011). This latter finding may be particularly beneficial for some men given the difficulties they suggested they faced when seeking to maintain meaningful relationships with family members whom they saw infrequently (section 5.3.2). These meaningful relationships are important for the men's masculinities.

A key finding emerging from the data is that the men demonstrated a desire and competence to continue their learning despite the challenges they faced with dementia and ageing, and to be socially included within a modern society. The technology enabled them to achieve these aims and so enhanced their sense of social inclusion. For some men, the use of novel technology spurred an interest to continue their learning outside of the TI to support their sense of social inclusion in other facets of their lives.

#### 6.3.3 Social interaction

The data suggested that the technology acted as a catalyst or a 'scaffold' (Upton et al, 2011) for social interaction. This was achieved through the act of co-viewing or through direct interaction with the technology.

The men were enabled to watch others interact with the technology, comment on their performances and so feel part of the activity. This was particularly beneficial in ensuring the quieter, more apprehensive men could also feel part of the group and helped to build up their confidence to also participate in the activities.

'Oh yeah, I mean it takes the pressure off you, doesn't it (watching)? If they can see two or three of them there really enjoying themselves, they relax and then they start to join in, don't they? I mean us playing bowls, they all get more and more excited, but when we did it the first or second time, they were a bit hesitant about it...then later on just before you had to pack it in, most of them were really coming on.' (Phil, Done Roaming, Interview)

Graham, a volunteer at the Old Boys also agreed with this sentiment, explaining:

'I think the IT thing is a really good idea because people can see up on a big screen what you're doing and we're all doing it, we're all making fools of ourselves. So gradually people became more interested and joined in...I don't think anybody really felt 'I don't want to do this.' (Graham, Old Boys, Interview)

This adds further support to the wider academic literature that explores the beneficial aspects and sense of social connection that can be attained through the act of co-viewing when engaging with technology (Kahlbaugh et al, 2011).

Data elicited from my reflexive field-notes demonstrated how social interaction was promoted through the men's direct use of the technology. This was achieved as the men discussed the technology and their own performances as well as offering advice to other men in the group.

'Well you put your hand in there and then stand like this. Then you punch it just like this (while making the movement).' (Joe, Old Boys, RFN session four)

Simon: 'Have you done it yet?' (to Dick)

Dick: 'Yes I had a go.'

Simon: 'It's quite difficult isn't it? You have to move your legs like this' (motions with his legs)

Dick: 'Yes I found it difficult as well.' (Marching On, RFN session seven)

This was particularly evident during games where the men were tasked with working together in teams. One of the most pertinent examples occurred when the men were required to work together to create a Mii character. For the Old boys this task generated a great deal of laughter as the men gave their female character a six o'clock shadow and a strong jaw line.

Bob, David and Joe talk together.

David: 'God look at what we're creating.'

Bob laughs out loud and they all smile at each other.

I: 'You've taken a female character and made them male.'

Joe: 'She looks good to me!' (all laugh)

Graham: 'I think I used to go out with her!' (all laugh) (Old Boys, RFN session four)

Predominantly however data suggested that the technology promoted and supported discussions about the men's lives, hobbies and interests. Consistent with other studies (Cutler et al, 2016; Evans et al, 2015; Upton et al, 2011) the iPad was shown to be a particularly effective tool for achieving this by providing applications, music, videos and pictures that acted as prompts for encouraging and maintaining social interaction. As the iPad was connected to the internet then these prompts could be found instantly, enabling it to respond to the men's interests as they became known. This was a particularly useful method for encouraging the quieter members of the group to engage in conversations. For instance, I was able to find photographs of Barry's old school (Done Roaming) and this enabled him to remember details about the buildings and the classes he attended. As Graham, a volunteer at the Old Boys discussed:

'I thought the iPad and You Tube were great...I didn't realise it had so much on it with the music so I thought that was really good for getting the men to talk about their lives...I thought the music worked particularly well, people seemed to resonate with it...and then people like Joe would talk about his Liverpudlian days and whatever.' (Graham, Old Boys, Interview)

Data elicited from my field-notes also demonstrated that other pieces of technology such as the Nintendo Wii and Microsoft Kinect could support social interactions between the men by enabling them to discuss aspects of their lives. The following excerpt of conversation preceded a golf game on the Microsoft Kinect.

Colin: 'Do you play golf?'

Simon: 'I haven't played in a long time but I used to.'

Colin: Where did you play golf?

Simon: 'Oh up in the north on various courses.'

Colin: 'I used to play at St Andrews.'

I: 'That's a professional golf course isn't it? Did you ever play professionally?'

Colin: 'No not professionally but I did used to play a lot.'

I: 'What was St Andrews like?'

Colin: 'It depends on the weather. It has the winds coming in and the water.'

*I: 'What was the most difficult hole?'* 

Colin: 'The 14th. It was bumpy and there is the water, and the weather. The weather can be a real sod!'

Simon: 'Yes I agree. I've played on courses like that.' (Marching On, RFN session eight)

Data from my field-notes also demonstrated the potential for the technology to act as a 'scaffold' (Upton et al, 2011) to support the discussions I undertook with the men. This was particularly beneficial when using the iPad in one-to-one interactions. For instance using Google Earth on the iPad I was able to work with Terry to virtually re-visit areas of East London he had grown up in.

'I then used the iPad to show Terry areas of East London where he grew up. We had an interesting chat about this and he was able to use the iPad to find his old street using Street View...He repeatedly commented that it had all changed as there were now a lot more houses which had sprung up everywhere. We continued to speak about the prices of London houses in the East End now and this clearly astounded him.' (Done Roaming, RFN session 4)

These social interactions provided me with a better understanding of the men's lives and contributed to the sense of connection I developed with them. This was important for creating a rapport with the men and for the overall success of the research (Dewing, 2008b; Murphy et al, 2015).

The key finding elicited from the data is that the technology was integral to supporting the social interaction that occurred throughout the groups by acting as a 'scaffold' (Upton et al, 2011), which helped to initiate conversations as well as maintain conversations between the group members. These discussions enabled a complex understanding of the men's lives to be ascertained as well as contributed to enhancing the social connection between the group members. This was important for the men's sense of social inclusion as well as their willingness to work with me as the researcher. This latter aspect was integral to the success of the overall research process.

## 6.3.4 Resist negative assumptions surrounding dementia

The technology provided an activity that the majority of men had limited experience of engaging with at home or within their rural community (as outlined in section 4.1). Therefore it can be considered an atypical activity for the men to participate in. Through engaging with the technology the men were enabled to challenge negative assumptions around their capabilities. This included their own perceptions of their abilities as well as those of the volunteers and the care partners.

Challenge negative assumptions of their own abilities

Feedback from the men as well as data elicited from my field-notes highlighted occasions across all three rural locations where the men surprised themselves when successfully engaging with the activities. This was particularly noticeable when the men appeared initially apprehensive about their ability to interact with the technology and required encouragement to engage with the games. Successfully engaging with the game contributed to a sense of positive well-being as the men accomplished tasks they initially perceived as difficult or beyond their capabilities.

'Oh I didn't expect that! (laughs)I won't continue now!' (having got a strike on his first go at bowling) (Bob, Old Boys, RFN session 6)

'As far as I'm concerned, I come here very glum, fed up and sorry for myself and I go away thinking that I can still do something even if it's something silly. I can still do something.' (Doug, Done Roaming, Focus group)

One of the most pertinent examples occurred during session six in the Done Roaming group. Terry initially refused to engage with the ice cream balancing game on the Nintendo Wii Motion citing dexterity issues with his wrist. However he noticeably became more interested in the game as he watched the other men play. With a little encouragement he eventually decided to participate and to his surprise beat the rest of the men by balancing the most ice creams on his cone. He exclaimed afterwards:

'Yeah the game (balancing the ice creams). I enjoyed it in the end. Was definitely not sure at the start! But now I'm the champion!' (Terry, Done Roaming, RFN session six).

During his interview, Simon described his initial apprehension and hesitancy towards engaging with the games. However as he became more confident in his abilities and his skills improved then he began to enjoy the experience.

'No, I think that's part of the whole game... I was hesitant in the early days thinking, oh god I don't think I can do this...what's all this about...and I wasn't quite sure. Then, you came up with some of these games and it's fascinating to see, and I began to really like it...In fact, actually, I got to a point where I thought, oh give me another go.'(Simon, Marching On, Interview)

This data demonstrated the potential for the gaming technology to challenge the men's negative assumptions of their capabilities. In successfully doing so, it enabled them a sense of achievement and contributed to their positive well-being.

## Challenge others' assumptions

In the Old Boys, where the volunteers demonstrated limited experience of dementia (as seen in Section 4.1), the data elicited from the interviews suggested that the TI challenged their views of dementia and the capabilities of the men. Tom in particular spoke at length of how he would no longer assume people with dementia were unwilling or incapable of engaging with new technology or being involved in groups.

'Just interesting to see how people who initially didn't look like they were that involved in it...even capable of being involved with it ... For instance Bill...I thought...he was going to be really difficult...I don't think he wants to be here, but he did and it was just his way...So just to see that obviously it makes me look at things differently...and I don't now automatically assume that they are (unable to participate), you know, probably give them more time than maybe I would have before. I think that's probably the main thing I've got from that.' (Tom, Old Boys, Interview)

For Brian, participating in the TI raised his awareness of dementia and spurred his interest in learning more about the condition.

'I found it to be quite rewarding. I know nothing about dementia at all, I don't think I've ever come across anyone that I know has got dementia so it was really interesting to meet the guys and to realise that there's such a broad spectrum that to be honest sometimes I wasn't sure who was the volunteer and who was the person with dementia... So it has made me want to find out more and also to keep supporting the group where I can.' (Brian, Old Boys, Interview)

It is interesting to note that this finding was only prevalent with the volunteers at the Old Boys. It is possible that as David in Done Roaming had a great deal of experience working with people with mental health conditions and dementia then he was already very aware of the need to maintain an open mind. It is unclear why this may have been the case for the volunteers in Marching On, but in the instance of Josh, whose wife had died of dementia, then the stress and emotional turmoil he discussed experiencing (during informal conversations alone with me) may have entrenched his views of people with dementia more widely. Data elicited from my field-notes demonstrated occasions where Josh appeared to call into question the abilities of some of the men despite having just watched them successfully interact with the games. This highlights the difficulties faced when ensuring volunteers keep an open-mind on the capabilities of people with dementia, particularly if they have experienced past personal challenges associated with the condition.

A few care partners across the three rural locations reported that their views of the men's interests and/or capabilities were challenged as a consequence of the men attending the TI. This was evident from both care partners who attended the TI (in the Done Roaming group) as well as those who didn't (in the Old Boys and Marching On).

'Bob could never explain it when he came home. He said, I've been on the computer, and I thought, God help us all. It obviously was enjoyable, and he said to me, we're so good at that, and I'm thinking, gosh really? So, that obviously was very good for his ego.' (Caroline, Old Boys, Interview)

'I think that when we first knew about it, the family thought it was, not quite hilarious, but knowing how John is not good with anything to do with gadgets, at all, he never has been, never professed to be, and we all thought it was almost a bit of a joke; and we were proved wrong because...John did take part and enjoyed it.' (Angela, Marching On, Interview)

A key finding emerging from my data is the ability for the technology to provide a platform from which the men can begin to challenge or resist negative assumptions of their capabilities. This includes their own assumptions as well as those of others such as their care partners and the volunteers. My finding provides further support for the use of atypical (those not commonly associated with people with dementia) activities to challenge the stigma and discrimination surrounding the condition (Genoe, 2010), thereby enhancing the social inclusion agenda more widely.

#### 6.4 Male-only environment

The male-only environment was a novel aspect of the TI and my data suggested that this environment was generally favoured by the men, their care partners and the volunteers, with one care partner describing it as a 'stroke of genius' (Caroline, Old Boys, Interview). On the rare occasions the male-only environment was not viewed favourably it was usually because the men reported the presence of women would add an attractive element to the group.

Bob: 'Don't know really (about including women in the group). I would say it would be better to have ladies than not.'

I: 'Why's that?'

David: 'They're prettier!' (laugh)

Bob: 'Steady! Steady! Nobody about is there?!...I've got no problem about women, especially if they're tasty!' (Old Boys, focus group)

'We didn't get no bit of crumpet up there then!? (laugh)...oh that would have been nice!' (laugh)(Dave, Marching On, Interview)

Only in the Done Roaming group, where the majority of care partners remained to watch the sessions, did Tel acknowledge other aspects that the women may bring to the group, other than their attractiveness.

'And females understand life much better than we men...Nature has given them the ability to look at all the kerbs, not just the one you're stepping on.' (Tel, Done Roaming, interview)

However, the men still favoured a male-only environment. Data ascertained from the interviews with care partners also suggested that they agreed with the concept of a male-only environment as it offered something different for the men than the typical activities they participated in within their rural area. These activities were often attended and/or run by women and as such the men could feel 'over womaned' (Veronica, Marching On, Interview).

Well, I think it's a good idea (men-only), I think too many of these Coffee Mornings and things that we go to are full of women. There seem to be more women than men, and I think the men only thing is good.' (Sue, Marching On, Interview)

My data demonstrated that the male-only environment appealed to the men as they perceived it provided them a relaxing and safe environment and enabled them to develop a sense of comradeship with others in the group. These aspects will now be discussed in more detail.

## 6.4.1 Relaxing and safe environment

My data suggested that the male-only environment ensured the TI was appealing to the men as it enabled them to relax and engage more freely in conversations with one another. The men reported that these discussions would have been more restricted if women were present as they would have disapproved of the swearing and the topics of conversation or would 'take over' so that it became a 'woman's club' (Bill, Old Boys, Interview). Subsequently, this would inhibit the men's social participation in the TI as they would be unable to express themselves freely.

'It's good amongst the boys you know? (With women)...you would sort of be limited in a lot of ways...you would have to be reasonable and so forth!' (Dick, Marching On, Focus group)

'If you can swear, which now and then you can do, then you would feel offended with the women there. Then they would take over. And you would never get a word in edgeways and the woman always has the last word. I feel more relaxed with just men only.' (Joe, Old Boys, Focus group)

This suggests that the men still perceived themselves as responsible for protecting their care partners against the harsh and abrasive language that was used within the groups. These characteristics are akin to a more traditional hegemonic masculine ideal and are ironic given that it was often the care partners that were required to provide emotional and practical support to the men in their daily rural lives. Once these perceived restrictions had been removed from

the men, they could freely engage in conversations that were 'a bit naughty' (Jean, Done Roaming, Interview). Indeed, data from my field-notes highlighted male typical discussions or 'male banter' that I perceived would not have occurred within a mixed gender environment. Instances included the men commenting on the female avatars such as Jess (Marching On, RFN session six) exclaiming 'She's got a lovely bum!' or David (Old Boys, RFN session 5) playing songs on the iPad with the lyrics: 'If you can't get fucked on a Saturday night you can't get fucked at all.' This sentiment was supported by Tom, the Old Boys volunteer, who reported, when asked if anything would be different in a mixed gender environment:

'Well, we wouldn't be singing rugby songs for start!' (Tom, Old Boys, Interview)

This data suggested that the male-only environment provided a safe psychological space (Phinney et al, 2016) where the men could feel comfortable expressing their masculinities without feeling restricted by the presence of women. A pertinent example was highlighted during an informal discussion with David's care partner, Anita (Old Boys, RFN session four) who received feedback from a female support worker at a Day Centre, that David 'spoke only when spoken to.' I reflected:

'This is entirely different from his persona at my TI. He regularly initiates conversations and makes rude comments that are cheerfully received by the rest of the men. David enjoys playing this role and the other men look to him to provide this banter. I feel the male-only environment is enabling him to relax and freely express this aspect of his male identity.' (Old Boys, RFN session four)

For men such as Doug, the male-only environment was something that he had been accustomed to during his working life. Therefore the familiarity of the environment coupled with the exclusion of women put him at ease and consequently enabled him to express himself.

'Yeah I think so (having a male-only environment). I'm ex-service as probably some of you are? And in an army run home from the age of 10 and I think blokes get on best with blokes...All these blokes if they got annoyed would swear and relieve their feelings if they needed to do that...and they can here.' (Doug, Location Two, Focus group)

Care partners also agreed with this sentiment, suggesting the TI provided the men an environment that they were accustomed to during their working years, yet they were rarely afforded now in their daily rural lives. Similar to Doug, they suggested that the familiarity of this environment enabled the men to relax and express themselves.

