Ulster University

Institute of Nursing and Health Research

REPORT

A Feasibility Study of Facilitated Reminiscence for People Living with Dementia

Professor Assumpta Ryan
Dr Claire McCauley
Dr Liz Laird
Ms Aideen Gibson
Professor Maurice Mulvenna
Dr Raymond Bond
Professor Brendan Bunting
Professor Kevin Curran
Dr Finola Ferry

June 2018

HSC Public Health Agency
Research and Development

The ATLANTIC Philanthropies

Funded by: HSC R&D Division, Public Health Agency and The Atlantic Philanthropies

Table of Contents

List of Tables

List of Figures

List of Appendices

Acknowledgements

Our sincere thanks to the people living with dementia and their carers who participated in our research. Over the course of our intervention, many participants faced their own challenges which included illness, hospitalisation and bereavement. Despite this, they remained committed to our study and for this we are immensely grateful.

The Reminiscence Network Northern Ireland and in particular to Faith Gibson for her inspiring work in the field of reminiscence and for her guidance in the early stages of the development of this study's proposal. We are very grateful to Marian Ferguson and Audrey Lockhart for coordinating the reminiscence training for our facilitators, Jim Simpson, Gabriel Carey, Loretta Carthy, Frances Taylor and Genevieve Canning who in turn played a key role in highlighting the value of reminiscence and in supporting our participants to engage enthusiastically with this activity.

Majella Magee, our Western Health and Social Care Trust Principal investigator who was instrumental in the successful recruitment of our target number of participants. We also acknowledge the contribution of Fiona Scott, Claire Harvey and Alison McCallion who issued letter of invitation on our behalf to potential participants. The contribution of Sally Doherty and her team at the WHSCT R&D office is recognised and appreciated. We also acknowledge the significant role played by the Foyle Branch of the Alzheimer's Society Home Support Network and the Alzheimer's Society Dementia Cafés for supporting the project and for assisting us with recruitment.

The Public Health Agency, Research and Development Division and Atlantic Philanthropies for having the vision to focus a funding stream on care provision to people living with dementia and their families. Dr Gail Johnston, Programme Manager, merits special consideration for her ongoing support and advice through the study. We also wish to acknowledge the part played by the review panel whose constructive comments strengthened the quality of our original proposal which although unsuccessful, was subsequently funded the following year. This was a complex project and our steering group was instrumental in getting it completed on time and within budget. We therefore acknowledge, Graeme Skelton (person living with dementia), Ashleigh Davis (carer), Caroline McCaughey (Alzheimer's Society Home Support

Network), Marian Ferguson and Audrey Lockhart (Reminiscence Network Northern Ireland), Sheila McCarthy (Pramerica), Cathy Mawhinney (Dementia Nurse specialist), Lorna Conn (Dementia Together Northern Ireland) and Majella Magee (Western Health and Social Care Trust).

Julie Cummins, Institute of Nursing and Health Research, Ulster University for being the first port of call when we needed advice on any aspect of the administration of the grant and for her assistance in the preparation of the final report.

And last but by no means least, I would like to personally thank my co-investigators who each brought their own unique skill set to the study and who made a significant contribution to this report. A special word of thanks to our researchers, Aideen Gibson, who got the project off the ground and who worked above and beyond the call of duty and Dr Claire McCauley for being the driving force behind the study and for managing the day to day aspects of the project so skilfully and sensitively. This was a collaborative venture involving the Schools of Nursing, Computing and Psychology at Ulster University and external partners. Sincere gratitude to Dr Liz Laird (Nursing) Professor Maurice Mulvenna, Professor Kevin Curran and Dr Raymond Bond (Computing) and Professor Brendan Bunting and Dr Finola Ferry (Psychology). The contribution of our external co-investigators; Marian Ferguson, Audrey Lockhart, Cathy Mawhinney, Dr Sheila McCarthy and Mr Graeme Skelton is acknowledged.

Assumpta Ryan

Professor Assumpta Ryan
20 April 2018

Abstract

Background: Reminiscence has been widely used as a therapeutic approach for people living with dementia (PLWD) and their carers. The literature suggests that an individualised approach, coupled with the involvement of family carers, may be associated with better outcomes. Recent studies have focused on the use of technology to support reminiscence but there remains a dearth of robust research in this area.

Aim: The aim of this feasibility study was to investigate the outcomes of a home based, individual specific reminiscence intervention facilitated through the use of an iPad app for people living with dementia and their family carers.

Design and Method: The study used a quasi-experimental design, incorporating quantitative and qualitative components in three phases. **Phase 1**: A User Development Group comprising a paired sample of 6 people living with dementia and their family carers worked with the research team to refine and test the technology. **Phase 2**: The refined application was implemented with a paired sample of 30 people living with mild to moderate dementia and their family carers with each participant serving as his or her own control. A reminiscence trainer from the Reminiscence Network Northern Ireland guided participants in the collection of memorabilia. An IT trainer then provided training in the use of the reminiscence app. Participants used the system for 12 weeks at home. Outcome measures, collected at three time points, examined the impact of reminiscence on mutuality, wellbeing, quality of life and quality of the relationship between participants living with dementia and their family carers. Health economics data were also collected to inform the design of a future cost-effectiveness analysis. **Phase 3**: Individual interviews were conducted with a sample of participants (n=31) to explore their experience of the intervention.

Results: User interactions revealed that people living with dementia used the app independently and more frequently than their carers. There were statistically significant increases in mutuality ($p < .0005$), quality of caregiving relationships ($p < .0005$), and emotional well-being ($p < .0005$) from baseline to endpoint for people living with dementia, and eta squared values were indicative of large effect sizes. For carers, there were no significant changes in mutuality, quality of caregiving relationship and emotional wellbeing scores from baseline to endpoint. Participating dyads perceived the intervention as a positive experience which focused on gains rather than losses in the context of memory retention and learning new skills.

Conclusion

A programme of training and individual specific reminiscence supported by an iPad app can deliver positive impacts pertaining to mutuality, caregiving relationships and emotional wellbeing in the context of early to moderate dementia. A large randomised controlled trial of technology facilitated and home delivered individual specific reminiscence, is warranted.

Chapter 1 - Introduction

Background

Dementia belongs to a cohort of progressive neuro-degenerative disorders with Alzheimer’s Disease being the most common accounting for approximately 60% of cases (Alzheimer’s Society, 2017). It is estimated that somewhere in the world, someone develops dementia every 3 seconds. Further, it is estimated that approximately 50 million people worldwide are currently living with dementia, with numbers expected to double every 20 years reaching 75 million by 2030 (Alzheimer’s Disease International, 2015).

In the United Kingdom (UK) 850,000 people live with the condition (Alzheimer's Society, 2017). Dementia is now a major public health concern with estimated annual costs of 26 billion in the UK (Alzheimer's Society, 2017). These costs are higher than the combined costs in the UK for cancer, stroke and heart disease (Alzheimer's Society, 2017). The oldest old (i.e. those aged 80 years and older) make up a high proportion of the estimated population of people living with dementia. However, there are approximately 42,000 people in the UK under 65 years diagnosed with dementia. Within Northern Ireland there are in the region of 19,000 people living with dementia. This number is predicted to rise to nearly 60,000 by 2051 which is the fastest expected rate of increase within the United Kingdom (AgeNI, 2017)

The onset of dementia is gradual and initial impairments are slight and vary from one person to another (Alzheimer's Society, 2017). However, as the disease progresses cognitive processes are inhibited and the ability to self-care is limited. The symptoms of dementia vary depending on the level of brain damage but memory loss, difficulty with thinking and processing information, communication difficulties and behavioural and mood changes are all recognised symptoms of dementia (Wayman, 2017).