"...all his working life he's been used to the company of men, he's never worked with women. And, all his hobbies were always to do with other men, they were never hobbies with men and women...the normality of socialising has probably, historically in his life, been with men and this is what he feels comfortable with." (Caroline, Old Boys, Interview)

'I think it was wonderful (the TI), because at the moment he is quite isolated in society and a lot of them miss the male camaraderie that they had...that they've had right through their business lives...and this is where they can feel themselves...feel relaxed.' (Grace, Marching On, Interview)

My data highlighted the importance of the male-only environment for creating a familiar and therefore relaxing and safe environment for the men, where they could freely express themselves without perceived restrictions that may be imposed by the presence of women. This environment enhanced the conceptual accessibility (Phinney et al, 2016; Wiersma et al, 2016) of the TI and ensured the men felt a sense of social inclusion.

## 6.4.2 Comradeship

The data suggested that many of the men developed a sense of 'comradeship' (Doug, Done Roaming, Focus group) and togetherness throughout the TI. This was generated through an acknowledgment that they were all on a 'similar level' (Dick, Marching On, Focus group). The men discussed a feeling of 'you're not on your own' (Gordon, Marching On, Focus group) and spoke in affectionate terms about one another, noting the 'warm side to the group' (Dick, Marching On, Interview) and the 'similar attitudes' (Ken, Old Boys, Focus group) where people 'were only too glad to add their little bit' (Dick, Marching On, Interview). As Bob illustrated:

'I go there and it's like alright Bob how are you doing? I don't think there's any there that will say anything against me. Yes they're good lads (laugh).' (Bob, Old Boys, Interview)

The feedback from Bob and Doug was particularly pertinent given their initial reluctance to engage with the TI and the other men in the early sessions. Although in the preliminary session of the TI, the conversations between the men were somewhat stifled (with the exception of Done Roaming), over time as the men relaxed and became more accustomed with one another then relationships began to develop (as highlighted in Section 4.3). Data elicited from my fieldnotes demonstrated numerous instances of the men's sense of comradeship and togetherness. These included: demonstrating to others how to play the games; shouting words of encouragement and support; passing around the biscuits and making the hot drinks; and supporting each other when navigating the venue or interacting with the technology. As these social connections developed the men discussed topics of conversation that were broader than their own life and the TI, such as the sports results and the Scottish Independence election (Old Boys) as well as the refugee crisis (Done Roaming). On occasions these conversations could be perceived as sexist, racist or homophobic and whilst they could be difficult to listen to, they demonstrated that the men were connecting on a broader level than just the activities and discussions initiated from the TI, as well as asserting their masculinities. These connections are important for their wider sense of social inclusion (Bartlett and O'Connor, 2010).

Furthermore, my data suggested that the men connected on a more emotional level and this supported the development of comradeship and solidarity. Although the men rarely spoke

openly about the issues they faced with dementia (and I never encouraged this) there was a sense that this connection was made.

'You know that you're talking to somebody about something and you know that they've got a bit of savvy. And you know what they're talking about and what they're thinking about...And I know that they know what I'm thinking about.' (Tel, Done Roaming, Interview)

The men reported that having the opportunity to be in the presence of, and emotionally connect with, other older men living with dementia provided them with a sense of comfort and reassurance.

'Well it's good to be with people and talk about things you have that you've experienced, and of course as I just said, meeting the Herberts in the same problem as yourself, it's a bit reassuring really.' (Jess, Marching On, Interview)

'...you don't walk about with a placard saying I've got dementia...So it's helped me by seeing other people had the same problem as I had. Whether it was to the same degree or worse, you know, but there was other people there that I could see had got the same problem, and they were living their life okay.' (Joe, Old Boys, Interview)

There was a sense that if women were present in the group then the men would not relate as well to one another as 'blokes take notice of others because they are blokes' (Doug, Done Roaming, Focus group) and therefore this feeling of emotional connection, comradeship and solidarity might be lost.

However, my data suggested that even within these male-only groups the men did not automatically bond with one another due to their differing attitudes. Terry discussed how these attitudes were integral to the group harmony:

'...if you put one bad badge in with the good ones, the good ones will all come falling down.' (Terry, Done Roaming, Interview)

This was most notable in Marching On, where the 'diversity' of the group and the 'certain attitudes' made it a challenge to manage the group and 'gel' the members (Tel, Marching On, Interview). Data ascertained from my field-notes suggested an animosity between some of the men within the Marching On group, based on their perceived social status that was expressed through their interests such as boxing and classical music. This would result in a few men making disparaging comments to others or refusing to engage with them. When these multiple masculinities could not be managed it resulted in men (Tel, Dave, Peter, Chris and Harry) leaving the group. Only after this point were the men able to form a more cohesive unit as discussed by Josh the volunteer:

'Now nobody is looking down their noses at somebody... I think that is what one or two had problems with initially. Like Harry and Tel, and I think that stopped them coming.'

(Josh, Marching On, Interview)

Chris' care partner, Thomasina also suggested this might have been the reason for her husband choosing to leave the TI when he was unable to recall his reasons.

'Perhaps his interests didn't correspond with many other people in the group, could that...? I mean...he was a university lecturer, he's written lots of quite highbrow books, he's passionately interested in classical music ...I think he didn't feel he fitted in or.' (Thomasina, Marching On, Interview)

Within the Done Roaming group, these clashing masculinities were also expressed by Doug again resulting in disharmony within the group; although in this instance, Doug became more willing to interact with the group as the sessions continued rather than leave the TI. Doug's initial reluctance to engage appeared to stem from his unwillingness to associate with people with dementia in groups targeted at this population of people. Informal discussions with him, elicited from my field-notes, suggested that he had internalised the stigma associated with dementia and this had threatened his sense of masculinity and his perception of his capabilities. Consequently he initially sought to reclaim this perceived masculinity by making disparaging comments and remarks about the other men. Over time however, once he realised the sessions did not focus on dementia and the men had interests that aligned with his, then he appeared more willing to engage with them. However during interview, he was still keen to disassociate himself from the men, even though he had appeared to enjoy their company during the TI.

Well, I found them a bit odd actually (other men in the group), but then I'm a Londoner. So I did find it very hard to become a friend of...an associate. Alright, they're there and they're in the same poo as you are, so that's about all it amounts to. I wouldn't want to visit them or go out with them. I don't know.' (Doug, Location Two, Interview)

This highlights the need to acknowledge the social positioning and heterogeneity of people with dementia (Hulko, 2009). Interestingly during the final focus group discussions, the men in Done Roaming and Marching On groups were hesitant about the groups increasing in size if the TI continued beyond the nine week research period. I perceived this to be indicative of the friction and the difficulties they had witnessed during the early stages of group development. Now that the groups had bonded and the men were more of a close-knit unit they were keen to preserve this harmony. In the Old Boys, where the group had not experienced such difficulties the men did not discuss a reluctance to see it expand in numbers. The close-knit cohesive nature of this group may be a feature of the 'bypassed' rural community (Keating et al, 2013) where the men are perceived as having similar social standing.

The key findings emerging from the data highlighted the importance of the male-only environment for affording the men a familiar and safe atmosphere where they felt comfortable

expressing themselves without perceived restrictions from women. Through openly expressing their masculinities it enabled them to develop a sense of social connection, comradeship and solidarity. These factors were important for their sense of social inclusion. However, enabling the men to express their masculinities resulted in the perceived social positioning and attitudes of the men becoming more pronounced. Consequently this led to frictions within the Done Roaming and Marching On groups. Where these could not be managed appropriately it resulted in men choosing to leave the TI.

## 6.5 Outcomes following the TI

The data demonstrated that by engaging with the TI the men were able to enhance their mood and social confidence; two important aspects for their perceived sense of social inclusion. For a few men, these benefits extended beyond the TI and were important for their willingness to reengage with their rural environments.

#### 6.5.1 Improved mood

Data ascertained from discussions with the men suggested their engagement with the TI enhanced their mood. As Dick exclaimed:

'If you've had a rotten start of the day, if you came here, then you feel a lot better... Yes those things like that they do linger don't they. You say cor that was bloody good, I enjoyed that.' (Dick, Location Three, Focus group)

For Doug, his participation in the TI helped to lift his spirits, providing him with a 'mental medicine' and preventing him from thinking about his condition.

"You come here and you start...fooling about with other people, you forget yourself and you forget you were a bit miserable with yourself. And that's good cause that lasts for a fair time. It's a good medicine...I'm still full of it yeah (after the club has finished). I'm talking to myself and I'm getting good answers (laughs!). I think it's a mental medicine.' (Doug, Location Two, Focus group)

This finding was also supported by data elicited from my field-notes, where I perceived instances of enhanced mood in the men once they had engaged with the activities. This was most notable in the men's body language including raising their fist in triumph or performing celebratory dances. I perceived this heightened mood to be attributed to their achievements at engaging with the technology.

For a few men, this positive mood extended beyond the two hours of the TI, as reported by care partners who described the men returning home with faces that looked 'alive,' 'energised' and 'fired up' (Caroline, Old Boys, Interview). The care partners reported that the men's participation in the TI appeared to reignite their interest and desire to engage and lead in conversations with them about the TI. This in turn raised the mood of the care partners as they could partake in conversations that the men showed obvious interest in.

'Yes, he used to talk more about it and that...the people he's met there and try and explain the games that he did on the computer...He was more animated when he came home, you know, wanting to talk about it and show me what he was doing.' (Shirley, Marching On, Interview)

As Linda reported during informal discussions, even though Keith only attended the first session due to his deteriorating health conditions, he was keen to share his new found interest with his daughter.

'I think he (Keith) really enjoyed it. He's been so uninterested in everything for a while now, so it was great to hear him talking to his daughter on the phone the other day. Telling her about the club and what he's been doing. He's not done that in ages. You've no idea how great that is!' (Linda, Old Boys, RFN session one)

This finding is particularly pertinent given the difficulties the men reported they faced when seeking to maintaining their relationships with family members (Section 5.3.2).

#### 6.5.2 Improved social confidence

Data elicited from my field-notes highlighted instances where the men appeared to progressively gain in social confidence throughout the nine weeks of the TI. I perceived this confidence was reflected in the way the men spoke to one another and engaged with me. This was particularly evident with men who were initially apprehensive at the start of the TI and reluctant to speak at length. One pertinent example from my field-notes during the Marching On group has been highlighted below:

'Gordon proceeded to tell a story about how he had left the tap running accidentally and it had flooded the kitchen...This got a lot of laughs from the men. Gordon's speech has improved a great deal since the first session...and he was able to tell the story confidently. I think his confidence has improved a lot...and now he is willing to talk for 5 minutes on his own. This would not have happened when the group first started as he spoke very little and struggled with his words.' (Marching On, RFN session 7)

There were two instances that suggested this heightened and progressive sense of social confidence infiltrated into other aspects of the men's lives outside of the group. Joe discussed his initial reluctance to drive to the TI as although he was still physically able, he lacked the confidence to do so. Over time, he became more assured of himself and began to use the car more frequently to attend the TI and to socially participate within the rural location.

'I know we've only played games... But it's helped me to start thinking for myself and trying different things out. It's really helped. Whereas I would sit at home before, I've now started to go to the library or the cinema. Always with somebody though but I wouldn't go with the wife before but now I said to her lets go to the library and the cinema.' (Joe, Old Boys, Focus group)

This new found social confidence and willingness for social inclusion within his rural location appeared a liberating experience for Joe, during feedback exclaiming:

'They (each session of the TI) have made me realise: Don't sit in the corner. Get out! Life hasn't finished just because you forget things.' (Joe, Old Boys, Focus group)

Angela also spoke of the difficulties Doug faced when coming to terms with his recent diagnosis of dementia. She reported that he was reluctant to participate in activities that she enjoyed doing (in this instance a dog training course) in the local rural area as he felt he would be judged. However while attending the TI, she felt he had grown in confidence and was now more willing and relaxed when socialising with other people in the rural area.

'And he just goes there (dog training classes), he doesn't actually speak to many people, but he speaks to one or two which he didn't do before. I think going to your Social Club made him so that he could mix with other people...Before...he didn't want to mix with people, he didn't want you to know...but...going to your Social Club, he discovered he was no different than others and he's better than some in his condition and it wasn't such a stigma, and that helped him...So it gave him more confidence when he goes to the dog classes.' (Angela, Done Roaming, Interview)

For both these men, their enhanced social confidence seemed to stem from their socialisation with other men with dementia living in their rural area and the opportunity to engage in new activities. Both men were socially isolated and spent a lot of time pondering their dementia diagnosis. Consequently, as highlighted in the academic literature (Burgener et al, 2015; Sabat, 2014), they internalised the stigma attached to the label of dementia and this detrimentally impacted on their sense of self-worth, perceived capabilities and social confidence. Through attending the TI, they were able to engage in new activities and socialise with other men in their rural environment who might have more limited capabilities than them but who were still living well with the condition. This challenged their assumptions of dementia and perceived capabilities, which in turn inspired them to re-engage and be socially included within their environment. This finding is consistent with Clare et al (2008) who suggested through the promotion of community, people feel less alone in their struggle against dementia and the associated stigma and discrimination, and this can provide them with more confidence.

## 6.6 Summary

Examining the findings through a social inclusion lens demonstrates that through engaging with the TI the men were able to fulfil important facets of social inclusion that were currently absent within their daily rural lives. The TI offered them an opportunity to: participate in an enjoyable activity within their local community; socially connect on a practical and emotional level with other men; engage with a novel activity that promoted life-long learning; and challenge negative assumptions associated with dementia. This resulted in a perceived enhancement in their mood and social confidence, which a few of the men extended beyond the confines of the TI. The TI

achieved this through various 'active mechanisms' (Dugmore et al, 2015) that appealed to the men and catered for their ranging masculinities; thereby enhancing their sense of social inclusion. These factors will be discussed in the final chapter when determining how social inclusion can be encouraged in older men with dementia residing in rural locations.

## Chapter 7: Enhancing male social inclusion in rural England

#### 7.1 Introduction

This was an applied, exploratory multi-method qualitative study situated within a Participatory Action Research (PAR) framework. An individually-tailored Technological Initiative (TI) drawing on commercially available gaming technologies (iPad, Nintendo Wii and Microsoft Kinect) was delivered over nine consecutive weeks in three rural locations of England. The focus of the TI was to promote social inclusion in older men (65 years or older) with dementia residing within rural environments. In accordance with the PAR approach adopted, the men were encouraged to contribute to the evolution of the TI and offer their feedback upon its completion. Twenty-two men provided me on-going consent to participate in the TI, although six men left the initiative before the end of the nine week period. Following completion of the TI, fifteen of the men participated in focus groups discussions and nineteen undertook open interviews. The information they provided was triangulated alongside data ascertained from interviews with fifteen care partners and five community volunteers as well as my own extensive reflexive fieldnotes. The preceding three chapters have presented my experiences of working with the men and outlined their thoughts about living within the rural locations and contributing and participating in the TI. This chapter will examine and discuss these findings in relation to the three research questions posed at the beginning of the thesis and explore them through a combination of a social inclusion and masculinity lens. It will situate these perceived experiences within the wider academic literature and in doing so will provide insights into how social inclusion can be promoted more widely in older men with dementia residing in rural areas. Following this, the chapter will discuss the strengths and limitations of the study before concluding by offering recommendations for policy, research and practice as well as highlighting potential areas for future research.

The three research questions posed in Chapter 1 of the thesis were:

- 1. How does the rural environment impact on the sense of social inclusion of older men with dementia?
- 2. What is the impact of a Technological Initiative on the men's sense of social inclusion?
- 3. How does a Technological Initiative promote male social inclusion?

Each of these three research questions will be addressed in turn drawing on the findings of my study, examining them through a combination of a social inclusion and masculinity lens, and situating them within the wider academic literature.

# 7.2 How does the rural environment impact on the sense of social inclusion of older men with dementia?

This is the first study to have explored the experiences of older men with dementia residing in rural areas of England. Although these findings are based on older men in one predominantly rural area of England, they have relevance for international work in this field.

Over the past twelve years, since Innes and Sherlock (2004) issued a call for understanding the impact of rurality on the social inclusion of people with dementia, researchers have sought to explore these experiences in rural areas of Australia (Alexander and Fraser, 2008; Hansen et al, 2005; Orpin et al, 2014), Canada (Dal Bello-Haas et al, 2014; Forbes et al, 2006; Forbes et al, 2011; Morgan et al, 2009), USA (Boise et al, 2010; Meuser et al, 2004) as well as in the UK (Blackstock et al, 2006; Clarke and Bailey, 2016; Gilmour et al, 2003; Hennessey et al, 2014; Innes et al, 2005; Innes et al, 2012). My study demonstrated that, in common with these previous studies, rurality continues to offer benefits and specific challenges to those with dementia and therefore highlights the need to acknowledge this geo-socio-cultural context within UK dementia policy (Alzheimer's Society, 2013; Department of Health, 2015).