Whilst dementia has a devastating impact on the individual, its effects are also acutely experienced by family and friends and impact on their relationship with the person living with dementia (Gonzalez et al. *2*015; Wayman, 2017). As symptoms worsen and dementia progresses, it is common for a person’s mood to alter and emotions to become affected. The person living with dementia can become confused and agitated with, not only themselves, but also with those around them as they feel disempowered by their loss of independence and the need to rely on others to assist them with everyday tasks such as washing, dressing and eating (Smith, 2016; Wayman, 2017). Many family members experience feelings of social isolation, depression, exhaustion and abandonment as a result of their caring role (McDonnell and Ryan, 2014) and are consequently at increased risk of psychological morbidity (Selwood et al. *2*007). This impact on family and friends can often lead to a loss of emotional support for, and communication with, the person living with dementia and consequently to a depletion in shared activities (Quinn et al. 2009; Damianakis et al. *2*010).

The use of anti-psychotic pharmacological treatments for the symptoms of dementia have been common practice despite limited effectiveness and the development of complicating side effects (Lawrence et al. *2*012; Gonzalez et al. *2*015; Alzheimer's Society, 2017). Non-pharmacological interventions are often considered as there is increasing evidence that these interventions can have commensurate effectiveness to pharmacological treatment and may, in fact, be preferable where medication can cause negative side-effects (Lawrence et al. *2*012; Woods et al. *2*012; Gonzalez et al. *2*015). One such non-pharmacological intervention is reminiscence and research has shown that it can encourage emotional and social connections (Gonzalez et al. *2*015).

Reminiscence therapy is defined as *"the discussion of past activities, events and experiences with another person or group of people, usually with the aid of tangible prompts such as photographs, household and other familiar items from the past, music archive and sound recordings"* (Woods et al. 2005, p1). Reminiscence works on the assumption that the memories can be accessed in the early to moderate stages of dementia. It therefore draws on a person's strengths and preserved abilities, rather than accentuating their impairments (Woods et al. *2*016). Reminiscence has the potential to improve mood, well-being, quality of life, social interaction, cognition and autobiographical memory for people living with dementia (Subramaniam and Woods, 2012; Lazar et al. 2014). However, these findings are not consistent across the high-quality research designs (Woods et al. 2005; Cochrane Collaboration, 2015).

Although reminiscence remains one of the most popular psychosocial intervention for people living with dementia and their families (Cotelli et al. *2*012), the delivery of such therapeutic programmes has presented challenges. Azcurra (2012) argued that in a recent Cochrane

Review of reminiscence therapy, the quality of the research was poor and limited by the size and selection of samples. A large randomised controlled trial conducted by Woods et al. (2012) on joint reminiscence groups for people living with dementia and their carers did not provide support for the effectiveness or cost-effectiveness of their intervention. The authors concluded that any beneficial effect for people living with dementia must be viewed in the context of raised anxiety and stress in their carers and recommended the exploration of other approaches to enhance relationships between people living with dementia and their carers (Woods et al. *2*012).

With advances in information and communication technology, it is not surprising that the potential for technology to support psychosocial intervention is an area of significant interest. The literature pertaining to the use of technology in reminiscence will be explored in more detail in the literature review in Chapter 2.

Context for the Present Study

Researchers at Ulster University have been undertaking research on technology facilitated reminiscence for a number of years. ‘Memory Lane’ was a personal digital assistant device developed by Dr Sheila McCarthy as part of her PhD studies at the university in 2009. This system provided portable storage for film clips, news items, music, photographs and other visual and auditory triggers of personal experiences that helped the user to reminisce and in doing so, to share and value their experiences. A User Sensitive Inclusive Design (USID) approach (Newell and Gregor, 2000) informed the development of Memory Lane. Three studies from that work were conducted with older adults as participants (McCarthy et al. *2*009, 2011, 2015). The findings indicated that the participants had enjoyed the opportunity to reminisce afforded by the device and that the use of photographs and music were particularly stimulating. However, participants’ sensory deficits hampered their use of the system.

At the time of its development, the Memory Lane software was deployed on a mobile computing device. This was necessary because modern tablet devices with downloadable applications were not available when the original study was carried out. In 2014, the research team secured funding to conduct a feasibility study of facilitated reminiscence for people living with dementia under the Commissioned Research Call (Dementia Care) which was jointly funded by the Public Health Agency, Research and Development Office and Atlantic Philanthropies. This funding enabled the team to carry out the present study, which built on the original Memory Lane findings by moving the software to a mobile tablet device and then testing it with people living with dementia and their family carers.

Aim

The overall aim of this feasibility study was to investigate the outcomes of a home based, individual specific reminiscence intervention facilitated through the use of an iPad app for people living with dementia and their family carers.

Design and Method

The study used a quasi-experimental design, incorporating quantitative and qualitative components in three phases.

Phase 1: A User Development Group comprising a paired sample of 6 persons living with dementia and their carers worked with the research team to refine and test the technology.

Phase 2: In Phase 2, the refined application was implemented with a paired sample of 30 people living with mild to moderate dementia and their family carers with each participant serving as his or her own control. A reminiscence trainer from the Reminiscence Network Northern Ireland guided participants in the collection of memorabilia. An IT assistant then provided training in the use of the reminiscence app. Participants used the system for 12 weeks at home. Outcome measures collected at three time points, examined the impact of reminiscence on mutuality, wellbeing, quality of life and quality of the relationship between the person living with dementia and their family carer. Health economics data were also collected to inform the design of a future cost-effectiveness analysis. Phase 2 also reports a novel component of the analysis in which *'in the moment'* questions, derived from the primary outcome measure (Mutuality Scale) were programmed during usage and correlated to the data generated at baseline, midpoint and endpoint. Although this was *not* a specific study objective, the research team felt that it would have been a missed opportunity not to explore this type of data collection, particularly for people living with dementia, who may be best able to describe their feelings 'in the moment' rather than through recollection of short term memories which may be compromised as a result of their dementia diagnosis.

Phase 3: Individual interviews were conducted with a sample of participants to explore their experience of the intervention.

Presentation of Report

In the interest of brevity, the term 'carer' will be used interchangeably with family carers. While the use of abbreviations to describe individuals living with dementia runs contrary to the person-centred approach that underpinned this study, the abbreviation PLWD will be used to refer to person(s) living with dementia.

The complexity of this study does not lend itself to a conventional or linear approach to the presentation of the report (literature review, design and method, results and discussion). The objectives, methodologies and results of the three phases of the study will therefore be described in detail in the following chapters. To assist the reader in navigating this report, the following contains a breakdown of each chapter's content:

Chapter 1: This introductory chapter provides background information pertaining to the rationale for the study. It highlights the context for the present study and its overall aim, objectives and design.

Chapter 2: This chapter reviews relevant literature on the use of technology in dementia and reminiscence.

Chapter 3: This chapter presents the aims, objectives, design, method and results of Phase 1 of the project, the development and testing of a reminiscence app for PLWD and their family carers.

Chapter 4: This chapter provides an introduction to Phase 2, highlighting aims, objectives, research design and ethical issues.

Chapter 5: Event logging and behavioural data analysis are presented in this chapter.

Chapter 6: This chapter reports on the analysis and results of the primary and secondary outcome measures.

Chapter 7: This chapter presents ‘in the moment’ data analysis and results.

Chapter 8: The heath economics component of the study is described in this chapter.

Chapter 9: This chapter presents the aims, objectives, design, method and findings of the qualitative phase of the study.

Chapter 10: This ‘Discussion’ chapter summarises the main findings and critically analyses them in the context of other research on the use of technology in dementia and reminiscence.

Chapter 11. The final chapter includes recommendations for policy and practice, pathway to impact and PPI.

Chapter 2 - Literature Review

Introduction

Prior evaluations of reminiscence have typically relied on static material such as photographs and personal items (O Rourke et al. 2011., Lazar et al. *2*014). It is now recognised that technology based applications have the potential to provide a more dynamic reminiscence experience (Lazar et al. 2014). Technology based reminiscence activities can be rapidly downloaded and ready for use or quickly personalised to the individual and family. Smaller mobile devices and a wider availability of wireless networks have also increased portability. Studies have shown that using computers with PLWD is highly rated by participants, families and staff (Tumura et al. *2*007; Astell et al. *2*010). However, a review of technology based interventions has indicated that, although the use of technology for reminiscence is an area of significant interest, there remains a need to explore the types and content of media beneficial to individuals at different stages of dementia (Lazar et al. *2*014).

Information technology and dementia

Kerssens et al. (2015) tested the usability, feasibility and adoption of the 'Companion' in a study involving seven people living with dementia and their caregivers. The Companion, designed to mitigate neuropsychological symptoms and cue daily health and wellness routines is a touch screen computer, with no keyboard or mouse, which delivered psychosocial interventions such as reminiscence, stimulated presence and orientation to place and person. Interventions were personalised and delivered in the home for a minimum of three weeks. Post-intervention measures indicated the technology was easy to us, significantly facilitated meaningful and positive engagement and simplified carers' daily lives. Participants living with dementia used the system independently but were limited by cognitive and physical impairments. The authors concluded that the Companion can help manage some of the neuropsychiatric symptoms associated with dementia and offer support to carers. The findings of Kerssens et al. (2015) are consistent with the work of other laboratories using technology to promote reminiscence and quality of life (Astell et al. 2010) and confirmed that psychosocial interventions can be delivered using computer based tools.

Lorenz et al. (2017) conducted a literature review to explore technology based tools and services for PLWD and their carers and concluded that, despite the wide range of technologies available for this client group, there was little evidence of widespread practical application. On the contrary, it appeared that PLWD and their carers frequently relied on everyday technologies re-purposed to meet their needs (Ayres, 2013). Consistent with other studies, the review identified the role of technology in supporting the delivery of therapeutic interventions, including home based reminiscence, to reduce caregiver burden and stress (Carers UK, 2014; O Shea et al. 2014). While Lorenz et al. (2017) acknowledged the significant role technology can play in supporting connection, communication and independent living, it also highlighted the challenges posed by the ever changing cognitive status of users. This was supported by a host of other studies which recommended that technologies for PLWD and their caregivers need to be accessible at the right time, adaptable to changing needs, easy to use and inexpensive to buy (Ayres, 2011; Mulvenna et al. 2011; Karlsson et al. 2014).

Technology facilitated reminiscence

For people living with dementia, their ability to present rational ideas and to reason lucidly is diminished (Wayman, 2017). However, it has been demonstrated that PLWD can participate in research and provide useful feedback on Information Technology (IT) solutions (Kerssens et al. 2015). The development of new treatments for dementia has become a UK government priority (Department of Health (DOH), 2016). The use of digital systems to facilitate reminiscing has been shown to be beneficial for PLWD (Lazar et al. 2014). Reminiscence systems have been defined as 'the use of technology to support reminiscence work' (Mulvenna et al. 2011, p.58). Technology that facilitates reminiscence increases opportunities for people living with dementia to participate in conversations and to enhance their social interactions (Subramaniam and Woods, 2016)

Many existing software systems, apps and online social networking websites provide opportunities to gather, browse and share multimedia resources (Lorenz et al. 2017). However, there is very little research into the usability of these systems for the purpose of reminiscing amongst people with deteriorating cognitive function. Thiry (2013) discovered that many older people do not use social networking sites or online communities because there is 'too much going on'. Consistent with the findings of other studies (Cosley et al. 2009; Good et al. 2012), Thiry's research indicated a need for software systems which were simpler, minimalistic and which required only the most basic support for content creation and management.

Recent advances in information and communication technology (ICT) have enabled increased opportunities for supportive interventions, such as reminiscence, to be conducted in the home (Karlsson et al. 2014). However, ICT facilitated reminiscence has posed documented challenges, as it usually relies on caregiver willingness to participate and to source appropriate memorabilia or stimulus (Sarne-Fleischmann and Tractinsky, 2008). Despite this, research into technology facilitated reminiscence has shown that it can facilitate opportunities for PLWD to retain an empowered role in their conversations, interactions and relationships (Lazar et al. 2014).

Lazer et al. (2014) carried out a systematic review of literature surrounding the use of technology in reminiscence therapy using ACM Guide to Computing Literature, PubMed and PsychINFO databases. Forty-four papers were selected for review and, although limited by the small sample size of some of the selected papers, the authors concluded that there are benefits to using ICT for reminiscence interventions. Some of these benefits have been reported elsewhere and include; access to rich and engaging multimedia reminiscence materials (Astell et al. 2010; Elfrink et al. 2017) opportunities for people with dementia to participate in social interactions and take ownership of conversations (Kerssens et al. 2015; Hamel *et al* ,2016) and a reduction of barriers due to motor deficits during interactions with media (Mulvenna et al. 2011; Kerssens et al. 2015). The authors recommended that future studies should explore the types and content of media beneficial to individuals at different stages of dementia. Additionally, Lazar et al. (2014) proposed that technology can reduce the burden of the delivery of reminiscence as it provides opportunities for remote therapy, thereby reducing travel and time commitments for carers.

A study by Mulvenna et al. (2011) examined the attitudes of older people (n=19) to using a device to reminisce as opposed to a card based approach. Participants in the study were randomly allocated to reminisce using either an iPad or more traditional images and cards. The results from the study indicated that participants enjoyed using the iPad. Using a parallel convergent mixed methods design, the feasibility of ‘Memory Matters’(MM), a mobile device application developed to promote reminiscence, was evaluated by Hamel et al. (2016). Eighteen people living with dementia and eight family carers were asked to use Memory Matters for four weeks. Consistent with the findings of other studies exploring similar devices (Lazar et al. 2014; Haesner et al. 2015), Hamel et al. reported that family and staff perceived MM favourably. Family participants enjoyed discussing the early years with the PLWD and on several occasions, residents shared memories in a direct response to prompts provided by MM. People living with dementia who had only interacted minimally, or who had never spoken before, interacted and supported each other while playing the application. The authors concluded that these findings support the social engagement potential of mobile devices that include stimulating interactive content (Bleakely et al. 2015, DeLello and McWhorter*,* 2015). However, Mulvenna et al. caution that the risk in adapting such technologies is that the essence and richness inherent in such a human activity as reminiscing are lost in translation and that older people may be expected to use technology as a proxy for interaction with other people (Mulvenna et al. 2011).

User engagement in technology research

As the use of computer applications or ‘apps’ and ubiquitous devices are fast becoming an integral part of everyday existence, there is a need to design digital systems that can be used by all, regardless of physical or cognitive abilities or impairments. The need to involve all stakeholders in systems design and to undertake usability testing of the user interface is imperative and is widely accepted as good practice (Carroll and Rosson*,* 2007; Span et al. 2013; O Connor et al. 2016). As a result, human-computer-interaction researchers have proposed standard instruments, protocols and metrics for measuring ‘usability’ as a construct (Sauro, 2016; Gibson et al. 2016). However, where the target user group has diminished cognitive abilities and perhaps also physical impairments, issues can arise that pose problems when using these standard methods for usability testing (Astell et al. 2009; Riley et al. 2009). There is widespread agreement in the literature that developments must take into account the needs, abilities and desires of the intended users especially in respect of those with cognitive impairments which can interfere both with their ability to participate in the development process and their ability to utilise the technology once created (Astell et al. 2009; Robinson et al. 2009; Span et al. 2013). It is, therefore, important that the design and development of digital systems and apps, should formally involve the intended target user group, and that their contribution should be evidenced in usability protocols (Sauro and Dumas, 2009; Brankaert and Ouden, 2015).