Similar to other research with older people (Bacsu et al, 2014; Menec et al, 2015) and those with dementia (Blackstock et al, 2006; Forbes et al, 2011), the men in my study drew from the narrative of the 'Rural Idyll' (Butler and Cohen, 2010; Cloke and Milbourne, 1992) to describe their positive experiences of living in the rural locations. This included the pleasant and picturesque landscape that offered a tranquil, safe space and promoted a sense of attachment, as well as the friendly and supportive informal support they received from the local rural community. These ensured that predominantly the men spoke of 'cracking on with life' (Harry, interview) or living well with dementia in their rural locations and this is why they had chosen to remain there. This resonates with other research in the UK that suggests people with dementia experience a sense of positivity and social inclusion within their rural environments despite the difficulties they may encounter (Blackstock et al, 2006; Clarke and Bailey, 2016). In my study, only Doug who had recently been diagnosed with the condition was not as positive about living with dementia in the rural environment. He appeared to have internalised the multiple jeopardies (Benbow and Jolley, 2012; Hulko, 2009; Innes, 2003; McParland, 2014) associated with ageing and dementia and this had detrimentally impacted on his self-worth and perceived capabilities; leaving him with a feeling of hopelessness. Whilst this stoicism displayed by the majority of men may be a product of traditional rural-dwelling masculinities (Hammer et al, 2013; Levan and Habben, 2003), it suggests that rurality can enable people with dementia to live positively with the condition and so experience a sense of social inclusion. This finding is also important for challenging the 'tragedy discourse' (McParland et al, 2016; Zeilig, 2014) and providing further support for research that demonstrates it is possible to live well with dementia (McParland et al, 2016; Wolverson et al, 2015).

However, in keeping with other national (Blackstock et al, 2006; Clarke and Bailey, 2016; Innes et al, 2014) and international studies (Forbes et al, 2011) the men were also realists who did not overly romanticise their rural life. They discussed macro and mezzo rural influencers of their geo-socio-cultural rural environment that worked independently and in conjunction with one another to both enhance and restrict their social inclusion. In addition to this they were also 'active social agents' (Bartlett and O'Connor, 2010; Bell, 2004) who were both a product as well as a co-constructor in their experiences of daily living within their rural environments.

Examining my findings through a lens of social inclusion as outlined in my definition of social inclusion in Chapter 2, highlights how, although the men had many of the material (Ward, 2009) facets to enable their social inclusion, the rural environment could both enhance and limit other important facets of the men's social inclusion, including opportunities to:

- Participate within the rural environment
- · Maintain and develop relationships
- Retain agency and respect

This finding resonates with the wider disability literature that highlights people with intellectual and physical disabilities often face challenges to their social inclusion due to their interpersonal relationships and the lack of accessible opportunities for participation within their community (Davey and Gordon, 2017; Simplican et al , 2015). This also resonates with Forbes et al (2011) who demonstrated how people living with dementia in rural locations of Canada faced challenges associated with experiencing quality relationships, having input into their care decisions and participating in activities within their community. Each of the aforementioned facets will be discussed in turn.

## 7.2.1 Opportunities to participate within the rural environment

The rural locations were perceived as safe and pleasant, consistent with the narrative of the 'Rural Idyll' (Butler and Cohen, 2010; Cloke and Milbourne, 1992). The men and their care partners reported a sense of attachment to the area and enjoyed interacting with it by taking walks out into the countryside. This was noted during discussions with the men as well as in their responses to the open-ended questionnaire. For men such as Bob and Doug, being enabled to undertake long walks on their own helped raise their spirits when they were feeling dejected. As both of these men (in addition to Bill) were familiar with their rural locations, they felt comfortable navigating them on their own.

This finding resonates with Clarke and Bailey (2016) who highlight the importance of familiarity with the rural location, for the sense of inclusion experienced by people with dementia living in rural England. It also offers further support for research that has highlighted the therapeutic benefits the natural landscape can provide (Butler and Cohen, 2010; Miller et al, 2011) particularly when promoting well-being and quality of life in people with dementia (Gilliard and Marshall, 2012; Mapes and Hines, 2011). Furthermore, research has suggested exercise may have a positive effect on the rate of cognitive decline and global function in people with Alzheimer's Disease (Farina et al, 2014) as well as improve selective attention and balance in people living with dementia in rural Canada (Dal Bello-Has et al, 2014). My research therefore confirms that rural environments can offer an attractive environment whereby mild exercise can be promoted and this has potential for the positive well-being and social inclusion of people with dementia.

The men and their care partners also spoke in glowing terms about the informal support they received from people living locally and this ensured they could remain socially connected within the local rural environment. All of the men had resided in the community for substantial periods of time (minimum 7 years and maximum 83 years) and over these years had developed these supportive networks that promoted their sense of social inclusion. This is in accordance with previous research that has pointed to the value of positive community connections and socialisation for the social inclusion of people with dementia (Bartlett and O'Connor, 2010; Cantley and Bowes, 2004; Cook, 2008; Hayes et al, 2008; Ryan et al, 2008) and these facets are integral to the UK's social inclusion policy agenda (Alzheimer's Society, 2013; Department of Health, 2015).

As found in previous research (Blackstock et al, 2006; Clarke and Bailey, 2016; Forbes et al, 2011), these informal networks were reported by the men and their care partners as important for ensuring they could participate within their rural community and were an essential resource for alleviating issues associated with a lack of formal dementia services. This was particularly the case for the Old Boys such as Bob, who resided in an area typical of a 'bypassed' rural community (Keating et al, 2013), yet managed to retain his sense of social inclusion through the informal rural networks that he had developed over his lifetime in the rural location. For men such as Jess, who lived alone after his wife died, the rural network was invaluable to mitigate issues associated with a lack of close-by familial support. People in the rural area would regularly visit him or drive him to attend events within and around the rural location. This demonstrates how these informal rural support networks can help to alleviate the risks of social isolation and exclusion that are particularly pertinent for older people (Age UK, 2015) and may be exacerbated in rural areas where younger family members often leave to pursue employment and educational opportunities in urban environments (Francis, 2012). For other men such as David, the supportive networks ensured they could continue with social activities they enjoyed such as golf or visiting the pub. Previous research has highlighted that social and recreational activities are important for maintaining a sense of identity (Genoe and Dupuis, 2011) as well as enhancing well-being (Phinney et al, 2007) and social inclusion (Bartlett and O'Connor, 2010; Cook, 2008). For Harry, the rural networks also ensured that he could continue to work after the on-set of dementia. Being enabled to contribute economically is an important facet (Buckmaster and Thomas, 2009; Levitas, 2004; Taket et al, 2009, 2014) or major life domain (Neely-Barnes and Elswick, 2016) of social inclusion. Whilst this was not a prevalent issue for the men in the study, given that they were all post retirement, this finding demonstrates this is something the rural support networks could accommodate. This may be particularly important for older men (Genoe and Singleton, 2006) and men living with dementia (Carone et al, 2014; Phinney et al, 2013) where the loss of employment may have detrimental impacts on their masculinities.

It is important to note however that only John had moved to the rural location post diagnosis. Therefore as posited by Innes et al (2005), these informal networks are likely to be more

supportive of the men as they were already part of them prior to the onset of dementia. Comments such as those by Caroline that people were supportive 'because they know the person you were...and it's quite hard to get to know the person you may become' (Caroline, Old Boys, Interview) resonate with Blackstock et al (2006) who posited that these rural close-knit informal support networks can be difficult to penetrate if you have dementia and only recently moved to the area. Therefore future research might usefully be focussed on exploring the experiences and perceptions of people with dementia who have recently moved to these rural locations.

Despite the positive facets of the rural environment that enabled the men to remain socially connected, they also reported issues they faced with accessing opportunities for social inclusion in their location. Research has highlighted the multi-faceted nature of 'accessibility' (Bevan, 2013; Farrington, 2003) that requires activities and services to be physically accessible and available at appropriate times as well as provide a physically and conceptually safe environment for people with dementia (Wiersma et al, 2016). My research suggested that multiple factors of the rural geo-socio-cultural environment restricted the accessibility of these opportunities for people with dementia, including, a lack of services, the rural landscape as well as discursive factors (Ward, 2009) such as a lack of dementia awareness in the communities. This was exacerbated by the men's reluctance on occasions to participate within the rural environment. These issues will now be discussed in turn.

Within the rural locations -and particularly during the winter months- the men reported a lack of available opportunities to socially and culturally participate in the rural environments. As such there was a focus on formal, structured services to provide these opportunities. However the perceived fiscal constraints were leading to a reduction in formal services for people with dementia. This was particularly evident in Location One, where it was felt these opportunities were limited as resources and finances had bypassed the community in favour of the more affluent rural locations and close-by urban settlement. My finding is similar to earlier national (Clarke and Bailey, 2016; Innes et al, 2006, 2014) and international studies (Morgan et al, 2011, 2015) that have demonstrated the reduction in formal rural care services, as they are reassigned to urban areas with higher population densities. This suggests there has been limited progress in terms of formal dementia services in rural settings over the intervening years.

The men and their care partners also reported that the physical aspects of the rural environment could make it difficult for them to independently access opportunities for social inclusion within their communities. For instance, the lack of transport options meant that the majority of men (with the exception of Joe and Jess who owned their own cars) were reliant on their care partners to transport them to any activities. This finding provides further support for the growing body of literature that reports inadequate transport options in rural areas (Innes et al, 2011, 2014; Menec et al, 2015; Szymczynska et al, 2011) and therefore advocates calls to improve services as a means to uphold the rights of people with dementia to be enabled to socially participate within their rural environments. In addition to this, men such as Joe and Keith also

reported difficulties accessing the rural environment due to their deteriorating physical capabilities and health conditions. Consequently, they rarely participated in the rural environment; thereby socially isolating themselves. This resonates with Blackstock et al (2006) who highlight how the once picturesque and safe rural environment can become a frightening and difficult landscape to traverse as people age; particularly if they experience disorientation and navigational difficulties associated with dementia.

Furthermore these issues were compounded at a mezzo level by the lack of dementia awareness that was reported in these rural locations; both amongst the rural residents as well as the health professionals. These discursive factors (Ward, 2009) have been reported widely within the disability literature for the challenges they can place on disabled people to access social and cultural opportunities within their community and develop meaningful relationships (Simplican et al, 2015). My findings also suggested that this was the same for the men with dementia in all three of the rural locations. Whilst these misunderstandings are common place (ADI, 2012) research has suggested they may be more prevalent in rural locations due to the close-knit informal networks (Innes et al, 2006). The men reported the stigma or 'fear' associated with dementia that led some rural residents to exclude them from opportunities to participate within their rural environment, particularly if they displayed 'anti-social' (Blackstock et al, 2006) behaviour. For instance Sue and Colin felt they were prohibited from attending the monthly community film event once Colin began to shout out during the movie. This stigma was also transferred to formal services for people with dementia including activity groups and health professionals supporting these services. For instance Terry (Done Roaming) felt he could not tell his neighbours that he had taken part in the research and spoken with me as they would think he 'had gone screwball' (Terry, Done Roaming, interview). These findings resonate with other research that demonstrates that the stigma attached to rural dementia healthcare services and health professionals can restrict their use by people with dementia (Bowes et al, 2016; Innes et al, 2014; Morgan et al, 2011) and subsequently their social inclusion within rural communities. This has implications for the recruitment of rural-dwelling people with dementia to community ecopsychosocial initiatives. In addition to this the men also suggested that health professionals adopted a more biomedical focus when supporting people with dementia, rather than a more holistic person-centred approach. Consequently this had adverse effects on their treatment of the men and/or their awareness of community ecopsychosocial initiatives and willingness to promote them. My findings resonate with Clarke and Bailey (2016) who have also reported on how a narrow bio-medical approach to understanding dementia can restrict the services offered to people in rural areas of England; leading to a focus on services solely designed to support the management of dementia rather than provide more creative activities that can enable a wider sense of social inclusion. This emphasises the importance of providing better dementia awareness training to rural healthcare providers and commissioning authorities to afford them a more holistic understanding of supporting people with dementia that is situated within a wider social inclusion or citizenship and human rights framework (Brannelly, 2016; Kelly and Innes, 2013).

#### 7.2.2 Maintaining meaningful relationships

Whilst the men reported a close relationship with their care partner, who was the prime resource for both practical and emotional support, they highlighted difficulties in maintaining relationships with people living within their rural community as well as their children and other family members. These positive relationships are important for promoting companionship, love and safety (Cook, 2008; Kitwood, 1997) and ensuring people retain a sense of connection that can enable feelings of social inclusion (Cantley and Bowes, 2004; Cook, 2008; Forbes et al, 2011). Although the men and their care partners spoke of friends and rural residents that provided them with support, there was a sense that this was often practical support for the men rather than any deeper emotional connection. This resonates with Simplican et al (2015) who suggest that people with disabilities can have a high number of social connections although they may offer limited satisfaction or emotional connection, and this detrimentally impacts on their sense of social inclusion. Consequently the men in my research were often reliant on their care partners to provide them with this unmet need. Joe in particular felt these difficulties were systemic in modern day communities where people preferred to 'keep themselves to themselves.' This is reminiscent of wider social inclusion literature (Bell, 2004; Winlow and Hall, 2013; Taket et al, 2014) that posits that weakened communities and diminished social capital can make it particularly difficult for socially excluded people, including those with dementia (Cantley and Bowes, 2004), to form meaningful relationships. Men and their care partners reported losing long-term friends after a diagnosis of dementia as a lack of understanding or 'fear' of the condition resulted in them tending to avoid them. These findings provide further support for research that has highlighted the fear associated with dementia (Corner and Bond, 2004) that can detrimentally impact on people's willingness to maintain meaningful relationships with people living with the condition (Forbes et al, 2011) and so ensure they can uphold these rights for social inclusion (Bartlett and O'Connor, 2010; Cook, 2008; Cantley and Bowes, 2004).

Furthermore, both the men and their care partners expressed difficulties in relationships with their children and other family members. Although some care partners reported their children were a useful source of support, these instances were minimal and often limited to those members who had some prior knowledge of dementia (such as John's family) or lived within the rural location (such as Bob's family). This latter finding highlights how bypassed rural communities (Keating et al, 2013) where people with dementia may have strong familial presence may be better equipped at ensuring people with dementia can maintain meaningful relationships with their family members. The issues the men encountered again originated from a lack of dementia awareness amongst these family members. Care partners reported that family members belittled the difficulties they faced exclaiming the men appeared 'fine' (Veronica, Marching On, interview) or were unappreciative of the time and emotional resource that was required to support the men. However as many of the family members lived outside of the rural areas then it was easier for them to avoid visiting and this detrimentally impacted on the relationships that the men were able to sustain with them. For men such as Doug who appeared to hold strong traditional hegemonic masculine values, then losing his role as the

father figure adversely impacted on his masculinity and subsequently his well-being and feelings of self-worth. This aligns well with Sabat's concept of selfhood (Sabat, 2001, 2002) and demonstrates the importance for people with dementia to maintain positive inter-personal relationships that enable them to express their 'third self,' that of the publically presented personae (Sabat, 2001). These issues have been reported in other people with dementia residing in rural areas of Canada (Forbes et al, 2011) and may be felt more pertinently in older men who hold traditional hegemonic masculine characteristics that emphasise their social position as head of the family. This finding supports other research that has explored the experiences of community-dwelling men with dementia and reported on the detrimental impact the condition has on their perceived loss of role within the family (Carone et al. 2014; Phinney et al, 2013). However conversely to Phinney et al (2013) who demonstrated how the families sought to work together to attempt to enable the men to retain their social position as a father and head of the family, this was not as apparent in my study. This is potentially due to the additional impact of rurality that meant many of the men's younger family members lived away from the rural location and so it was easier to maintain their distance rather than seek ways to regularly engage the men and support their sense of social inclusion. Again this highlights the importance of reducing the stigma of dementia at a societal level, thereby ensuring people with dementia can maintain relationships that are essential for their sense of social inclusion.

#### 7.2.3 Retain autonomy and respect

Having the recognition as a competent individual and trusted to undertake social roles in the community is an important facet of social inclusion for people with disabilities (Cobigo et al, 2012; Simplican et al, 2015). This is also true for people with dementia who have the right to retain autonomy and to be treated with dignity and respect. These rights enable them to sustain their social inclusion (Bartlett and O'Connor, 2010; Cook, 2008; Innes, 2009; Kitwood, 1997) and support the maintenance of self and well-being (Caddell and Clare, 2010; Kelly, 2010; Kitwood, 1997; Sabat, 2014).