Span et al. (2013) conducted a systematic review on the involvement of PLWD in the development of supportive IT applications. Consistent with other studies, the methods most frequently used to involve participants were interviews (Gibson et al. 2016; Hamel et al. 2016; O Connor et al. 2016), observations (Mulvenna et al. 2011; Hamel et al. 2016) and usability tests (Sauro and Dumas, 2009; Gibson et al. 2016). In most studies, participants were objects of study and informants. The authors concluded that involving PLWD in developing supportive IT applications is limited and a fairly recent phenomenon. People living with dementia were mostly involved in the explorative and technical development phases. Only a few publications describe their involvement in all stages (Astell et al. 2007, Hanson *et al* 2007., Riley et al. 2009). However, their involvement improved the usefulness and acceptability of the device and may have had an empowering effect on the individuals.

In the UK, O'Connor et al. (2016) explored the barriers experienced when co-producing a memory and reminiscence app. A focus group and interviews were conducted with PLWD/carer dyads (n=4) and personnel involved in the design of the app. Consistent with the findings of other studies, the researchers recommended that developing digital applications with PLWD and their carers needs to be well thought out, planned and executed to address poor attitudes and inaccurate perceptions (Lorenz et al. 2017), lack of digital literacy, knowledge and skills (Span et al. 2013; Kerkhof et al. 2017) and to ensure that any compromises made in the design are justified and add value for money (Nijhof et al. 2013; Gibson et al. 2016). The authors concluded that more research into designing digital devices with PLWD and carers should be done to uncover the complexities involved and to help develop a robust methodology that is theoretically grounded.

A Dutch study by Kerkhof et al. (2017) used eight focus groups involving people with mild cognitive impairment or dementia and informal carers. The aim of the study was to explore users' requirements for the development of a tool for selecting usable apps in the domain of self-management and meaningful activities. Findings highlighted the importance of enhancing the navigation experience of PLWD by minimising the need for scrolling, providing an easy and intuitive user experience, minimising the use of excessive screens and clicks and presenting clear instructions on a step by step basis. Both PLWD and their carers found entering codes and passwords annoying. Informal carers considered the apps built for Android more difficult to operate than those built for Apple because the Android misses a clear home key. Studies into the use of touchscreen technology by PLWD have shown that the Apple iPad and its apps were primarily used because of the intuitive interface and user-friendliness (Upton et al. 2011; Groenewoud and deLange, 2014; Kerkhof et al. 2016) and because less instructions were needed for independent use of easy to operate apps (Lim *et al* 2013; Astell et al. 2016). This suggests a general preference for Apple as a platform for people living with dementia. Recognising the limitations of the small sample size, the authors recommended that tools should be designed and developed in close cooperation with intended users and other stakeholders such as family carers and experts to ensure user-friendliness.

Barriers to user engagement

The reasons for lack of involvement of PLWD in the development of technology are many and have been explored in the literature. The stigma associated with dementia and the paternalistic attitudes of some professionals have been identified as contributing factors (Werner and Heinik, 2008, Span et al. 2013). The distress caused to PLWD when devices are in the early stage of development or do not work have also been highlighted as barriers to user engagement (Orpwood et al. 2007; Riley et al. 2009). While, the lack of involvement of PLWD in application development may be partly explained by this phenomenon of anticipated stress, other researchers have not reported any such distress (Hansen et al. 2007; Robinson et al. 2009). It is important to note that, despite the possibility of distress, Span et al. (2013) found that many participants enjoyed taking part in research and believed that their well-being seemed to increase as a result of their contribution. This confirms the assertions of Whitlatch and Menne (2009) and Hellstrom et al. (2007) concerning the importance of involving people with dementia in all aspects of dementia research, including usability testing of technology support systems.

Other factors such as cognitive impairment and frailty have been identified as barriers to user engagement by PLWD. Several studies have included recommendations to overcome these barriers such as prioritising the wellbeing of participants, allowing sufficient time, providing active and continuous support and ensuring that the study location is dementia friendly (Hanson et al. 2007; Riley et al. 2009). Many authors have described the learning potential of people with dementia, (Deschamps et al. 2007; Hanson et al. 2007; Van Tilborg et al. 2011) whereas, Riley et al. (2009) refer to the inability of people with dementia to learn new skills. It is noteworthy that in their review of the literature on involving PLWD in the development of supportive IT applications, Span et al. (2013) concluded that cognitive impairment is no reason to exclude PLWD from research. Nevertheless, it is important to ensure that ethical issues are carefully considered in light of the potential vulnerability of this population group.

Multimedia

The use of multimedia in reminiscence was arguably the first stage in the growth of use of technology in reminiscence systems and there are a significant number of research projects and publications highlighting such work (Astell et al. 2010; Hamel et al. 2016; Subramaniam and Woods, 2016). It is natural, perhaps that the reminiscence process, which uses visual and hearing senses (as well as others) could be enriched with multimedia material encompassing photographs, videos, audio recordings and music as well as historical material such as newspapers. The multimedia paradigm also lends itself to extending the concept of memory books, used in traditional reminiscence activities, where a carer or family member compiles a personal storybook with images and pictorial mementos of a person's life. Using multimedia, technology-based reminiscence can animate the material thus making it more attractive and attention-holding than the paper-based alternative. However, since the process of creating a memory book provides rich reminiscing opportunities, care must be taken not to replace this type of work with a more mundane and less user-centred multimedia authoring process.

It is noteworthy that there is evidence to suggest that older people experience no negative effect in using touchscreen devices such as tablet devices versus paper for reminiscing (Upton et al. 2011; Wright and Mulvenna, 2012). It could be argued that viewing photographs on modern screens may not recreate the same tactile experience as holding and touching them. However, with the advent of higher resolution screens, recent studies have shown that older adults aged 60 and above found reading and viewing images easier when using backlit electronic devices due to the increased contrast between the text/images and the background (Kretzschmar et al. 2013).

In recent years, a major development in computer–assisted reminiscence has been the Computer Interactive Reminiscence Conversation Aid (CIRCA), designed to support PLWD and the people who care for them. CIRCA is an interactive multimedia touch screen system that contains a wide range of stimuli to prompt reminiscing. The programme highlights the significance of ease of use regarding such interventions and emphasises the importance of touch screen technology so that PLWD can become actively involved in the process. Astell et al. (2010) evaluated the utility of CICRA in facilitating PLWD (n=11) and their professional carers (n=11) to engage in mutually satisfying interactions. Although limited by the inclusion of generic rather than personal content, the authors concluded that CIRCA was engaging both for PLWD and their carers, prompting long-term memories and occasional stories from PLWD in ways that no other type of reminiscence based activities had previously achieved (Alm et al. 2009; Astell et al. 2010).

Building on this work, the Computer Assisted Reminiscence Therapy (CART) project in Nottingham was designed to use mobile tablet computer technology to structure reminiscence therapy sessions in care settings for PLWD. Pringle and Somerville (2013) explored whether using multimedia technology could develop the reminiscence process further by creating personal computer files for a group of care home residents (n=8). These personal files contained personal photographs, general photographs and a playlist of songs of significance to the PLWD. Pringle and Summerville compared the CART process with the existing approach to reminiscence involving structured conversation or memory books. Findings suggested that using the tablet technology increased the engagement time from 10 minutes using a memory book to 20 minutes using the computer. Perhaps the most significant observation of the use of technology was the way in which it appeared to expand conversation and increase the depth of memory by adding extra details. The authors acknowledged that while many of the current generation of PLWD may have never interacted with a computer before, they can benefit enormously from tablet-based computer assisted reminiscence packages (Astell et al. 2009). Limitations of Pringle and Somerville's study have been reported elsewhere and include the small sample size (O Rourke et al. 2011; Lazar et al. 2014), the short duration of the project (Kerssens et al. 2015; Hamel et al. 2016) and the involvement of staff in the intervention (Kerssens et al. 2015; Hamel et al. 2016).

Lazar (2014) carried out a small study to assess how a multi-functional interactive technology system, designed to facilitate engagement in activities in people living with dementia, was perceived by staff (n=7), residents (n=5) and families (n=4). Participants were observed using the system twice a week for two hours and the researcher took notes, including rating factors such as whether residents interacted with staff, each other and the system. Interviews were also held with staff on a regular basis. As reported elsewhere (Sarne-Fleischmann and Tractinsky, 2008; Hamel et al. 2016), the findings suggested the staff and family members found benefits in using the system, such as providing residents with something to do, giving residents a sense of accomplishment and enabling conversations around new topics. People living with dementia were able to use and benefit from the system with the assistance of a member of the research team of staff, but not independently (Gibson et al. 2016).