The care partners mostly understood the importance of these rights and reported on how they went to great lengths to ensure they promoted them, particularly in the home environment. For instance, Joan and Angela would enable their husbands to contribute to the household chores independently and Sheila would support her husband so that he could maintain his role as the housing secretary. These were important for the men's masculinity and self-worth and ensured the home environment was a positive one for them, where they felt socially included. Literature from the wider disability field has highlighted the importance of understanding the domestic domain when supporting social inclusion for people with disabilities (Neely-Barnes and Elswick, 2016). This also resonates with Bartlett (2016) who has argued the need for research to better understand the domestic sphere and how equality and inequality for people with dementia can be enacted within this space. Through this means she posits that the Dementia Friendly Communities initiative (Alzheimer's Society, 2013) can be advanced as well as the wider social justice and inclusion agenda. My finding supports these calls to further explore how the

experience of the home environment can assist the social inclusion of rural-dwelling people with dementia.

Within the wider rural environment however the men reported challenges that they faced to maintain their agency and to have their opinions valued and respected. This finding resonates with the wider social inclusion literature that posits that 'social inclusion/exclusion' is a dynamic process where people can experience social inclusion in certain situations and aspects of their life (in their home as was the case with the men) within their wider experiences of social exclusion (Cobigo et al, 2012; Hunting et al, 2015; Taket et al, 2014; Ward, 2009). While a few of the men reported engaging with the rural environment independently such as Doug, Gordon and Bill, these instances were rare and often the men were reliant on their care partners to drive them around or accompany them when they went out. The emphasis that some men placed on losing their driving licence highlights how integral it was to their sense of masculinity; representing their loss of independence and autonomy. This resonates with Coston and Kimmel (2013) who suggest the revocation of the driving licence is felt more by men not only as a practical restraint but also for what it symbolises in relation to traditional concepts of masculinity; a diminishment of their autonomy and control and so a lessening of their masculinities. Within the rural environment where the car is paramount for participating within the community and maintaining a sense of autonomy and social inclusion then this perceived deficiency in their masculinity is likely to be continually enforced. Again, therefore, this finding provides support for the need to enhance public transport within rural areas to promote agency for people living with dementia in these locations (Innes et al, 2011; Szymczynska et al, 2011) and may be particularly important for men, as a means to enable them to sustain important facets of their masculinities.

The men and their care partner's reported that the lack of dementia awareness amongst the rural communities, including health professionals and family members, also adversely impacted on the autonomy and respect that they felt they were afforded. This usually occurred as a result of discursive factors (Ward, 2009) such as people's ill-informed perceptions of the men's capabilities. For instance Joe reported his son looked upon him as 'a nutter' and didn't value his opinions and Jess described his son arranging for people to turn up at his house without informing him of this. Furthermore, other men such as David and John reported instances of being 'infantilised' (Kitwood, 1997) by health professionals and Joe described a story where he had to 'pester' a doctor to fill in the papers he required to enable him to drive and so maintain independence. These situations highlighted how the rural environment and members of the rural community denied the men respect and hindered their opportunities for a voice, to exert control over their own lives and consequently inhibited their social rights as citizens. These findings are consistent with research that demonstrates people with dementia feel they receive less respect once they have been diagnosed with the condition (Burgener et al, 2015) and this can result in a sense of depreciative self-worth (Burgener et al. 2015; Sabat, 2014) and detrimentally impact on their social inclusion (Bartlett and O'Connor, 2010; Cantley and Bowes,

2004; Cook, 2008; Innes, 2009). It also resulted in some men such as Joe, feeling that they had to wear a 'social mask' (Davey and Gordon, 2017) rather than disclose their dementia diagnosis for fear this would impact on their social inclusion and residents willingness to engage with them. These discursive factors may be particularly destructive to the maintenance of identities within older men who have indicated a desire to uphold traditional hegemonic masculine ideals of independence and autonomy (Tannenbaum and Frank, 2011; Thompson and Langendoerfer, 2016).

My findings, consistent with other research (Bowes et al, 2016; Clarke and Bailey, 2016) offer further support that there remains a need to provide training to rural healthcare providers as well as raise dementia awareness within rural areas more widely. It is important that this training is situated within a social inclusion or citizenship framework that promotes the human rights of people with dementia (Brannelly, 2011; Clarke and Bailey, 2016; Kelly and Innes, 2013) and moves beyond a narrow biomedical focus that solely emphasises maintaining the safety of a person with dementia or enabling them to manage their condition appropriately. It is also essential that this training acknowledges masculinities where desires to maintain independence, self-reliance and imperviousness to pain often detrimentally impact on older men's health-related behaviours; resulting in them avoiding seeking professional help as a way to preserve masculinity (Tannenbaum and Frank, 2011; Thompson and Langendoerfer, 2016).

Consequently healthcare providers must be attuned to these masculinities and feel enabled to offer dementia support that is respectful of them.

Interestingly, although aspects of the geo-socio-cultural rural environment sought to hinder the social inclusion of the men, the men also reported on occasions where they influenced their own sense of social inclusion. For instance they highlighted instances where they were apathetic towards participating in the rural environment or attending structured activities as they did not appeal to them. This resonates with the wider social inclusion literature that emphasises the individual agency of people, whereby they have the ability to choose whether to socially engage or exclude themselves (Brown et al 2015; Taket et al 2009, 2014) even when presented with opportunities for social inclusion (Davey and Gordon, 2017). It is also reminiscent of authors in the dementia field who have called attention to the role of people with dementia as active social agents (Bartlett and O'Connor, 2010; Bell, 2004) who are co-contributors as well as products of their social inclusion. Furthermore, care partners also described instances where the men opted against enacting their sense of agency and instead looked to them to make the decisions. They attributed this to the men's lack of social confidence. This resonates with psychosocial constructions of dementia (Keady et al, 2013; Sabat, 2014) that highlight the range of emotions people with dementia can face when confronted with neurological issues, such as embarrassment, anger, depression (Sabat, 2014) and apathy (Manera et al. 2015), that adversely impact on their behaviour and motivation when living with the condition. This finding has also been reported by Clarke and Bailey (2016) who demonstrated that people with dementia in rural northern England played an active role in their social exclusion, choosing not

to participate due to feelings of embarrassment and perceptions that their standing in the community had diminished with the onset of dementia. It is also reminiscent of Forbes et al (2011; page 37) who described one of their participant's lives in rural Canada as getting 'smaller and smaller with nothing to look forward to' as the symptoms of dementia increased thereby hindering their willingness for social inclusion within their rural environment. The psychological issues experienced by the men in my study may be particularly devastating for them due to their perceived privileged social standing prior to the onset of dementia, as consistent with research by Hulko (2009).

These findings offer further support for the need to acknowledge the role that people with dementia have in their interpersonal and social relationships (Bartlett and O'Connor, 2010). As such it is integral that ecopsychosocial community activities appeal to the men and seek to raise their motivation and social confidence so they feel enabled to re-connect and re-contribute to their rural environment; thereby enhancing their sense of social inclusion as well as ensuring they can sustain important facets of their masculinities. With this in mind, the discussion now turns to the impact of the TI on the men's sense of social inclusion.

# 7.3 What is the impact of a Technological Initiative on the men's sense of social inclusion?

The majority of men reported that the TI was welcomed and enabled them to participate within their local environment, thereby ensuring they could address the perceived challenges they were experiencing for their sense of social inclusion. Those who had previously engaged least with their local community or demonstrated apathy towards participating within their rural environment (such as Joe, Doug and Terry) exhibited as much enthusiasm as the other members towards the TI. As such the TI provided a social and leisure opportunity that the men willingly chose to engage with. Adopting a social inclusion lens in accordance with my definition of social inclusion in Chapter 2, demonstrated that the TI afforded the men the unconditional opportunity to:

- participate within their local environment
- engage in a 'meaningful activity'
- socially connect and develop meaningful relationships
- continue their individual growth and life-long learning
- challenge negative assumptions around dementia
- have their voices heard and validated.

These facets are consistent with the wider disability literature that has highlighted the need for participation, inter-personal relationships and recognition and value when promoting social inclusion in people with disabilities (Cobigo et al, 2012; Simplican et al, 2015). These are also considered to be fundamental rights for the social inclusion of people with dementia (Bartlett and O'Connor, 2010; Cantley and Bowes, 2005; Cook, 2008; Forbes et al, 2011) and should be guiding principles in any frameworks for health and ageing (Bartlett and O'Connor, 2010).

Importantly, the men's responses to the pre-initiative questionnaire suggested it was these psychosocial benefits that were more important to the men then obtaining a better understanding of their dementia. This finding is in accordance with other research that has demonstrated the desire of people with dementia to engage in activities that are meaningful to them within their local community (Han et al, 2015; Phinney et al, 2007, 2008) and emphasised the need to provide more opportunities for social and recreational activities that appeal to people with dementia (Miranda-Castillo et al, 2013). My work therefore provides support and signposts for the way in which initiatives can be designed to address the needs of older, socially isolated men with dementia in general and especially in rural environments.

Through engaging with the TI the men reported perceived positive impacts on the their mood and social confidence, which for a few men extended beyond the confines of the two hours of the TI and into their lives within the rural community. This finding is consistent with the growing body of literature that demonstrates the benefits of ecopsychosocial initiatives for people with dementia (Dugmore et al, 2015; Olazaran et al, 2010; Oyebode and Parveen, 2016) as well as the emerging literature that explores the benefits of leisure activities (Dupuis et al, 2012; Fortune and McKeown, 2016; Genoe and Dupuis, 2011, 2014; Phinney and Moody, 2011) and the use of commercial gaming technology to support the well-being (Bowes et al, 2016; Evans et al, 2015; Fenney and Lee, 2010; Leahey and Singleton, 2011; Leng et al, 2014; Padala et al, 2012; Upton et al, 2011) and healthy ageing (Cutler et al, 2016) of this population.

Interestingly however, the TI differed from other community initiatives the men were offered within their rural areas (particularly in Locations Two and Three) through its use of an atypical activity; commercial gaming technology. Older people (Heart and Kalderon, 2013; Peek et al, 2014) and particularly those with dementia in rural areas, are often assumed to be uninterested or incapable of engaging with this medium. Commonly, this is due to assumptions that younger people (Heart and Kalderon et al, 2013) and those living in urban areas (Townsend et al, 2013) are more likely to interact with technology that their older or rural counterparts (the 'digital divide') coupled with arguments that people with dementia require dementia-specific technology (Astell, 2013). Whilst these views may be changing, particularly in Europe (Bowes et al, 2016), the limited research in this field as highlighted in section 2.7.3 suggest there are still difficulties in promoting this medium to people with dementia. Consequently, this is not an activity you would commonly associate with this population, and the reports from the open ended questionnaires that showed only six men had prior experience in using the technology (David, Joe, Phil, Terry. Jess and Tel) support this assumption.

Contrary to this however, the men in my research, irrespective of the length of time they had been diagnosed with dementia and their limited previous experience of using technology, were willing and capable of engaging with the commercial gaming technology. Furthermore, they also reported a desire to learn more about the equipment and the games and to improve on their performances; with men such as Jess requesting specific learning agendas to support their development and others such as David and Joe seeking to use the equipment outside of the TI

to supplement their learning. This resonates with other research that has demonstrated the desire and ability of people with dementia to engage with commercial gaming technology (Cutler et al, 2016; Evans et al, 2015; Leahey and Singleton, 2011). The use of this atypical activity offers great benefits for the social inclusion agenda by enabling the men to learn something new as well as challenge negative assumptions of dementia.

The men reported an enjoyment at interacting with systems they perceived synonymous with modern society and this was important for their sense of development and wider social inclusion. Although the technology is atypical to the men it was evident that it was viewed by them as a typical activity for people generally within society. Therefore, enabling them to engage successfully with this activity enhanced their sense of social inclusion and the connectedness they felt with society. For some men such as Joe and Keith, they were keen to share this new knowledge and learning with their younger family members, thereby developing a connection with them and so enhancing their sense of social inclusion. This resonates with Fortune and McKeown (2016) who emphasise the need for people with dementia to feel embedded within their community to feel total social inclusion. It is unlikely that this sense of social inclusion would have been felt as pertinently if the clubs used dementia-specific technology as this is not as widespread throughout society and draws attention to the men's dementia and the modifications that have been made to enable them to use it. Furthermore, as the commercial technology is synonymous with modern society then there is also the potential for it to be used as a 'hook' to encourage other members of the rural communities to engage with the groups if they are interested in learning more about the equipment; thereby further embedding the groups within the rural community. This may be particularly beneficial in rural environments where the rural/urban technology divide (Townsend et al, 2013) means that other members of the rural community are unlikely to have used some of the technology previously. This finding provides further confirmation that people with dementia should be offered opportunities for life-long learning even post-diagnosis to support their growth as individuals (Alzheimer's Scotland, 2009; Bartlett and O'Connor, 2010; Cutler et al, 2016; Ryans et al, 2008) and so maintain their sense of social inclusion. It also suggests that commercial gaming technology may be a particularly useful means to enable an enhanced sense of social inclusion due to what it symbolises; something that is fundamental within modern society.

The use of an atypical activity also enabled the men to challenge negative assumptions of their capabilities as well as those of other people. Challenging these negative assumptions is important for promoting a wider social inclusion agenda beyond the confines of a community ecopsychosocial initiative (Phinney et al, 2016). Section 5.3 demonstrated that within the rural areas the men perceived they were subjected to a lack of dementia awareness and ill-informed assumptions around their capabilities that adversely impacted on their sense of social inclusion. Consistent with other literature (Bartlett and O'Connor, 2010; Burgener et al, 2015; Cook, 2008; Kitwood, 1997; Sabat, 2014) these opinions were internalised by the men and detrimentally impacted on their assumptions of their own capabilities, as well as people's willingness to

socially include them within their communities. My research demonstrated that encouraging the men to engage in a novel, atypical activity began to challenge their views of their own capabilities and subsequently provided them a sense of self-achievement when successfully accomplishing the games; thus heightening their mood, confidence and sense of well-being. For men such as Joe and Doug, this was a particularly liberating experience as they were able to challenge their own assumptions of their capabilities and so afford themselves a sense of hope when living with dementia that inspired them to become more socially included within their rural environment. Furthermore, my research suggested that the activities were also found to challenge other people's expectations of dementia. This finding provides support for Genoe (2010) who has argued that by engaging in atypical leisure activities people with dementia can begin to challenge these negative discourses and assumptions of dementia and ageing. They also echo that of Cutler et al (2016) who suggested that a 'Tech Club' could be used to challenge expectations of dementia and therefore promote a wider Healthy Ageing agenda. Engaging in activities such as commercial gaming technology, enable people with dementia to challenge negative discourses of the condition and so benefit the wider social inclusion agenda that seeks to promote dementia-friendly communities (Alzheimer's Society, 2013). This finding is consistent with Dupuis et al (2016) who reported that a community-based arts group provided a co-transformational space whereby people with dementia could challenge their own and others' (artists, actors and researchers) views of dementia and so bring about a deeper, more meaningful positive personal change in themselves and other individuals. As such my research supports other authors' (Cutler et al, 2016; Genoe, 2010) calls for an increase in the awareness of atypical community-based ecopsychosocial initiatives amongst practitioners to benefit the wider social inclusion agenda.

# 7.4 How does a Technological Initiative promote male social inclusion?

A core objective of the research was to develop an initiative that would appeal to older men with dementia in rural England and so enhance their sense of social inclusion. My findings outlined in the previous sections suggest that the TI was successful in enhancing facets of the men's social inclusion that were currently restricted within their rural environments. In accordance with my social inclusion definition, this included: providing unconditional opportunities for the men to access and participate in a social initiative and develop inter-personal meaningful relationships that enabled their personal growth and sense of connection and solidarity as well as ensuring they felt valued and positioned as equals and could maintain their sense of agency.

The following discussion seeks to address calls (Dugmore et al, 2015; Kenigsberg et al, 2016; Oyebode and Parveen, 2016) to provide more detailed insights into the processes whereby ecopsychosocial initiatives result in benefits for people with dementia. Emerging research in this field is limited at present, predominantly focussing on 'Men in Sheds' (Wilson and Cordier, 2013; Milligan et al, 2015) initiatives (that mainly focus on older men without dementia) and footballing initiatives (Carone et al, 2014; Solari and Solomons, 2012; Tolson and Schofield, 2012). Therefore this was the first study to explore how social inclusion is promoted in older men with dementia using a Technological Initiative. Adopting a masculinity lens as outlined in my

definition of masculinity in Chapter 2, my findings suggested that, consistent with other limited research (Bartlett, 2007; Coston and Kimmel, 2013; Phinney et al, 2013) the men retained aspects of their masculinities and some that were akin to that of traditional Western hegemonic ideal. Subsequently the TI provided the men a non-threatening social space in which they could perform, express and reaffirm these masculinities; thus contributing to their sense of social inclusion. Acknowledging these masculinities is critical in a landscape that often strips older people of their identity as gendered and sexual beings (Milligan et al, 2015; Thompson and Langendoerfer, 2016) and ignores the impact of gender and social positioning on their experiences of dementia (Hulko, 2009; Innes, 2009; Phinney et al, 2013). By understanding the perceived impact of the TI through the addition of a masculinity lens it was possible to determine how the initiative was effective at recognising the identity of the older men and promoting it through the inter-personal environment (Kelly, 2010, 2014), thereby enhancing their sense of social inclusion.