Karlsson et al. (2014) explored the process of acceptance and integration of a 'Digital Photography Diary' (DPD) as a reminiscence and conversation aid. Seven couples in which one individual within the couple had Alzheimer's disease tested the DPD for six months. Data were collected on three sequences with interviews, observations and screening instruments. Factors contributing to regular use have been reported elsewhere and include 1) how the DPD matched expectations (Kerssens et al. 2015), 2) patterns of use (Gibson et al. 2016), 3) support (Hanson et al. 2007), 4) experienced usefulness (Karlsson et al. 2011) and 5) reaction from family and friend (McHugh et al. 2012; Stenthouse et al. 2013). These findings support an earlier study by Karlsson et al. (2011) which concluded that there is a need to consider the integration of digital devices into the daily lives of PLWD as a process that requires a considerable amount of time as well as active support and encouragement from the family member.

Caregiver support

In the UK, an estimated 700,000 family and friends are caring for a PLWD and over 24 million people know a family member or friend with dementia (Alzheimer's Research UK, 2015). There is widespread variation in the literature on the impact of reminiscence on family carers with many studies reporting the significant challenges faced by families (Aguirre et al. 2011; Woods et al. 2012; Melunsky, 2015; Charlesworth et al. 2016). A consistent theme in all the studies exploring technology facilitated reminiscence is the centrality of support provision by formal and informal carers. In an Irish study, McHugh et al. (2012) explored the role of ICT in supporting caregivers of PLWD. Interviews were conducted with 14 spousal caregivers and analysed using a grounded theory approach. Findings revealed specific areas in which technology could alleviate caregiver burden based around three key themes; support needed, social isolation and the relationship between the PLWD and caregiver. As reported in previous studies (Astell et al. 2011; Lazar et al. 2014), the authors highlight the importance of consulting carers to ensure that technology design is grounded in an understanding of the problems being addressed. Participants expressed the need to access information about dementia and how to manage the change in their lives (McDonnell and Ryan, 2014) while also requiring informal support in the context of mentorship and reassurance (McKeown et al. 2010). Social isolation was a key issue because of the difficulties in leaving the house and in sustaining social networks (Melunsky et al. 2015). The third theme related to the interaction between the caregiver and the PLWD. Participants reported a 'disappearance of the relationship' due to personality changes in the PLWD and the desire to avoid distress or confrontation (Reiger and Gitlin, 2017). Consistent with the literature on family caregiving (Ryan et al. 2013; McDonnell and Ryan, 2014; Melunsky et al. 2015), Mc Hugh et al. highlighted the need to encourage caregivers to protect their own mental and physical wellbeing, not least because of the positive consequences for the caregivers to continue their caring role. The study concluded that ICT can facilitate communication between PLWD and their carers while also supporting connectivity between carers and their family and friends. Similar to Lazar et al. (2014), the authors cautioned that the benefits of technology for PLWD must be considered in the context within which they may place additional demands on an already strained population of family carers.

Personal versus generic memorabilia

The benefits of using personalised versus generic materials have been explored in a number of studies. Astell et al. (2010) found that generic photographs prompted more storytelling by individuals with dementia. In contrast, Yasuda et al. (2009) found that people showed more interest and less distraction while viewing personalised photo-videos than while viewing TV shows. The potential for emotional distress when a person living with dementia fails to recognise himself or herself or others in personal photographs has been recognised in the literature (Gowans et al. 2004). Similarly, discomfort or distress may arise if reminiscence materials contain disturbing images such as photographs of wartime or of deceased relatives, leading to the recommendation that decisions of whether to include potentially distressing images or videos should be based on the wishes of participants and their families as well as on their reactions to different types of media (Smith et al. 2009).

Sharne-Flecischmann and Tractinsky (2008) examined the effectiveness of a personalised multimedia system developed for use by people with Alzheimer's Disease (n=5) and their carers. The system was developed iteratively using the opinions and observations of PLWD and their carers as the primary evaluation mechanism. The results indicated high user satisfaction levels with the system and a strong tendency towards repeated use. The system was found to be effective in promoting conversations and invoking personal memories. The results showed a clear preference for personal as opposed to generic materials, when both were available. Contrary findings were reported in other studies. Mulvenna et al. (2011) showed no difference in how participants (n=11) viewed three types of images (personal, generic and shared experience). There was also no evidence that participants spent longer viewing and discussing images that were not personal, as suggested by Astell et al. (2010). An American study by Boyd and Shenk (2014) used personal and generic videos to engage PLWD (n=11) and concluded that both personal and generic videos can be used by minimally trained individuals to engage this client group. Participants showed a slight, though not significant, preference for looking first at personalised videos although in keeping with the findings of Astell et al. (2010), the generic videos generated more diverse comments on a broader range of topics. A more recent study by Astell et al. (2016) evaluated the concept of familiarity in gameplay with PLWD (n=30) by comparing a known game with a novel game and measuring whether users were able to play these games independently and whether they enjoy doing so. The authors concluded that PLWD were able to play touch screen games independently. Familiarity alone was not enough of a reason to make a touch screen game suitable. Rather, novelty in touch screen game selection can be important for PLWD and success with the game is not necessarily required to achieve enjoyment.

Life stories

Story telling about a life is a way for people living with dementia to construct and express meaning in their lives and has an important impact in helping people identify themselves. According to Hardy and Summer (2010), narrating the story of one's life can be seen as a way to sustain a sense of self. There are many tablet/smart phone apps that can be used to create a digital personalised story including My Story Book Creator, Story Maker or Book of You. While there is evidence of the potential benefits of multimedia and personalisation for people living with dementia (Stenhouse et al. 2013; Subramaniam and Woods, 2016), Alm et al. (2009) caution that too many stimuli can overwhelm PLWD and therefore a judicious balance between engagement and over stimulation needs to be sought.

Digital story telling is a generic term used to describe the use of new media technologies to create innovative narrative forms. Still images usually drawn from the storyteller's personal photograph albums are combined with a recorded voiceover scripted by the storyteller and sometimes music is added. In reflective digital storytelling, this results in a rich tapestry that is at once effective, affective and reflective (Hardy and Summer, 2010). The process is person centred with participants retaining control over the story that is told. O Neill and Hardy (2008) have identified that storytellers experience a strong feeling of humanity as a result of the experience.

Digital life story books have three main advantages. First, it is easy to document and retrieve personal memories that match the idiosyncrasies of individual life stories. Second, technology provides multimedia for the storage and retrieval of memories. Sound, music, photos and movies can be easily added beside anecdotes and verbal cues. Third, technology makes it possible to use the life story book in an interactive way. Informal caregivers and family members and friends can add new memories or remarks on memories that were especially vivid to them. Of particular significance is the ability to update and adjust the life story book even when the dementia progresses.

Stenhouse *et al*. (2013) conducted a study whereby digital stories were made with seven people with early stage dementia as part of a learning package for student nurses. The authors reflected on their experience and observation from facilitating the four-day digital story making workshop. Despite considerable challenges in developing a story and anxiety about using the technology, all participants engaged in creating their own digital stories. During the workshop, a number of positive changes were observed among participants including increased confidence, improved speech, a sense of purpose and increased connection. These improvements appeared to be the product of the person-centred facilitation and the creative process which supported self-expression and a sense of identity. Consistent with the findings of other studies (Kelly 2010, Peisah et al. *2*011), the authors concluded that participation in the workshop engendered some improvements in participants’ social interactions.