My findings revealed that the TI supported the social inclusion of the men by appealing to their masculinities through the activities offered, the environment created and the approach adopted. Each of these will be examined in turn.

## 7.4.1 Enabling technological activities

The multiple and varying activities provided by the TI were reported by the men as integral to their appeal predominantly as they resonated with their past interests and leisure experiences. Indeed, where the activities could not cater for their interests then some of the men declined to participate or opted to leave the initiative (Chris and Harry). This finding resonates with the wider literature that has identified the need to tailor activities towards the personal interests and capabilities of people with dementia more widely (Cohen-Mansfield et al, 2009, 2010; Kolanowski et al, 2011) and is consistent with current Information Communication Technology (ICT) guidelines (Lazar et al, 2016; Tak et al, 2015) that demonstrate the need for a diversity of materials that can be tailored towards the backgrounds, abilities, interests and preferences of people with dementia. It also supports other limited research that has suggested older men (Genoe and Singleton, 2006; Milligan et al, 2015; Wiersma and Chesser, 2011) and those with dementia (Phinney et al, 2013) will seek to maintain activities they have been accustomed to throughout their lives. By providing these person-centred activities (that were predominantly absent from the rural environments), the men were enabled to re-engage with, and/or discuss leisure and social interests that had once formed an integral part of their masculinities but they were now no longer able to participate in due to the detrimental impacts of ageing, dementia and/or the geo-socio-cultural rural environment. Through this they were able to re-position themselves in accordance with their younger masculinities thereby enabling the activities to become more 'meaningful' to the men and affording them an opportunity to reclaim a sense of their masculine identities that may have been lost. Consequently this enhanced the sense of enjoyment and achievement they received from engaging with the games and promoted their sense of social inclusion. This resonates with other academic literature that highlights the

importance of 'meaningful activities' for the well-being of people with dementia (Harmer and Orrell, 2008; Phinney et al, 2007; Roland and Chappell, 2015; Vernooij-Dassen, 2007) and consequently for their sense of social inclusion (Bartlett and O'Connor, 2010). It also provides support for Thompson and Langendoerfer (2016) who suggest that older men often position themselves in accordance with traditional masculinities that have influenced them across their life course.

Using multiple commercial technological devices ensured the activities could be directed towards the interests and masculinities of the men and so maintain their meaningfulness to them. At present, no other research has explored the use of multiple commercial technological devices with older men with dementia. However, findings from Cutler et al (2016), suggest this may be important for appealing to the multiple interests of community-dwelling people with dementia as opposed to other initiatives that use only one piece of technology in isolation such as the Nintendo Wii (Chao et al, 2013; Fenney and Lee, 2010; Leahey and Singleton, 2011) or the iPad (Evans et al, 2015; Leng et al, 2014; Upton et al, 2011); thereby limiting the activities that can be undertaken and consequently its appeal. My findings suggest that offering a range of activities through multiple commercial gaming technological devices may be particularly beneficial when seeking to appeal to and socially include older men with dementia, given their diverse interests and willingness to maintain similar leisure activities over their life course. However, there were also instances where the activities evoked a sense of pressure on the men to perform particularly when they were tailored towards their previous leisure experiences and interests, and so their younger masculine identities. For instance men became frustrated when they could not successfully engage with games they were proficient at in their younger years, as was the case with some men during the boxing game in the Marching On group or with David and the tennis game in the Old Boys. These instances were detrimental to the men's well-being and needed to be carefully managed. This finding is reminiscent of Wiersma and Chesser (2011) who warn that leisure activities can reinforce men's identities as 'old men' by highlighting how their ageing body can no longer achieve the traditional hegemonic values of masculinity as defined by Western culture. This can result in detrimental impacts to the men's sense of identity and consequently their well-being. Fortunately in my study, the men were able to situate the blame for their performance on the gaming technology and so diffuse any threat they may have faced to their masculinities. The finding demonstrates that the gaming technology can evoke a sense of pressure on the men to perform to a certain standard, particularly when the activities are reminiscent of those they successfully participated in during their youth, and this needs to be managed appropriately in an environment that is psychologically safe (Phinney et al, 2016). This finding also has implications for the broad brush assertion that person-centred activities are always the most appropriate for people with dementia (Kolanowski et al. 2011).

The commercial gaming technology also enabled the men to engage with jovial activities and, as reported by Greg, the volunteer in Done Roaming group, this was perceived as integral to the success of the TI. This was promoted through the humorous nature of the games (such as

smacking moles around the head with a mallet), the light hearted music and graphics or the movements required to interact with them (such as hula hooping). These games promoted a sense of 'play' that was embraced by the men and this finding resonates with the wider academic literature that highlights the importance of enabling people with dementia to participate in playful or humorous activities to benefit their sense of well-being and social inclusion (Astell, 2013; Killick, 2013; Phinney et al, 2016). Generating a sense of humour in activities may be particularly important for older men with dementia who have been shown to use this emotion to alleviate issues of awkwardness and/or embarrassment (Bartlett, 2007). This was demonstrated by Joe in the Old Boys when he made a joke of his driving as he struggled to interact with the Mario Kart Racing game. This finding also aligns well with research on older men that suggests they prefer relaxed activities rather than those that require them to display actions that are akin to their younger, traditional hegemonic ideals such as strength, competitiveness and physicality (Genoe and Singleton, 2006; Kilmartin, 2000; Milligan et al, 2015).

However, interestingly, the men in my study also demonstrated a willingness to engage in friendly competition as well. This is contrary to other research that suggests this traditional hegemonic masculine characteristic is no longer a desire in older men (Genoe and Singleton, 2006; Milligan et al, 2015) and provides support for Thompson and Langendoerfer (2016) who argue that older men still look to be successful and garner respect in the eyes of other men. The men reported that engaging in this friendly competition, which was rarely afforded them in their daily rural lives, was beneficial to their sense of achievement and thereby sense of well-being and social inclusion. Interestingly, this finding was most pertinent in the Done Roaming group where care partners were also present. This offers further support for the assertion of a 'performative' gender where men express certain aspects of their masculinity in particular social contexts and in relation to those who are present (Connell and Messerschmidt, 2005). Where the men were able to use the women to increase their ranking compared to other men (Genoe and Singleton, 2006; Kaufman, 1994) then their competitive side was most apparent. My finding runs contrary to the 'Men in Sheds' literature that purposefully seeks not to promote competitive activities within their environment as it is perceived that this is unwanted by older men (Milligan et al, 2015). It highlights that competitiveness can still be an important characteristic for older men with dementia, and activities that promote this may be beneficial for their well-being and sense of social inclusion. However, in the men's daily rural lives or during rural community ecopsychosocial initiatives they are not provided an outlet to express this characteristic and this may lead to an assumption that it is not required. My finding suggests that commercial gaming technology can be used to promote fun and friendly competition between older men with dementia and may enhance their sense of social inclusion, as such it warrants further exploration. Furthermore, this finding also adds to the debate on the appropriateness for care partners to be present in community ecopsychosocial initiatives for people with dementia (Wiersma et al, 2016), suggesting in male-only initiatives they may help to bring out important male characteristics that can be beneficial for the well-being and sense of achievement

experienced by the men. However, this must be managed appropriately to ensure they do not restrict the voices and autonomy of the people with dementia (Wiersma et al, 2016).

Finally, a further finding from my study was the important role the commercial gaming technology played in promoting and sustaining social interaction between the men. All of the technological devices (iPad, Nintendo Wii and Microsoft Kinect) were shown to be capable of stimulating discussion between the men. Typically these conversations revolved around aspects of the technology such as discussing how to use it or improve their scores, or aspects of the men's lives that were prompted by engaging in the technology. My research suggested that the iPad was the most beneficial piece of technology for enabling and sustaining these latter types of conversations, due to its flexibility to respond to the men's interests by providing a range of media such as songs, films and photographs that acted as a 'scaffold' (Upton et al, 2011) to enable the conversations to flow. However there were instances where the Nintendo Wii and Microsoft Kinect also prompted as well as facilitated discussions between the men. This finding resonates with wider research on dementia-specific touchscreen technology such as CIRCA (Alm et al, 2004, 2009, 2010) that has demonstrated its success at stimulating and maintaining conversations through the use of various forms of media and games, as well as other research that has explored the use of the iPad (Cutler et al, 2016; Evans et al, 2015; Upton et al, 2011) and the Nintendo Wii (Fenney and Lee, 2010; Leahey and Singleton, 2011) with people with dementia. This means of communication, whereby the men are encouraged to socially interact whilst, or through, engaging with the technology is better suited to the 'shoulder-to-shoulder' method of communicating that is reported as beneficial for men in the 'Men in Sheds' literature (Milligan et al, 2015). My finding resonates with this and suggests that the commercial gaming technology, and particularly the iPad, can be used in a similar manner to create a more preferable method of socialising for older men with dementia. This means however may offer benefits over the 'Men in Sheds' initiative as the technology can support or 'scaffold' (Upton et al, 2011) the conversations as well as stimulate them, whereas the activities within the 'Men in Sheds' are likely to only initiate discussions. Whilst this latter method may be suitable for older men generally it may limit the depth and range of conversations facilitated in older men with dementia due to the adverse impacts of the condition on the men's memory and recall abilities. Furthermore, these commercial devices are likely to be favoured in community ecopsychosocial initiatives given that they are more widely available in the market and cheaper than dementiaspecific products (such as that by Astell, 2009, 2010), yet appear to fulfil similar needs.

# 7.4.2 A facilitative male-only environment

The men reported that the male-only environment appealed to them. This finding is consistent with other research that has demonstrated that male-only social and leisure groups may be attractive to men and consequently beneficial at counteracting the effects of social isolation in this population in the UK (Carone et al, 2014; Milligan et al, 2015) and internationally (Waling and Fildes, 2016; Wilson and Cordier, 2013; Wilson et al, 2015).

Whilst this environment was rarely afforded the men in their daily rural lives, they reported feeling relaxed and confident speaking openly at the TI. Partly, this was attributed to the familiar nature of the environment that the older men may have been accustomed to during their working years but also because the environment was perceived by the men as non-threatening to their masculinities. They reported that this was due to the exclusion of women and the understanding that they were all in a similar situation with regards to their health. As such, there was no perceived requirement for the men to demonstrate and maintain traditional hegemonic masculine identities that emphasise having to protect women (particularly from harsh language that may offend) as well as display strength, capability and control (Kimmel 1996) and suppress displays of emotion and vulnerability that are affiliated with femininity (Genoe and Singleton, 2006). Therefore this enabled them to talk openly about their lives and so afforded the men a greater connection with one another. Indeed, Milligan et al (2015) have demonstrated that when older men with dementia are situated within a male-only environment with other men without dementia, than the latter perform actions associated with traditional hegemonic masculinities that seek to exclude or 'other' (McParland et al, 2016) those with dementia, thereby restricting their social participation and sense of social inclusion. However, my research showed that in a male-only environment, when all men are living with dementia and therefore on a 'similar level' (Dick, Marching On, Focus group), they are confident socialising within the group and expressing their masculinities. This finding resonates with wider research that has demonstrated the importance of creating a psychologically safe and non-threatening environment (in addition to physically safe) when working with people with dementia more widely (Bevan, 2013; Dupuis et al, 2012, 2016) and engaging them in activities (Phinney et al, 2016; Wiersma et al, 2016). It also supports the wider disability literature that emphasises the need for people to be able to attend social and leisure opportunities within their community where they can be themselves and not have to wear a 'social mask' (Davey and Gordon, 2017). My research suggests a male-only environment consisting of solely older men with dementia may be one means to achieve this when working with and seeking social inclusion for this population.

Furthermore, my research demonstrated that the male-only environment facilitated the social connection that the men felt with one another and enabled them to bond on a deeper, more emotional level. This was particularly pertinent for the men, given the difficulties they reported in forming these emotional connections within their rural environments and with their families. The men discussed feeling a sense of 'you're not on your own' (Gordon, Marching On, Focus group) or camaraderie and comradeship with one another as well as a connection on a 'man-to-man' level that provided them a sense of attachment, comfort and solidarity. These have been highlighted as important facets in establishing a sense of social inclusion for people with disabilities (Simplican et al, 2015) as well as those with dementia (Cook, 2008; Kitwood, 1997; Ryan et al, 2008). This finding also resonates with Bartlett and O'Connor (2010) who emphasise the importance of enabling people with dementia to connect on a more emotional level, thereby ensuring they can develop and sustain social inclusion. For men such as Doug and Joe, the

opportunity to witness other men living with dementia in their rural area and develop a sense of connection was beneficial to their wider social inclusion within the rural locations. In their daily lives both these men were relatively isolated and rarely saw others living with dementia. They had both internalised the stigma attached to the condition and this detrimentally impacted on their perceived capabilities and social confidence. Through witnessing other men living well with dementia they were able to challenge their assumptions of the condition and their perceived capabilities. Consequently this provided them with a 'mental medicine' (Doug, Done Roaming, Focus group) and inspired them to 'start thinking for myself and trying different things out' (Joe, Old Boys, Focus group). This is consistent with the wider academic literature that has found through the promotion of community, people feel less alone in their struggle against dementia and the associated stigma and discrimination, and this empowering experience can provide them with more confidence (Clare et al, 2008; Keyes et al, 2016; Phinney et al, 2016; Wiersma et al, 2016). This also resonates with Dupuis et al (2016) who demonstrated the importance of providing community spaces whereby people with dementia can interact with others and so shift their assumptions and understandings of their condition. My finding therefore suggests that a male-only environment may be a useful method for developing this sense of emotional connection, solidarity and social inclusion in rural-dwelling older men with dementia, as it provides a 'psychologically safe' (Phinney et al, 2016) atmosphere, whereby men are able to openly express themselves and relate to one another.

However my research demonstrated that the male-only environment did not necessarily ensure the social inclusion of all the men and instances of tension were present within the groups that needed to be managed. Where this was difficult to overcome then it resulted in men leaving the TI. For instance in the Marching On group, by creating an environment where the men were enabled to express their masculinities it highlighted where the perceived social positioning and interests of the men were juxtaposed to one another. This created tensions in the group and meant that five of the men chose to leave. This finding provides further support for Hulko (2009) who has urged researchers, professionals and practitioners to acknowledge the social positioning and heterogeneity of the lived experiences of people with dementia rather than solely focus on their condition. Furthermore, within the Done Roaming group, tensions were evident throughout the TI between Doug and the rest of the men, although Doug chose to remain a member of the group. In this instance, Doug was initially keen to preserve his perceived masculine status, which closely resembled a traditional Western hegemonic masculine ideal, and in doing so belittle, and disassociate himself, from those he perceived as socially located within the 'fourth age' (Gilleard and Higgs, 2015). Only when Doug was able to move beyond these perceptions of dementia, during the nine weeks of the TI, did he realise the commonalities he had with the other men in the group (in terms of his interests) and the support they could provide him as someone who was newly diagnosed with the condition, based on their experiential knowledge. This finding provides support for McParland et al (2016) who posit that dichotomising the discourse of dementia into either 'tragedy' or 'living well' can result in some people with dementia further excluding others who are also living with the condition and

who ironically may be able to provide the best forms of support due to their lived experiences. This may be particularly the case in older men who are keen to be perceived as still retaining valued masculine characteristics such as autonomy and strength (Tannenbaum and Frank, 2011). My research suggested that focusing on the common interests of the men rather than their label of dementia was important for moving beyond biomedical constructions of the condition and so generating this sense of social connection and solidarity, particularly with Doug. This finding further supported my decision to have the men name their groups, thereby taking the focus away from dementia. This resonates with similar research by Phinney et al (2016) who reported a major appeal of a walking group for people with dementia was keeping the focus away from dementia.

Finally, it is important to note the sometimes sexist, racist and homophobic remarks made during the TI. These demonstrated that some men still retained traditional Western hegemonic masculine ideals that favoured those who were white men and heterosexual (Kimmel, 1996) and the social environment created by the TI enabled them to 'perform' or express these characteristics. Therefore although there were no men in the groups who were non-white British or openly homosexual this suggests that had there been any present then they may have found it more difficult to feel socially included. This finding resonates with Regan (2016) who reported that their Muslim male participant experienced difficulties in receiving dementia support due to their culture and ethnicity rather than their gender alone. This demonstrates the import role of ethnicity on the experiences of social inclusion in men with dementia and again emphasises the importance of acknowledging all aspects of a person's social positioning and not just their 'dementia' (Hulko, 2009) when seeking to promote social inclusion. Interestingly my research suggested that 'bypassed' communities (Keating et al, 2013) may be better equipped to develop this sense of connection and solidarity between older men with dementia. In the Old Boys group, there was a noticeable lack of tension between the men when compared to the other two groups who resided in more affluent 'bucolic' rural communities. As such, it is possible that the men perceived themselves to be of a similar social standing and were therefore more willing to connect and collaborate. This finding provides support for Keating et al (2013) who reported on the more supportive close-knit community networks in financially poorer 'bypassed' communities when compared to the wealthier 'bucolic' rural communities. This highlights the multiple and diverse nature of the socially constructed rural environment and both the benefits and challenges this can have when seeking to promote social inclusion for older men with dementia.

## 7.4.3 An empowering approach

My research was situated within a PAR framework and this was reported by the men-as well as their care partners and the volunteers- as an integral factor in the success of the TI. Adopting this inclusive research approach, whereby the men were re-positioned as experts in the evolution of the TI, and their voices and opinions were sought and validated was perceived as a welcomed and empowering experience by the men, particularly given the lack of respect they reported they experienced on occasions in their daily rural lives. This finding resonates with

authors who have demonstrated the empowering impact that PAR research approaches can afford marginalised or oppressed populations more widely (Chevalier and Buckle, 2013; Fenge, 2010) as well as those with dementia (Wiersma et al. 2016). It provides further support for the wider social inclusion literature that advocates the need to include those populations that may be considered socially excluded in more inclusive research approaches such as PAR (Taket et al, 2009, 2014) as well as literature in the dementia field that promotes authentic partnerships (Dupuis et al, 2012,2016) and trusting relationships with people with dementia to enhance the research process (Dewing, 2008b; McKeown et al, 2010; Murphy et al, 2015; Wiersma et al, 2016; Wilkinson, 2002) and promote a sense of social inclusion (Bartlett and O'Connor, 2010; Cook, 2008). This empowering approach may be particularly important for older men who retain traditional Western hegemonic masculinities that value autonomy, agency and independence (Kilmartin, 2000; Tannenbaum and Frank, 2011). Whilst these approaches are considered gold practice standard when developing dementia-specific technology (Span et al, 2013) these lessons have yet to be widely adopted when designing and implementing ecopsychosocial initiatives for community-dwelling people with dementia. My research suggests that this approach is possible and can be a beneficial process for the social inclusion of men with dementia as well as ensuring that the initiatives are suitable for the needs of their intended audience.

Furthermore, my research suggested that the PAR approach may be particularly beneficial for a younger male when working with older men with dementia. Positioning myself as a cocollaborator in the research process rather than a 'teacher,' ensured I reduced the power and influence I possessed in the research process. Consequently this was beneficial for the development of the TI and the relationships that I developed with the men. This finding supports that of Golding (2011), who has reported that the most effective interventions are those that cast older men as co-participants in shared group activities, and can be better understood through the adoption of a masculinity lens. Consistent with my definition of hegemonic masculinity, this tends to favour men who are in their early mid-life, white, middle class, heterosexual and perceived to have characteristics such as strength, capability and control (Kilmartin, 2000; Kimmel, 1996). As such, within the social environment of the TI, there is potential that the men may have perceived me as closer to this ideal and consequently this could have threatened their own masculinities as well as their willingness to open up and engage with me and the research. This may be particularly pertinent in rural areas where there may also be a distrust of 'outsider' health professionals (Hansen et al. 2005; Morgan et al. 2011; Szymczynska et al. 2011), as was also reported by the men in my research. However, adopting an approach that reduced the power dynamics between the researcher and participants whilst also positioning them as 'experts by experience,' in line with PAR approaches (Kemmis, 2008; Gaventa and Cornwall, 2008) enabled me to overcome these potential pitfalls. It ensured the social environment created, respected their masculinities and so enabled me to develop positive working relationships with the majority of men. This was highlighted over the course of my study as I progressed from an initial position of 'outsider' researcher to 'one of the lads.' This supports

Bryce's (2012) assertion that it is possible to move between that of an 'outsider researcher to one of an 'insider,' and this can have beneficial impacts for the research process. My finding highlights the importance of considering both the gender of the facilitator/researcher and the approach adopted when working with older men with dementia to ensure their sense of social inclusion. It provides support for Genoe and Singleton (2006) who posited that older men in their study may have suppressed some of their thoughts and feelings when working with a female researcher due to traditional hegemonic masculine ideals that were performed during their interactions. This has implications for community ecopsychosocial initiatives, which may often be delivered by female support workers.

# 7.5 Summary

This is the first study to explore the experiences of older men with dementia residing in rural areas of England and to seek to promote their social inclusion through the use of an individually-tailored Technological Initiative. My findings demonstrated that although typical policy directives and traditional concepts of social inclusion would not necessarily perceive white British older men to be a socially excluded group - particularly given they reported no economic or financial difficulties - the onset of dementia, combined with the geo-socio-cultural facets of the rural environment, inhibited aspects of their social inclusion. Despite predominantly living well with dementia and experiencing elements of social inclusion within their lives, the men reported challenges they faced in relation to: a lack of, or reduction in, structured services within their rural location; barriers presented by the rural landscape as they aged with dementia; and a lack of dementia awareness amongst the rural community and their family members. These factors worked in tandem to restrict the men from engaging within their rural community, developing and sustaining meaningful relationships and maintaining a social position of autonomy and respect. These findings resonate with other academic literature (Blackstock et al, 2006; Clarke and Bailey, 2016; Forbes et al, 2011) and may be felt more pertinently by white British older men given their perceived privileged social positioning prior to the onset of dementia. Furthermore, the men demonstrated the power they retained in contributing to their own social inclusion; choosing on occasions to not engage with the rural environment when it did not appeal to them or they were experiencing periods of apathy. My findings are therefore consistent with the wider academic literature and demonstrate that rural areas of England can enhance as well as inhibit the social inclusion of older men with dementia. They also highlight the importance of introducing physically and conceptually accessible community ecopsychosocial initiatives that appeal to men, value and respect them, and enable them to be themselves when re-engaging and re-connecting with their rural environment; thereby enhancing their sense of social inclusion.

The introduction of the TI was welcomed by the majority of the men and enabled them to address these important facets of social inclusion that were currently absent from their daily rural lives, namely: engage in a 'meaningful activity;' socially connect and develop meaningful relationships; continue their individual growth and life-long learning; challenge negative assumptions of dementia; and have their voices heard and validated. This helped to enhance

the mood and social confidence of the men, which for a limited few extended into their lives outside of the initiative. Whilst some of these findings resonate with the wider academic literature on the benefits of leisure activities (Dupuis et al, 2012; Genoe and Dupuis, 2011, 2014; Phinney and Moody, 2011) and ecopsychosocial initiatives (Dugmore et al, 2015; Olazaran et al, 2010; Oyebode and Parveen, 2016) for people with dementia, they also contribute knowledge to an emerging area of research that demonstrates the potential for commercial gaming technology to be used by people with dementia to enhance their social inclusion. My findings showed that by engaging with the technology the men were provided a welcomed opportunity to learn something new and this afforded a sense of social inclusion and connection with modern society that may not have been achieved by typical activities for people with dementia. Furthermore, my research showed that the technology could provide a platform whereby the men could challenge negative perceptions of their capabilities and so contribute to their own self-worth as well as the wider social inclusion agenda.

Finally, my research was the first to use a combination of social inclusion and masculinity lenses to explore the 'active mechanisms' (Dugmore et al, 2015) of a Technological Initiative for older men with dementia. In doing so, I demonstrated that the older men retained their masculine identities despite the onset of dementia and therefore it was important for this to be acknowledged and respected throughout the delivery of the Technological Initiative. My findings suggested that this was accomplished through: providing an activity that enabled the men to demonstrate and reaffirm their masculinities; creating an environment that ensured the men could freely express themselves and so socially and emotionally connect; and adopting an approach that empowered the men, reduced the threat to their masculine identities and ensured I could develop positive working relationships with them. This approach was welcomed by the majority of the men and has important implications for the design and delivery of future ecopsychosocial community initiatives that aim to promote social inclusion in older men with dementia. Before addressing these implications and providing recommendations, I will first discuss the limitations and strengths of my study.

## 7.6 Limitations of my study

A possible criticism of this research is the sampling strategy adopted to recruit older men with dementia for the study. As the participants were self-selected then it is likely they had an interest in the technology or in socialising within their rural area. This is noticeable in the fact that many of the men (particularly in the Done Roaming and Marching On groups) already attended activities in the area for people with dementia and none of them reported any fear about engaging with the TI. Whilst this latter aspect might be attributed to the stoic characteristics of the older men or the successful advertising of the TI following feedback from the consultation sessions, it is possible that the sample consisted of men who were naturally more adventurous and willing to socially engage and therefore may not be representative of other older men with dementia in the rural areas. Furthermore aspects of the socio-cultural rural environment are also likely to have influenced the size of the groups and characteristics of the men. These include the stigma of dementia services and 'outsiders' who deliver them as well as

the need for care partners or members of the rural community to ameliorate transport issues and so enable the men to participate. Therefore, those men who had the support networks and means to participate as well as the motivation to do so would be more likely to have participated in the TI. This potentially influenced the perceived outcomes from the research. Therefore caution must be taken when generalising the findings to other older men with dementia residing in rural locations.

In addition to this, and consistent with the demographic breakdown of the three rural areas, all of the older men that took part in my research were White British. My findings demonstrated that this may have impacted on the sense of social inclusion experienced by older men from other ethnic backgrounds if they had been present in the groups and therefore it is necessary to be cautious when generalising my findings to other, more diverse rural areas. Furthermore as masculinities vary between cultures and social classes (Thompson and Bennett 2016) then this may have impacted on the findings from my study.

My study also did not include any follow-up interviews with the men and their care partners. Consistent with challenges reported in the PAR literature (Fenge, 2010), the financial and time resources required to conduct the study made it difficult to also include any follow-up work. Therefore information cannot be elicited on the on-going benefits the TI may have had on the social inclusion of the men. There was also difficulties using the PAR approach and working with the men over an extended period of time, particularly during the 10 month gap between the conclusion of the TI and the feedback of the data elicited. During this time many of the men had either forgotten the TI or could no longer participate due their deteriorating health conditions. In future studies when conducting a PAR approach, it may be beneficial to keep in more regular contact with the men. Certain themes elicited from the analysis could be sent through to them as and when they became apparent, rather than waiting until the end of the analysis process before seeking feedback. This would have ensured the men remained engaged with the research in the interim periods.

Finally, my study highlighted other aspects of the men's social positioning that impacted on their sense of social inclusion, particularly within the Marching On group. Although I was aware of these aspects, they were not specifically focussed on when using a masculinity lens. Adopting a wider lens such as 'intersectionality' may help to highlight these facets such as ethnicity, education and wealth. Future studies may therefore benefit from adopting a broader lens such as intersectionality when attempting to understand how to promote social inclusion in community-dwelling people with dementia.

# 7.7 Strengths of my study

A major strength of my study was my decision to situate the research within a PAR framework. This enabled me to work closely with members of the rural community including dementia practitioners as well as the older men who resided there. Through adopting this approach I was enabled to develop the TI, taking into account the geo-socio-cultural rural context, so that it was

fit for purpose. Furthermore adopting this approach and re-positioning the men as experiential experts and co-collaborators in the research enabled me to establish a positive working relationship with them throughout the course of the study. This ensured the men were willing to open up to me and consequently led to me being able to gather more insightful and honest data of their lives and experiences as well as providing them with a sense of empowerment. It also enabled me to develop a more empathic approach to data collection and analysis and so a more insightful understanding of the perceived impact of the TI for the men. This is consistent with Wiersma et al (2016) who advocates PAR approaches as a means to work in collaboration with people with dementia and develop community-based initiatives that are appropriate for their intended users.

Adopting a PAR approach also ensured that I worked with the men as co-collaborators to publicise the research, develop guidance documentation and seek ways to ensure the groups continued after the research period. These 'action' elements that are integral to 'real world' research (Robson, 2011) have the potential to bring about change for the men and their care partners within the rural locations. In the future this could potentially lead to wider change within the UK by publicising the benefits of atypical activities for people with dementia and challenging the negative discourses associated with dementia (Dupuis et al, 2016; Genoe, 2010), providing the supporting structures are in place. In this way my research not only sought to understand the men's experiences, but also looked to action change, in the hope this would have longer term benefits for them.

Ironically, not adhering strictly to a PAR approach brought benefits for the research process as it enabled me to introduce the commercial gaming technology to the men. It is unlikely that the men would have chosen to use this technology as a focus for the community ecopsychosocial initiative as many were unaware of it in their daily lives. As such the men would not have realised the enjoyment this medium might afford them or the benefits it might have for their wider sense of social inclusion; by enabling them to learn something new and feel a wider sense of social connection with modern society as well as challenge negative assumptions of their own capabilities and those of others.

Undertaking a multi-method qualitative approach to data collection meant that I could gather different types of data from multiple perspectives: the men, their care partners, the volunteers and my own. This enabled me to triangulate the data (Flick, 2014) and so produce a more robust set of findings. Collecting this data across three rural locations also allowed me to better interrogate the data in relation to the rural locations thereby enabling it to be generalised to other rural locations within the UK. Dugmore et al (2015) noted during their review of the literature that only one study using qualitative methods to understand the perceived impact of psychosocial initiatives for people with dementia reflected on the likely impact of the researcher on the research process and only three studies reported using some form of respondent validation. By triangulating the data I collected, seeking feedback from the participants as well as reflecting on my role as the researcher throughout the process, I have set myself apart from

other studies and answered this important call. Furthermore, in adopting a qualitative approach I have also been able to provide more detailed insights into the delivery process, factors for success and evaluation of ecopsychosocial initiatives for people with dementia, thereby again addressing an important neglected aspect of research (Dugmore et al, 2015).

Finally the TI that was developed in collaboration with the men included a full range of modern commercial gaming technologies. This ensured that the initiative was more inclusive and men were not excluded due to a disinterest in one piece of technology or one game. With the exception of Cutler et al (2016) current research in the field has elected to use methods that can be perceived as more exclusionary such as using only one piece of technology or one game. These initiatives are likely to face challenges when catering for the multiple interests in the group. This is consistent with Lazar et al (2016) who has emphasised the importance of using a range of games when designing such initiatives as this will ensure it is enjoyable for the people with dementia attending as well as those who are running it, thereby ensuring its continued success.

## 7.8 Contributions of the research

This section presents the key contributions to knowledge my thesis makes for theory, research and practice within the dementia field.

#### 7.8.1 Theoretical contributions

My research has outlined the importance of incorporating a masculinity lens when exploring means to enhance social inclusion in older men with dementia. Often research within the dementia field views people living with the condition as a homogeneous population (Hulko, 2009) and even when studies are undertaken with solely men with dementia their gendered identities are often overlooked (Phinney et al, 2013). Consequently this results in a broad brush approach to enhancing social inclusion within community-dwelling people with dementia that at presents appears to be failing older men living with this condition. My research has contributed theoretically to this body of knowledge by demonstrating that masculinities always matter in men's lives (Thompson and Langendoerfer, 2016) including in those with dementia.

Consequently it is essential to apply a masculinity lens when understanding how to promote social inclusion within this population using ecopsychosocial initiatives. Adopting this lens shows that the activities offered, the environment created and the approach undertaken to enhance male social inclusion must all cater for the masculine identities to ensure their success.

My study has been the first to examine the perceptions of older men with dementia living in three rural areas of England. Through the use of qualitative research methods and the adoption of a social inclusion lens to explore the findings, I have provided support for other international and national research that demonstrates the on-going impact of rurality on the social inclusion and exclusion of rural-dwelling people with dementia. My research has contributed to the small but growing body of literature that challenges the 'tragedy' discourse and highlights the potential for people to live well with the condition (Wolverson et al, 2015). It has also exposed the

difficulties that white, older men with dementia face when attempting to remain socially included within their rural environment. Within traditional political discourse on social inclusion, this subgroup of people may not be considered socially excluded due to their perceived privileged social positioning and there is potential for them to be overlooked within dementia research (Bartlett et al, 2016). However my research has shown they face similar difficulties as the wider population of people living with the condition, both nationally and internationally, when attempting to maintain their sense of social inclusion within rural areas.