Subramanian and Woods (2016) designed a study to establish an evidence base for the acceptability and efficacy of using multimedia digital life story books in comparison with conventional life story books. Participants included PLWD (n=6) in care homes, their relatives and care staff. A participatory design was used to create a life story movie based on previous completed conventional life story books. Data were collected using quantitative and qualitative approaches. The results indicated that five of the six participants showed additional improvements in measures of quality of life and autobiographical memory. All participants showed improvement or stability in depression scores. Thematic analysis showed that participants, relatives and care home staff viewed digital life story books as a very useful tool for triggering memories and generating positive emotions. Savage (2017) reported similar findings with regard to the ‘Book of You’, a web app that uses digital media to facilitate PLWD to complete a profile of their memories and life stories. As previously highlighted, the accessibility of the app on a tablet computer or other mobile devices was important (Ancient et al. 2011; Lim et al. *2013*) as was its portability, which meant that it could remain with the individual, regardless of location (Astell et al. 2016; Kerkhof et al. 2017).

Despite the many potential benefits of integrating technology into life story work for individuals with dementia, there are barriers (Palmer et al. 2012). Research has shown that iPads are preferred over Android devices by PLWD (Kerkhof et al. 2017). However, iPads are not inexpensive. In addition, the completion of life story work can be a time-consuming process. Smith et al. (2009) developed multimedia life stories for individuals with Alzheimer's disease or mild cognitive impairment. This necessitated the gathering of photographs, videos, audio-clips and music which were subsequently complied into a digital video format. The success of the study was measured by the completion of the multimedia biography and caregiver interviews at various stages, from completion of the multimedia biography to one-year later. Although positively evaluated, the authors reported that it took an average of one hundred and thirty hours over five to six months to create the biographies and that the success of similar ventures will, therefore, require a significant amount of training and support for PLWD and their carers (Palmer et al. *2*012). The need for further research in this area has been recognised by Elfrink et al. (2017) who have recently published a study protocol to examine the effects of an online life story book (OLSB) on neuropsychiatric symptoms. Their study will investigate the impact of the intervention on carers and provide a preliminary health economic evaluation.

Summary

This chapter has reviewed the evidence around the positive and negative effects of technology facilitated reminiscence on PLWD and their families. Most of the studies reported the benefits of technology facilitated reminiscence from the perspective of the PLWD. These included positive effects on mood and social engagement. Positive outcomes for PLWD can have a secondary impact on family caregivers. Seeing improvements in the PLWD can decrease the stress experienced by families caring for someone living with dementia. However, few studies have explored the long-term benefits of technology facilitated reminiscence, acknowledging that it may be difficult to quantify given the progressive nature of a dementia diagnosis.

The reported benefits of reminiscence for families are somewhat varied. Some studies indicated positive outcomes whereas others reported that family members experienced increased stress and anxiety. The impact of reminiscence on caregiver burden and on the relationships between the family caregiver and the person living with dementia has identified some conflicting findings in this review. Some studies reported a reduction in caregiver burden whereas others highlighted the key role of already overburdened families in supporting the reminiscence process.

Relative to other interventions, reminiscence is not considered expensive but support is still required to enable family members to engage in joint reminiscence activities. Although limited by the small sample sizes of most studies, the review highlighted the need for greater user engagement throughout the research process and for studies to take cognisance of the need to support people living with dementia to engage in technology facilitated reminiscences, without adverse consequence for their carers. The study which is the focus of this report sought to address these issues.

Chapter 3 - Phase 1:

Developing and testing a reminiscence app for persons living with dementia and their family carers

Introduction

The involvement of individuals living with the early stages of dementia in research is increasingly recognised as providing an invaluable resource to inform the development of feasible and impactful services (Hanson et al. *2*007). Using qualitative methodologies has further advanced this by enabling their voices to be heard, and crucially understood, gaining a deeper understanding of how the condition is experienced within their own lives (Beuscher and Grando, 2009). Therefore, in the context of this study, the person living with dementia and their family carer were considered ‘a dyad’, with both sets of views and experiences equally elicited and valued. By using this approach, the co-creation of the reminiscence app was informed by dyads living with dementia to ensure that barriers to its use were reduced and participants’ abilities were harnessed (Lazar et al. *2*014).

This section reports on Phase 1, which examined the value of several common usability testing protocols, methods and metrics in evaluating the usability of a personalised reminiscence app among PLWD and their family carers. For ease of reference, an acronym ‘InspireD’ (**In**dividual **Sp**ecific **Re**miniscence in **D**ementia) will be used throughout this report to refer to the reminiscence app developed and tested in this study.

The InspireD app was co-created and designed with input from PLWD and their family carers. Seven dyads comprising a PLWD and their primary carer evaluated the perceived usefulness and level of user acceptability of the InspireD app. These dyads comprised one Lead User Dyad and a User Development Group comprising 6 dyads (6 PLWD and their 6 carers).

Aim

The aim of Phase 1 was to ascertain the needs and capabilities of PLWD and their family carers when using a tablet application.

Objectives

The specific objectives of Phase 1 were to:

- Investigate the potential of creating an interactive reminiscence application that logs a user's behaviour patterns and intelligently repurposes content based on the user's history.
- Gauge the level of understanding of main menus, sub menus, icons and overall layout of the application.
- Gauge the level of understanding of uploading, modifying and deleting content.
- Gauge the level of understanding of creating an account, logging in and logging out of application.
- Ensure the application is comprehensive and has captured all relevant information pertaining to the larger study.
- Establish if it is clear to the user how to navigate from screen to screen.
- Establish whether the content is easy to see and engages the target user.
- Ensure that icons and buttons are appropriate and meaningful to the user.
- Establish the appropriateness of standard usability protocols and assess the usability of apps for PLWD and their family carers.

Theoretical Framework

There is growing evidence to support individual specific 'made to measure' cognitive interventions in the mild to moderate dementia trajectory (Amieva et al. 2016). The theoretical model underpinning all phases of this study is the person-centred care approach proposed by Kitwood (1997) which involves recognising a person living with dementia as a unique individual by personalising care, promoting freedom of choice, engaging in effective communication, building good relationships and working together. Kitwood's approach recognises the importance of focusing on a person's strengths and recognising the importance of the person's biography in sharing and influencing their current presentation. These values were highly relevant to our study as the reminiscence was individualised and consequently, catered for the needs, preferences and interests of the person living with dementia with the overall aim of supporting personhood and promoting well-being. In the intervention phase of our study, the individualised reminiscence activity was encouraged and supported by the family carer. A model of simple reminiscence (Webster et al. 2010) was used as this involves mainly unstructured autobiographic storytelling, interests and preferences and use of triggers to provoke spontaneous reminiscence and social interaction. This approach required only basic skills in facilitating the process and was therefore suitable for use by carers in maintaining a person-centred approach to care.

The team were conscious of the research area being a fast moving field and therefore adopted an Agile software development approach (Aydin et al. 2005). The Agile development process has emerged in the past ten years as one of the ways for IT developers to adapt to the cycle of constant change. In essence, rather than making software development a process that remains static from the initial design stage, the Agile method allowed us to create a functional prototype of the system early in the project, test key features with selected users and then adapt it accordingly throughout the implementation phase. The process was then repeated with feedback and upgrades on a constant, iterative loop so that once the project was complete, we had the most relevant up-to-date system for continued use. It is also important to note that the focus of our study was on individualised specific, home-based reminiscence which, although facilitated through the use of bespoke software in the proposed study, was designed to address many of the limitations identified in previous studies (Subramaniam and, Woods 2012; Woods et al. 2012) and make a significant contribution to the body of knowledge on the use of reminiscence.

'InspireD' – A Reminiscence app

The size, capacity and low cost of ubiquitous devices and mobile tablet computers have made them an attractive option for designing and delivering reminiscence systems. A cross-platform device agnostic tablet application (InspireD) was developed to facilitate the activity of reminiscing for people in the early to moderate stages of dementia. Two key priorities in the development of the app were 1) to enable PLWD and their family caregivers to select and store personalised memorabilia (photographs, videos, sounds, music) and 2) to provide easy access to these visual and audio-visual cues to support bespoke reminiscence.