My research has contributed to the literature that continues to develop our understanding of the benefits of community ecopsychosocial initiatives for people with dementia and the ways in which these benefits are facilitated. More specifically however it provides further support to a small but emerging body of knowledge that examines the feasibility and benefits of using commercially available gaming technology with community-dwelling people with dementia. At present this research is in its infancy and with the exception of Cutler et al (2016) tends to only explore the use of one piece of technology and a limited range of games. My research has shown that it is possible to use a wide array of commercially available technology and games with older men with dementia to offer them a range of activities and hence choice in line with their activities. This includes the use of the Microsoft Kinect; a device that is yet to be explored in community ecopsychosocial initiatives. Using these technologies in tandem with one another as part of a Technological Initiative can ensure that the activities are more socially inclusive by enabling them to be tailored towards the interests and capabilities of the target population, as emphasised in recent guidelines by Lazar (2016). This is important when attempting to appeal to a hard-to-reach group such as older men with dementia living in rural locations. Furthermore my research suggests that this atypical activity for people with dementia can provide in-themoment benefits that enhance the sense of social inclusion for older men with dementia but also enable them to challenge negative perceptions of their capabilities. This has wider implications for the social inclusion agenda and highlights the benefit that commercial gaming technology may enable as an ecopsychosocial initiative.

#### 7.8.2 Methodological contribution

My study demonstrated the potential benefits of adopting a PAR approach when collaborating with people with dementia, both to the research process and to the final initiatives developed. It also highlighted the potential benefits this approach may afford older men with dementia in particular, by enabling them to exercise important characteristics of their masculinities such as autonomy, control, strength and competitiveness which may have be hindered through the onset of dementia. This approach is advocated within the wider social inclusion literature (Taket et al, 2009, 2014) for its potential to raise the status of socially excluded populations within the research process as well as empower them. Whilst the importance of establishing authentic (Dupuis et al, 2012, 2016) and positive working relationships (Dewing, 2008b; Murphy et al, 2015) with people with dementia has been documented as important for enhancing their social inclusion (Bartlett and O'Connor, 2010; Cantley and Bowes, 2004; Cook, 2008) there are limited

studies that have specifically applied a PAR approach (Wiersma et al, 2016). Furthermore, whilst collaboratively working alongside people with dementia is considered gold standard practice when designing dementia-specific technology (Span et al, 2013) these lessons have yet to be applied when designing, delivering and evaluating social and leisure activities that use commercial gaming technology with people with dementia. My research therefore adds valuable knowledge to this area of research.

My study used a range of qualitative methods to understand the perceived impact of the TI on the social inclusion of the men. This enabled me to capture a greater depth of data then if I had relied on one method alone. Through using a range of methods I was able to triangulate the data (Flick, 2014) and build a multi-layered understanding of the men's experiences. In accordance with Phinney and Moody (2011), situating these experiences within the men's wider geo-socio-cultural environment enabled me to undertake a deeper analysis and therefore ascertain more insightful understandings of the impact of the TI on the men's sense of social inclusion.

My research also provided support for the importance of applying research methods flexibly in PAR research (Kemmis, 2009) and so enable them to maintain a 'moral sensitivity' (Heggestad et al, 2013) towards people with dementia. Whilst it would have been interesting to use methods such as Photovoice and Walking Interviews with all of the men, it was important that their wishes were respected and that I adapted my approach accordingly so as to ensure their social inclusion. For instance Genoe and Dupuis (2013) have reported the difficulties in solely using Photovoice methods as it restricts the numbers of people who are willing to take part in the study due to their inability to use the camera or lack of interest in it. My study provides support for the need to tailor research methods towards the interests of those people with dementia participating in the study, and this may require multiple and varying methods. Where men were interested in walking in their rural environments or using a camera to take photos, then these more creative methods could be adopted and were successful. However it was important not to force these on the men, as it may have been detrimental to their well-being and excluded them from the study. Consequently other methods such as standard interviews were a welcomed and effective method.

# 7.8.3 Practical contributions

Through working in collaboration with the men I have developed an individually-tailored Technological Initiative using commercially available gaming technology and demonstrated the benefits it can afford the social inclusion of older men with dementia in rural England. In conducting the research I have addressed calls by Dugmore et al (2015) to provide a better understanding of ecopsychosocial initiatives for people with dementia. This includes offering insights into the process of delivery, the 'active mechanisms,' and the impact of the initiative for people with dementia. In doing so I have provided dementia practitioners with an in-depth understanding of the initiative that they can apply within their areas of work. Although this thesis has only briefly addressed the processes involved in the delivery of the TI (within Chapter 4) a

practical guidance has been created in collaboration with the men that is accessible to practitioners in the field. The guidance documentation can be found at:

https://www1.bournemouth.ac.uk/sites/default/files/asset/document/a-how-to-guide-using-gaming-technology 0.pdf

This guidance ensures that my research can contribute to the development of initiatives aimed at supporting community-dwelling people with dementia and will help to raise awareness of the use of atypical activities to support the wider social inclusion for this population. Although Bowes et al (2016) have posited that practitioners' views towards technological activities are slowly changing around their five rural European test sites, my experiences while delivering the TI within the rural locations suggests more awareness of the potential for this medium is required. I hope that this guidance can address some of these issues.

Furthermore, through the successful implementation of the TI, I was able to work in collaboration with the men to secure funding from an external charitable organisation that enabled the groups to continue within the rural areas. This is evidence of the success of the initiative and its ability to contribute positively to the social inclusion of older men with dementia in rural England.

My research has also highlighted that masculinities persist in older men post a diagnosis of dementia. It is therefore important to acknowledge and respect these gendered identities when setting up and delivering community ecopsychosocial initiatives to benefit their social inclusion. Raising awareness of this learning to community practitioners and volunteers will enable them to reassess the activities they provide to ensure they can appeal to older men living with dementia in their rural area. Whilst Bartlett et al (2016) have posited that it is still unclear how practitioners and health professionals can incorporate gender awareness into the support they provide, I have gone some way to addressing this concern for older men with dementia. Furthermore my research has demonstrated the importance of understanding the gender of the practitioners and volunteers running initiatives for people with dementia and the impact this may have on the interactions and relationships developed with those attending. Again it is important this learning point is communicated to practitioners to ensure they can match the personnel responsible for delivering the initiative to the target population.

# 7.9 Key recommendations and future research

In this section I set out the key recommendations arising from my research for academics, practitioners and policy makers that will enable development within these areas as well as future research that can expand on these findings.

#### 7.9.1 Recommendations for academics

Academics who wish to influence practice would be advised to:

- Explore experiential accounts of living with dementia in rural areas both nationally and internationally. This research will provide detailed insights into the multiple geo-socio-cultural rural environments as well enable a better understanding of the changing needs of this population. This will ensure that community ecopsychosocial initiatives can be tailored accordingly to meet the changing unmet needs of people with dementia and so sustain their sense of social inclusion. These experiential accounts are also likely to provide a more balanced account of living with dementia that can be used to ensure the perpetuation of the 'tragedy discourse' is challenged.
- Acknowledge the impact of gender on the experiences of social inclusion in older men living with dementia. Adopting masculinity theories will ensure older men are not perceived as an androgynous population and will therefore enable a more complex understanding of the interplay between gender and dementia and the perceived impact this has on the lived experience. This will support the development of initiatives designed to enable social inclusion within older men with dementia. Furthermore, it is important to be aware of the changing masculinities. Whilst this research has explored the masculinities of today's older men, future generations are likely to exhibit different forms of masculinities and aspire to different hegemonic masculine ideals (Thompson and Bennett, 2016). It is important that academics have a detailed understanding of this so as to ensure the social inclusion of future men with dementia.
- Make use of a combination of commercial technological devices and games. This will
  ensure the activities can be tailored towards the interests and capabilities of the
  intended audience. Consequently this is likely to increase the appeal and therefore
  sample size of future studies within this area.
- Adopt methodological approaches that enable them to work closely with people with dementia over a prolonged period of time and seek to promote their voice. This can include Participatory Action Research or ethnographic approaches. This will ensure the social inclusion of people with dementia is maintained throughout the course of the research and will enable close relationships to be developed that are likely to result in more honest and meaningful feedback.
- Develop dissemination material from their research that is accessible to a wider population of people including other academics, practitioners, volunteers and people living with dementia and their care partners. Ensuring research can reach a wider audience is important for enabling a wider positive social change for the lived experiences of those with dementia and their care partners.
- Consider a range of methods for 'hearing the voice' (Goldsmith, 1996) of people with
  dementia and tailor them to the interests of those taking part, therefore enabling them to
  be 'morally sensitive' (Heggestad et al, 2013) and socially inclusive. Whilst more
  creative research methods may be interesting and potentially beneficial for the

- research, they may not appeal to everyone. If only these methods are used, they are likely to socially exclude people with dementia from research that could add valuable knowledge to the field.
- Consider and reflect on their motivations and practice throughout their research and how this is likely to have impacted on the data gathered. Dugmore et al (2015) have reported that these reflections are rarely made explicit in qualitative research that uses ecopsychosocial initiatives for people with dementia, yet are likely to have influenced the design of the initiative and the overall research. Ensuring researchers are open about their assumptions and motivations will add credibility to their work and will enable others to replicate it.

#### 7.9.2 Recommendations for practitioners

Practitioners who wish to influence practice would be advised to:

- Acknowledge the masculinities of older men with dementia and cater for these throughout the delivery of any proposed initiative. Initiatives must respect these masculine identities and seek to create environments that limit the perceived threats men face to their masculinities whilst also providing an opportunity to reassert their male identities in what is often a feminised world for them. Practitioners could achieve this by considering the activities, the social environment and the method of delivery that are likely to appeal to and promote the social inclusion of older men with dementia.
- Explore the use of typical societal activities that are considered atypical for people with dementia. These activities have the potential to promote wider social inclusion by enabling people with dementia to develop a sense of connection with modern society as well as provide a platform where people with dementia can challenge negative assumptions of their capabilities. Over time if practitioners become more accustomed to using dementia atypical activities and disseminate the findings more widely there is the potential to bring about gradual social change to promote more dementia-friendly communities and challenge the notion of 'dementia-appropriate' activities.
- Incorporate activities that promote a sense of friendly competition between older men with dementia. This typical male characteristic is still apparent in older men with dementia yet is rarely afforded them in their daily lives. Providing them an opportunity to express this, in a psychologically safe environment, can be beneficial to their well-being and sense of achievement. It is also important to be aware of the impact of care partners within ecopsychosocial initiatives. Whilst they may provide additional benefits for the groups there is also the potential for them to restrict the voices of people with dementia and so their involvement needs to be managed carefully (Wiersma et al, 2016).
- Include the views of people with dementia when designing, recruiting for, delivering, evaluating and disseminating the findings from, community ecopsychosocial initiatives.
   This practice is considered 'Gold Standard' when developing dementia-specific

- technology (Span et al, 2013) and it is important that these lessons are transferred to the development of social and leisure initiatives.
- Seek out training to ensure they are confident using any technology with people with dementia. Bowes et al (2016) reported the importance of staff support when introducing technology to people with dementia in rural areas. If these initiatives are to be used more widely with people with dementia then practitioners will need to be confident in running the activities.

# 7.9.3 Recommendations for policy makers

Policy makers who wish to influence practice would be advised to:

- Consider the complex and changing rural environments both nationally and
  internationally and the benefits and obstacles they provide for people with dementia
  when attempting to age in place. Developing a rural-specific 'dementia-friendly
  communities' agenda will ensure that initiatives designed to promote social inclusion are
  not simply transferred from urban to rural environments but acknowledge the differing
  and changing rural cultures.
- Promote the use of community ecopsychosocial initiatives to benefit the social inclusion
  of people with dementia. However there is a need to ensure that funding is made
  available for more atypical initiatives that pay particular attention to the gendered
  identities of their intended audience.
- Consider the dynamic and changing processes of social inclusion for people with dementia. In certain aspects of their life, people with dementia may feel socially included whilst in other aspects they may experience exclusion. It is important for policy to understand these processes and so identify where, when and how to intervene effectively (Ward, 2009) to sustain the social inclusion of people with dementia.
- Consider the specific needs of males in policies and actions aimed at promoting social
  inclusion more widely. This will require an acknowledgement of the on-going role that
  masculinities have in the experiences of older men with dementia. It may be beneficial
  to establish a specific male social inclusion agenda such as those in Australia and
  Brazil, exploring ways to promote social inclusion in this hard-to-reach population.
- Seek means to ensure better public transport is made available in rural areas. This will
  enable people with dementia to retain a sense of independence and autonomy and so
  feel able to participate and be socially included within their communities. This may be
  particularly important for older men with dementia.

#### 7.9.4 Future research

Future research would be advised to:

 Use the guidance developed from my research to explore the impact of a similar
 Technological Initiative in other rural areas both nationally and internationally and with other populations living with dementia, including women and those with younger onset. In areas of the world where the 'Shed' is not a recognised concept then a Technological Initiative may be more appropriate for encouraging social inclusion in older men with dementia than the 'Men in Sheds' initiatives. Furthermore, the TI could be used as a means to explore more diverse populations of older men with dementia.

- Explore the use of the Microsoft Kinect with people with dementia. This was a novel component of the Technological Initiative and is yet to be explored in any other studies with people with dementia. My findings suggest that this piece of technology can appeal to older men with dementia and may be one way for them to engage with activities if they encounter challenges with other sensor technology such as the Nintendo Wii (due to the combination of movement alongside the use of a controller). This echoes the calls of Marston et al (2013) for future studies to explore the use of the Microsoft Kinect more widely with people with dementia. Furthermore, as commercial gaming technologies continue to advance then future research can explore the use of more modern technology with people with dementia such as the Oculus.
- Compare the experiences of rural-dwelling older men with dementia and their care partners to those of urban-dwelling. My research demonstrated that some men and their care partners drew from the discourse of the rural/urban binary opposition suggesting their experiences would be inferior in an urban environment. This is consistent in research with older people (Orpin et al, 2014) and those with dementia (Blackstock et al, 2006) and future research would benefit from examining if this discourse is accurate both nationally and internationally. Furthermore as masculinities differ between cultures (Thompson and Bennett, 2016) it would be beneficial to compare how these impact on the experiences of social inclusion in urban and rural-dwelling older men with dementia.
- The research demonstrated that practitioners and health professionals in the rural areas
  might benefit from dementia awareness training. Future research could seek to develop
  training that not only seeks to raise dementia awareness more broadly amongst these
  populations but also takes into account rurality and masculinities and how these may
  impact on their professional practice.
- Explore how the findings from this study can be used to challenge public discourse of dementia and so benefit the social inclusion agenda more widely within the rural environments and further afield. The promotion of guidance documentation such as the one developed during this research may be one way to achieve this, however others might include publicising videos or photographs of the Technological Initiative.

#### 7.10 Conclusion

This was an applied exploratory multi-method qualitative study situated within a Participatory Action Research (PAR) framework. Working in collaboration with older men with dementia, I developed an individually-tailored Technological Initiative (TI) drawing on commercially available computer game technologies (iPad, Nintendo Wii and Microsoft Kinect) and delivered it over nine consecutive weeks in three rural locations of England. Twenty-two men provided me on-going consent to participate in the TI and provide feedback on the initiative. This information

was situated within the men's rural geo-socio-cultural environment and triangulated with that gathered from fifteen care partners and five community volunteers as well as my own extensive reflexive field-notes. Examining the data using inductive thematic analysis I have been able to contribute knowledge to a range of areas that have direct relevance for policy, practice, research and theory.

This was the first study to examine the experiential accounts of older men with dementia living in rural areas of England. My research revealed that although predominantly older men with dementia across the three rural locations lived well with dementia, certain aspects of the geosocio-cultural environment worked in conjunction with their subjective experiences of dementia to limit their sense of social inclusion. These factors made it difficult for them to engage in activities within the rural communities, develop meaningful relationships and maintain a level of autonomy and respect. This has important implications for the ageing in place agenda. It also highlights the need to acknowledge the geo-socio-cultural rural environment within our understandings and conceptualisation of social inclusion as well as the policies and practices used to promote social inclusion for people with dementia.

This study was the first to use a range of commercially available gaming technologies including iPads, Nintendo Wii and Microsoft Kinect in conjunction as part of an individually-tailored Technological Initiative for older men with dementia in rural areas. The research suggested that in accordance with a growing body of literature in this field the men were successfully able to engage with the technology and enjoyed doing so. The Technological Initiative enhanced the mood and social confidence of the men by enabling them to address certain aspects of their social inclusion that were currently absent within their daily rural lives. This included offering them the opportunity to: engage in a meaningful activity within their rural area; socially connect and form meaningful relationships with other men in the communities; and have a voice and regain a sense of autonomy. Furthermore the use of an atypical activity enabled the men to learn something new and so continue their life-long learning as well as challenge negative assumptions around their capabilities. These are important for their sense of social inclusion as well as the wider social inclusion agenda.

Finally the research demonstrated that masculinities persist in older men with dementia. Consequently the concept of social inclusion needs to incorporate an understanding of the male identities and highlight the additional difficulties this may have for promoting social inclusion within older men with dementia. This has important implications for the need to establish social inclusion policy that acknowledges these masculinities and for practitioners seeking to promote social inclusion in older men with dementia to cater for this in the activities they provide, the environment they create and the approach they adopt.