An Agile software development approach (Astell et al. 2009) was adopted to allow a functional prototype to be created early in the development lifecycle, with testing and refinement taking place throughout the development process. The app was implemented using appcelerator Studio, an Eclipse-based IDE that provides an environment to build, test, package, and publish apps for various platforms, including iOS and Android. The code is written in Javascript with native User Interface (UI) elements being invoked at runtime. It incorporates local facilities for persistent data storage in SQLite database and facilitates the use of 3rd party Application Programming Interfaces (API) for Flickr and YouTube (Figure 1).

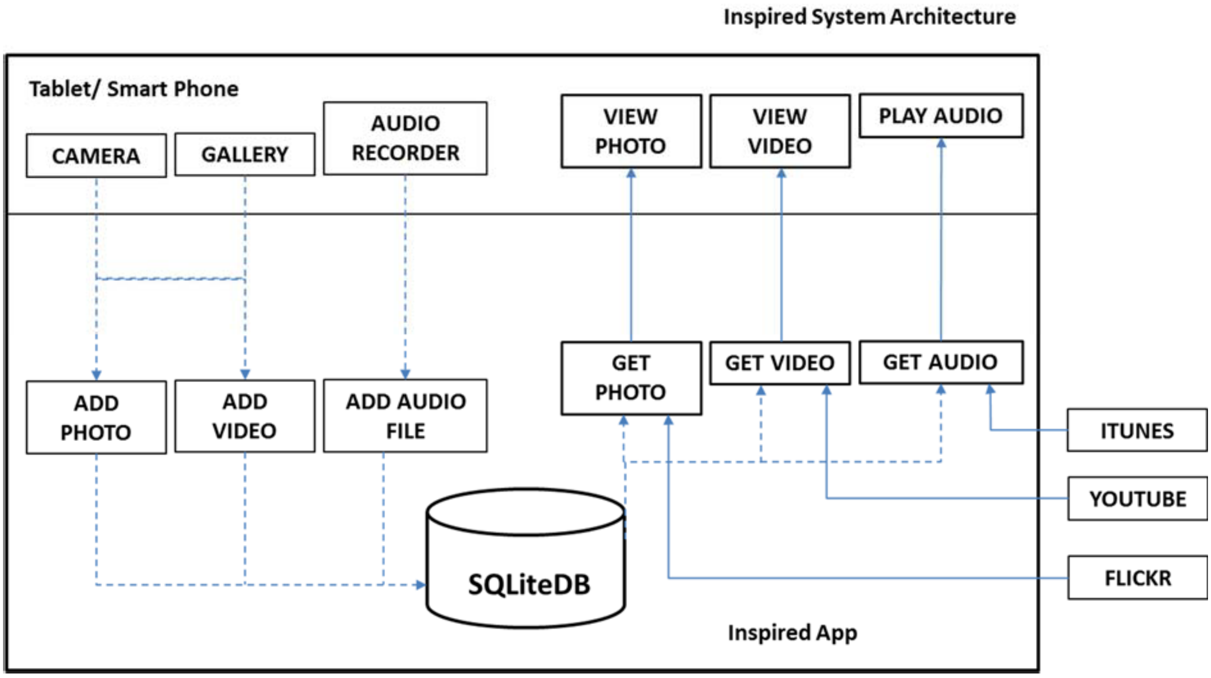
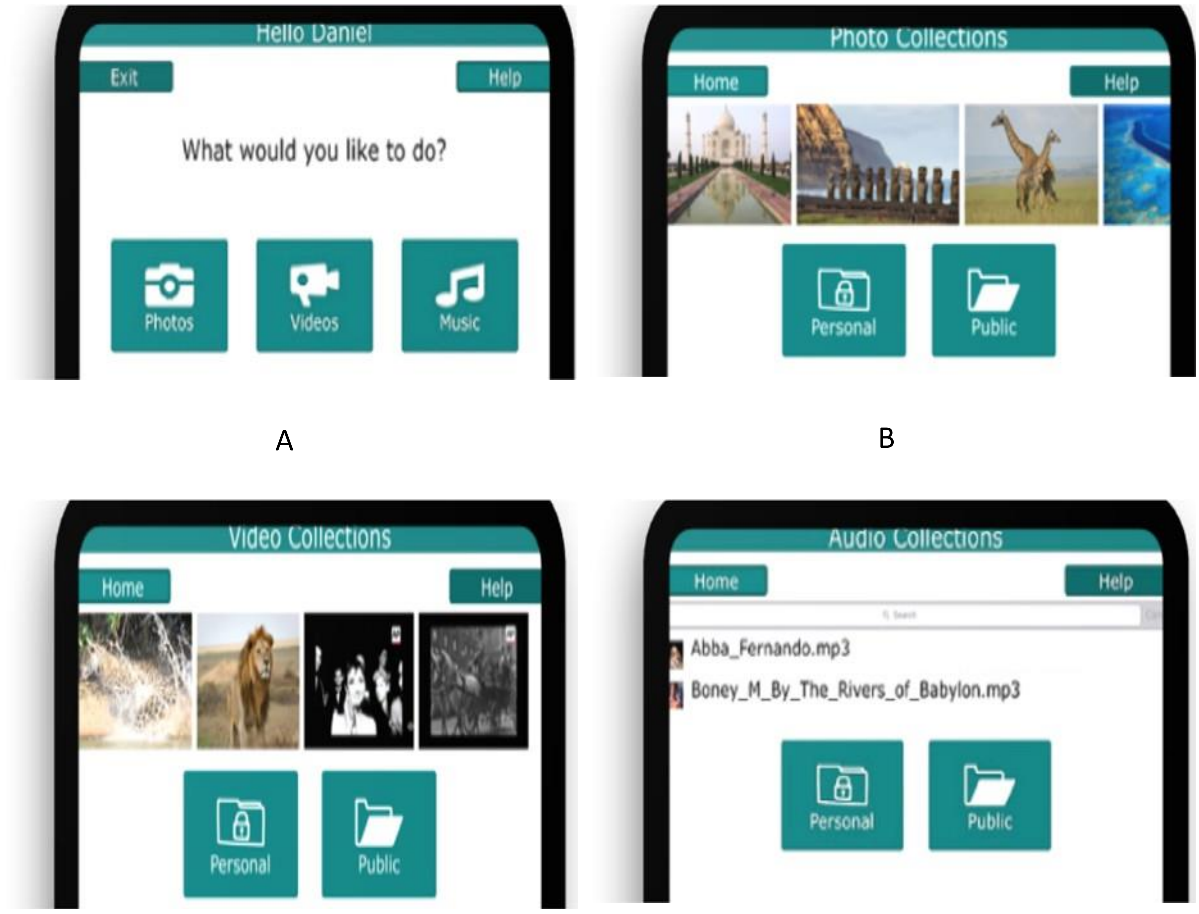


Figure 1: InspireD app – System Architecture

The app consists of a user interface that is usable and responsive across a variety of mobile devices (tablets, mobile phones). It is also possible to use the system on a PC or laptop via the web browser. The main user (and co-users, i.e. family carers) can upload images, video clips and audio clips to the app. SQLite database functionality is used to store and manage data natively. The main user interface consists of a simple screen for PLWD to upload files with help from a reminiscence trainer or family carer. A multi-screen layout allows users to choose which memorabilia they wish to access (fig 2a); view photos, (fig 2b) watch videos (fig 2c) listen to audio files (fig 2d) and browse selected resources. The interface adheres to the Responsive Web design pattern and each screen therefore responds to a user's behaviour and environment based on screen size, platform and orientation. The underlying code consists of a mix of flexible grids and layouts, images and an intelligent use of CSS media queries to ensure that a consistent user experience is felt even if moved to another mobile platform.