This research has been a journey of insight and development academically, professionally and personally. At times it has taken to me to the very limits of my perceived capabilities yet the rewards have been plentiful. Over the course of the research I have understood the importance

of working closely with the men, to collaborate with them as co-experts in the study and to always take the time to stop and listen to their voices. These relationships have been empowering for the men but have also provided me with support through some very difficult periods. This research has shown me the difficulties endured by the men when attempting to uphold their rights to be socially included within society. Whilst I acknowledge a vast amount of work must be undertaken to improve their situation, I hope that this research can contribute in some small part to a wider social change both within their rural environments and more globally. This will ensure that people such as my Gran and Bill, and those millions of people worldwide can live as well as they possibly can.

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Appendix 1 Ben Hicks PhD

### **Appendix 1**

### Kitwood's Malignant Social Psychology (Kitwood 1997)

1. Treachery: using forms of deception to distract or manipulate a person, or force them into compliance

- 2. Disempowerment: not allowing a person to use the abilities that they do have; failing to help them complete actions that they have initiated
- 3. Infantilization: treating a person very patronisingly
- 4. Intimidation: inducing fear in a person through the use of threats or physical power
- 5. Labelling: using a category such as 'dementia' as the main basis for interacting with a person and explaining their behaviour
- 6. Stigmatization: treating the person as if they were a diseased object
- 7. Outpacing: providing information or presenting choices at a pace too fast for a person to understand
- 8. Invalidation: failing to acknowledge the subjective reality of a person's experience
- 9. Banishment: sending a person away or excluding them-physically or psychologically
- 10. Objectification: treating a person as if they were not sentient beings
- 11. Ignoring: carrying on in the presence of a person as if they were not there
- 12. Imposition: forcing a person to do something or denying the possibility of choice
- 13. Withholding: refusing to give asked-for attention or to meet an evident need
- 14. Accusation: blaming a person for actions or failure of actions that arise from their lack of ability or their misunderstanding of the situation
- 15. Disruption: intruding suddenly or disturbingly upon a person's action
- 16. Mockery: making fun of a person's actions or remarks
- 17. Disparagement: telling a person that they are incompetent, useless or worthless; giving them messages that are damaging to their self-esteem.

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### **Appendix 2**

#### Kitwood's Positive Person work

 Recognition: an individual with dementia is acknowledged as a person, known by name and affirmed in their uniqueness. Recognition is not purely verbal and does not need to involve words

- 2. *Negotiation:* people with dementia are being consulted about their preferences, desires and needs, rather than being conformed to others' assumptions
- 3. *Collaboration:* working together with people with dementia to undertake household chores or personal care. An action is not 'done' to the person but is a process where their own initiative and abilities are involved
- 4. *Play:* play has no goal outside of the activity that enables spontaneity and self-expression
- 5. *Timalation:* form of interaction where the prime modality is sensuous or sensual. It can provide contact and reassurance, while making few demands of the person with dementia
- Celebration: People with dementia retain the ability to celebrate. Celebration is a form of interaction in which division between care partner and the person with dementia nearly vanishes
- 7. *Relaxation:* Providing opportunities for a person with dementia to relax. This might involve being with them or in actual bodily contact
- 8. *Validation:* Acknowledge the reality of a person's emotions or feelings and giving a response on the feeling level
- 9. *Holding:* Psychological holding (providing a safe psychological space for someone) or physical holding
- 10. Facilitation: Enabling a person with dementia to do what they would not be able to do otherwise. This can also involve collaboration. It can also mean enabling an interaction to occur.
- 11. *Creation:* The person with dementia offers something to the social setting using their abilities and social skills
- 12. *Giving:* The person with dementia can express concern, affection or gratitude, makes an offer of help or presents a gift

Appendix 3 Ben Hicks PhD

### **Appendix 3**

### Recruitment flyer and information sheet

# SOCIAL CLUB FOR MEN WITH



Do you want to meet other men with dementia in your community...
Do you want to take part in fun activities using new and entertaining gadgets
and gismos...

Do you want to play an active role in your community to raise the awareness of dementia...

Do you want to contribute to research and improve the well-being of other men with dementia...



As part of a Doctoral research study a Social Club is running for older men (65 years +) with dementia. The Social Club will run for nine weeks and is completely free to attend; so what have you got to lose?



Venue: Date: Time:



For more information please see attached Information Sheet.

If you are interested, please contact the lead researcher Ben Hicks on:

Bournemouth University Dementia Institute (BUDI)



Dementia Institute (BUDI)

# Information sheet: Exploring the benefits of a social club for older men with dementia in rural areas of England



My name is Ben Hicks. I am conducting a Doctoral study which is partfunded by Bournemouth University Dementia Institute (BUDI) and Age UK. It aims to bring older men (65 years or older) with dementia living in rural areas of England together in an informal, social environment to take part in activities and have fun!

You are invited to initially take part in the social club which will run for 9 weeks and enable you to meet other men in your area with dementia over a cup of tea and biscuits, help collect information for the research and contribute to the final guidance documentation produced.

The guidance that will come from these sessions will help improve the lives and well-being of men with dementia throughout the UK.

However the research also consists of two other parts (Part 1 being the social club) which will continue to run for a period of a year and you will also be encouraged to participate in the other parts of the study if you wish. The four parts of the study are:

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**Part 1:** You will be invited to a men only social club which will run for 9 weeks and is free to attend.

Venue:		
Date:		
Time:		

There will be one session every week lasting for two hours. During the sessions we will use activities on gadgets and gismos such as the Nintendo Wii, Nintendo DS, Microsoft Kinect and iPads, for example bowling on the Nintendo Wii, or puzzle games on the iPad, even singing on the Microsoft Kinect! The activities may involve some mild exercise and will give you something new to try out. Above all though they will be fun and entertaining! The social clubs will be run by me and will be supported by volunteers. Your care partner will also be invited to stay if they would like to watch and enjoy a cup of tea and biscuits, although the activities will only be for you.

Throughout the sessions you will be invited to share any thoughts you have about the club and the activities you take part in. You will also be given the opportunity to collect your own information through photos and videos and so contribute to the research project.

Part 2: Once the social clubs have finished (around October time) I will ask if I can accompany you on a walk around your local neighbourhood. The walk can be as long or as short as you like and you can choose the areas we visit; it could be to your local pub, or favourite park. I'll leave it up to you! I want to find out from you what it's like to live in your neighbourhood, what you like or don't like; places you find interesting or enjoy visiting. If you feel for any reason that you are unable to walk around your local area, then don't worry we can just talk about your experiences in the comfort of your own home.

**Part 3:** Around June 2015, I will invite you to attend a final discussion group. Here you will be given the chance to tell everyone what you think about the research findings and the final guidance that is produced.

As well as contributing to my PhD thesis, this research will also be presented in journal papers and presentations so we can share what we found. All the personal information collected will only be seen by me and my supervision team and will be stored according to data protection regulations at Bournemouth University. All information will be kept confidential and all names and identifying features will be removed when writing up reports and publications. If any photos or film clips are used which can identify you then we will ask for your permission beforehand.

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Your participation in the research is totally voluntary. If you decide at any point that you don't enjoy participating then you can stop without any questions. If you would like to take part in the study, I will ask you to sign a consent form. For more information or to register your interest in participating in the study then please contact me:

Thanks for reading this and I hope to see you soon!

### Appendix 4

Volunteer recruitment flyer

### YOUR COMMUNITY NEEDS YOU!!



Will you contribute to novel and important research to improve the lives of men with dementia...
Will you play an active role in your community and raise the awareness of dementia...

Would you like to learn how to use new and fun technology in a relaxed social environment...



Your support is needed for a Doctoral research study which aims to set up a Social Club for older men (65 years +) with dementia to provide them with activities using new and entertaining gadgets and a chance to meet others in similar situations.



Venue: Date: Time:



For more information please see attached Information Sheet. If you are interested, please contact the lead researcher Ben Hicks on:

Bournemouth University Dementia Institute (BUDI)

Appendix 5 Ben Hicks PhD

### Appendix 5

### Questions used in the pre-TI questionnaire

- 1. How did you hear about the social club?
- 2. Do you attend any other groups in the area for people with dementia? If so what are they?
- 3. During your free time what activities do you like to do?
- 4. Have you ever played on any of the gaming technology pictured here before?
- 5. Why did you decide to take part in the research?
- 6. Do you have any concerns about taking part in the research?
- 7. How old are you?
- 8. How long have you lived in your area?
- 9. How long have you lived with dementia?
- 10. How would you describe your ethnicity? Please tick the appropriate box.

### Appendix 6: Table of themes

### Table of themes for rural life for the men

\*These codes run counter to the main themes reported but are still important to understand. They have been discussed within the main body of the thesis.

Themes	Sub themes	Coding
Rural Idyll	Positive living	Men accepting of condition
		Dementia has no impact on life
		Fighting dementia
		Dementia adversely impact on general well-
		being*
	Pleasant rural	Remote surroundings
	environment	
		Pleasant/peaceful environment
		Familiar environment
		Environment good for walking
	Supportive informal	Care Partner provide practical/emotional
	networks	support
		Care Partner respect agency of men
		Supportive family
		Friendly rural residents
		Supportive/understanding rural residents
		Beneficial to be known prior to onset of
		dementia
		Preference for rural over urban environment
Challenge	Barriers of accessing	Services are provided and used*
to the idyll	structured activities	
		Limited financial resources for services
		Limited healthcare staff to run/refer to
		services
		Seasonal activities restrict participation
		Men reluctant to access services
		Care Partner difficulty providing activities
	Barriers of accessing	Detrimental impact of dementia/ageing on
	rural landscape	accessing rural environment
	'	Detrimental impact of dementia on
		motivation/social confidence to engage
		Lack of public transport
		Dependency on Care Partner for accessing
		environment
		Men restricted to home environment
	Lack of dementia	Limited support from rural residents
	awareness	
		Lack of understanding from rural residents
		Lack of support/connection with family
		Lack of understanding from healthcare
		Stigma of dementia/dementia services

### Table of themes for impact of the Technology Initiative (TI)

\*These codes run counter to the main themes reported but are still important to understand. They have been discussed within the main body of the thesis.

Theme	Sub theme	Codes
TI enables	Enjoyable participation in the	Enjoyable/fun initiative in the
participation with rural	community	community
community		
		Opportunity to leave the home
		environment
		Transport issues for attending
		TI*
		Engage in community
		independently
		Activity that do together*
	Social participation in rural	Meet/socialise with new
<del>-</del>	community	people
Technology as an	Person-centred activities	Technology provides
enabler		opportunities to engage with
		old leisure interests
		Technology offers a variety of
		activities
		Technology can be tailored to
		capabilities of the men
		Technology intuitive for men
		Unappealing games and activities*
	Fun and releved atmosphere	
	Fun and relaxed atmosphere	Fun engagement with games  Games detrimental to well-
	Provides stimulation	being of men*  Tech provides mental
	Flovides stillidiation	stimulation
		Tech provides physical
		stimulation
	Competition	Tech provides competition
	Competition	Competition supports
		achievement*
	Life-long learning	Tech provide progress with
	Life long learning	society
		Technology provides
		opportunity to learn something
		new
		Desire to learn about the
		technology
		Desire to improve
		performances
		Games provide sense of
		achievement
	Social interaction	Talk about technology and
		performances
		Technology prompt/sustain
		conversations about the men's
		lives
	Resist assumptions of	Challenges men's views of

	dementia	their capabilities
		Challenge volunteers views of
		the men's capabilities
		Challenge Care Partner's
		views of men's
		interests/capabilities
Male-only	Preference for environment	Preference for male-only
environment		environment
facilitates social		
connection		
		Females add positive
		elements to the groups*
	Relaxing and safe	Presence of women would
	environment	restrict men's ability to express
		themselves
		Male-only environment is
		familiar to the men
		Male-only environment
		promotes relaxation
	Comradeship	Social connection/network
		between the men
		Emotional connection of living
		with dementia
		Difficulties with diversity of
		men's experiences/interests*
		Reluctance of men to
		engage/get on with others*
Empowering approach	Approach empowers the men	Researcher provided choice
		Researcher's positive
		personality traits
		Researcher offered good
		support to men to engage with
		the technology
		TI did not bring focus on
		dementia
Beneficial outcomes	Enhanced mood	Improved mood of the men
for the men		during the TI
		Improved mood of the men
		after the TI
	Social confidence	Improved social confidence
		during the TI
		Improved social confidence to
		engage outside the club

Appendix 7 Ben Hicks PhD

## Appendix 7 Researcher's notes on the Old Boys

Men	Researcher's notes
Keith	Comfortable and confident socialising and keen to try new technologies. Wheel chair
	impacted on mobility. Only attended the 1st session due to poor health.
David	I developed a close relationship with him as I travelled to and from the group. A funny
	'man's man' and provided much of the 'banter' in the group with conversations on sport,
	pubs and women or singing rude rugby songs.
Joe	Friendly and confident man. Developed a close relationship with David and they would
	often joke around together. However lacked confidence in his abilities and would make
	numerous references to the 'good old days' where he felt he was better able to
	accomplish tasks.
Ken	Friendly and outgoing although had communication difficulties. Greeted the men with a
	smile and a nod although struggled to have long conversations. Had a good pre-
	existing friendship with Bob.
Bill	Intelligent man with a physics and maths degree. Often quiet and reserved, only
	engaging in the group when spoken to. Required encouragement to use the technology
	and usually only did once he had watched others use it.
Bob	Quiet man who had some communication difficulties. Enjoyed listening and laughing
	along with the other men.

### Researcher's notes on the Done Roaming

Men	Researcher's notes
Phil	Incredibly friendly and out-going and enjoyed socialising with the men. Loved playing the keyboard and would play the group in and out at each session Easy to develop a close relationship with and enjoyed the friendly competitive nature of the games; always looking to be champion for the day!
Doug	A proud man who was initially very difficult to develop a relationship with. Would often attend the group crying or angry, exclaiming that he hated getting old and being burdensome. Enjoyed engaging in conversations about cars and motor racing and when younger spent a lot of his time working up old classic cars.
Terry	An incredibly friendly man who had been very out-going and had travelled a lot.  Developing dementia had knocked his confidence though and on occasions he would take some encouragement to engage with the games.
Norman	A very friendly man who enjoyed socialising in the group. Spoke often about his son and was clearly very proud of him. He was relatively competent using the technology and required little encouragement to take part or support when engaged. He spoke often about the issues he faced having prostate cancer.
Barry	A friendly man, although he struggled to engage in group conversations due to issues with his eyesight and hearing. Most of the interactions I had with him were in one-to-one situations. These conversations tended to revolve around his farming days as well and when he used to play rugby. He required a walking stick to move around and would bring his own chair to each session.

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### Researcher's notes on Marching On

Men	Researcher's notes
Jess	A very friendly and confident man. Would entertain the men with rude jokes and had an infectious laugh.
Gordon	Although he had communication difficulties was very outgoing and keen to support and engage with the other men. A very friendly man and I developed a good relationship with him.
Tel	A reserved man who liked to sit at the back and watch others. He was very talkative within the group and friendly with some of the men.
Dick	A relatively quiet man who would not say a great deal unless he was spoken to. Although he was more willing to speak in a one-to-one situation, he always seemed to laugh along with the group.
Colin	A reserved man and didn't say a huge amount within the groups, although he occasionally made rude comments to make the men laugh. At times he could be a little irritable and on occasions I found it difficult to develop a relationship with him. He used a walking stick to move around the room.
John	A tall, broad and imposing man with hands that dwarfed mine. He appeared quite intimidating but was the gentlest natured person I met, always looking to help out where he could. At the start of each session he made a point of greeting everyone in the group and offering around the biscuits.
Harry	He was very enthusiastic and enjoyed participating in the activities. He had some communication difficulties which made it difficult to communicate with him verbally. He left the group after week five as his wife felt that he did not want to return.
Chris	A very well to do man, who reminded me of an English Teacher from my old school. He enjoyed classical music and would play the group in and out of each session on the piano. He had written many books on gardening and French literature and was more confident talking about these topics.
Simon	An enthusiastic and friendly man. Although he required a stick to walk and could be unstable on his feet, he was always willing to give the activities a go. I developed a good relationship with him and he also developed a good friendship with Gordon.
Dave	He was very difficult to develop a relationship with as he did not say a great deal and would often sit at the back out of the way. Would often shrug his shoulders or refuse to talk even in one-to-one situations. He had difficulty hearing and relied on a hearing aid. However I felt on occasions he purposefully turned it down or off so he didn't have to engage in the group.
Peter	A very quiet man who again tended to take a back seat within the group. I found it very difficult to develop a relationship with him as he said very little whilst he was in the group.