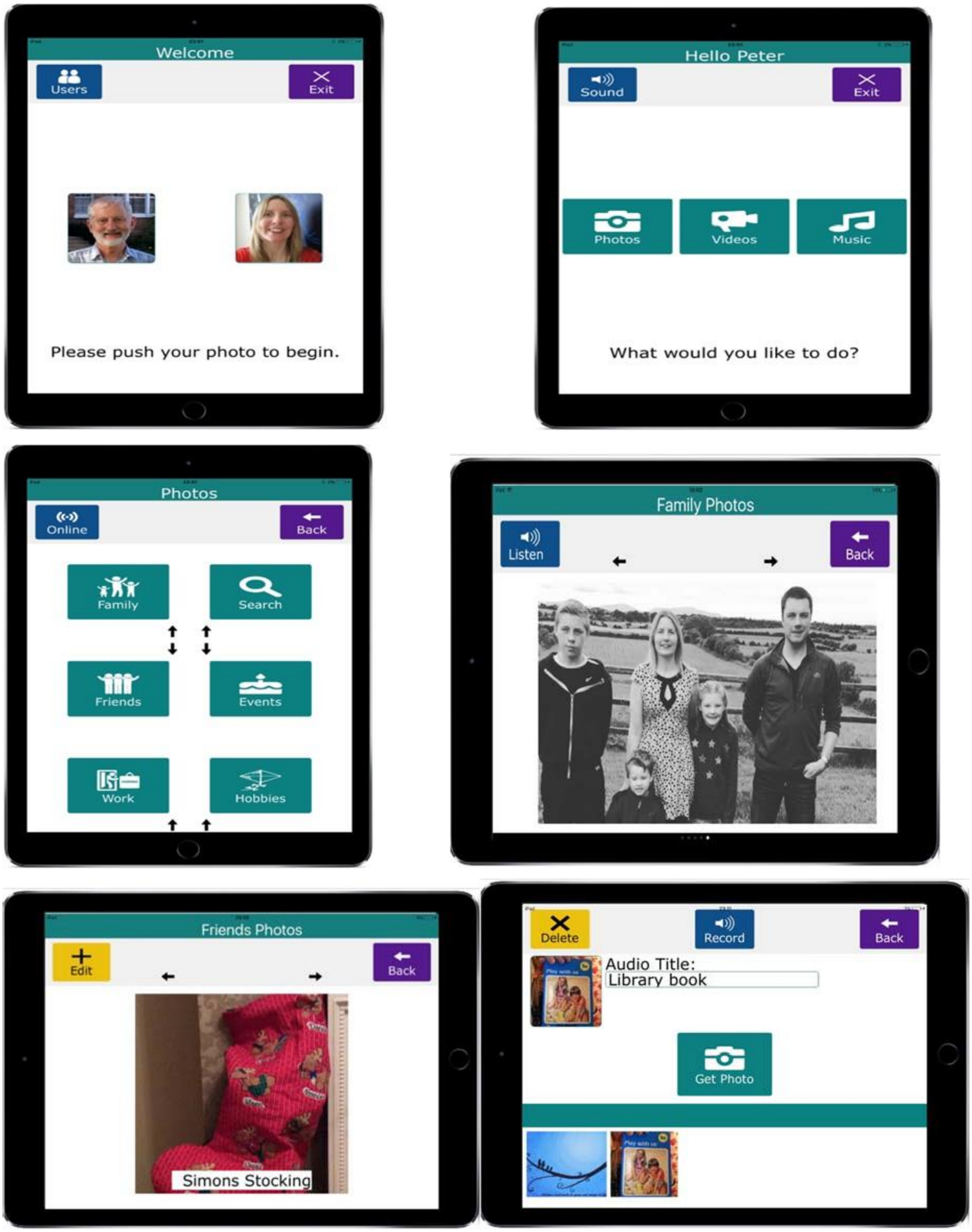
A

B

Figure 2: The InspireD app user interface

The user data is contained within a local SQLite database, which can be easily queried with reporting services enabled. Multimedia reminiscing resources (photos/videos/audios) are also stored locally in the app data directory. The system was designed with scalability in mind for future enhancements as it is envisaged that the final version will be a secure, cloud-based application, where data will be accessible via a secure Internet connection for authorised users.

The design of the app is minimalist, using verbal descriptors as well as images and icons to reinforce and indicate functionality to the user. Data are organised and presented primarily in the form of on-screen menus. The welcome screen is a simple login screen where the user confirms their identity by clicking on a photo of themselves. Figure 3 shows various screen shots of the inspired APP.



Please push your photo to begin.

What would you like to do?

Audio Title:
Library book

Figure 3: Various Screen Shots of the InspireD app

Evaluating Usability

Usability is measured in terms of how easily a system can achieve its goals and how efficiently a user can interact with the system through its user interface. Nielson defines usability as 'a quality attribute that assesses how easy user interfaces are to use' (Nielsen, 1993). Standard protocols to measure these attributes can be classified as: observation; concurrent thinking-aloud; single ease questions; recording by video and/or audio; and the systematic usability scale which is a post-test survey. These methods in turn provide metrics that are used by researchers to determine the usability of the user interface.

Observational approaches

Nielsen believes that observing people using a system is the best way to understand what works and what does not work during the user experience (UX) (Nielsen, 1993). He advocated a protocol of realistic, representative actionable tasks and the observations of users as they attempt each task to the best of their abilities. The scenarios involve typical tasks that reflect the system's intended use, and these mimic the real world as far as possible. It is also important for the observing researcher to not provide prompts or hints to the user but to instead patiently observe how the user progresses. The concurrent 'Think-aloud' protocol (TAP) is a common observational technique for eliciting insight into the user's cognition and thought processes. It was first utilised for evaluating user interface design by Lewis (1982). This protocol requires the user to perform a number of tasks while 'thinking aloud'. The researcher records the user actions (written or sometimes using tape recordings or video recordings) for each of the tasks, as well as noting any problems and user perplexities. Although subjective, it is a simple method that can provide valuable data that can be used for improving information systems. Video analysis recording (REC) is commonly used to record and measure UX and usability. The availability of small mobile testing units to record user interactions with an app or website can provide invaluable insights into the usability of a system. This moderated 'lab' usability testing scenario is still one of the best ways to capture the rich experience of interacting with a mobile device (Sauro, 2016). It allows researchers to capture the rich interactions between the user and the device as well as any verbalisation from 'thinking-aloud'. Video analysis also allows for detailed event annotations, frequency of use errors and the use of timestamps to measure task completion times. Very often, the webcam is also used to detect any user frustration with the interface.

Questionnaire-based approaches

The Single Ease Question (SEQ) is a 7-point rating scale to assess how difficult users find a task (Sauro and Dumas, 2009). Using the 7-point rating scale, the user estimates the level of difficulty of the task before and after attempting it. This measure has greater validity since the metric is recorded immediately after each task as opposed to the end of the session. The systematic usability scale (SUS) is a post-test survey, first used in 1986, that has become an industry standard questionnaire for measuring the usability of a system (Bangor et al. 2008). It consists of 10 questions that facilitate answers in a Likert scale format. Each question has 5 response options (or ratings between 1 and 5 where 5 = strongly agree). The systematic usability scale instrument is a well-balanced survey since it consists of 5 questions with negative connotations and 5 with positive connotations. All Likert ratings are then converted to a systematic usability scale score (or SUS score) and the mean SUS score is used to represent the usability of the system. The formulae to calculate the mean SUS score is presented in the following equation where *n* is the number of subjects, *m* is the number of questions (*m*=10) and $q_{i,j}$ is a rating from one question by one subject (whilst *norm* = 2.5 in order to provide a normalised ratio or score out of 100).

$$\overline{SUS} = \frac{1}{n}\sum_{i=1}^{n} norm \cdot \sum_{j=1}^{m} \begin{cases} q_{i,j} - 1, & q_{i,j} \bmod 2 > 0 \\ 5 - q_{i,j}, & otherwise. \end{cases}$$

A mean SUS score greater than 68 is considered above average based on the distribution of SUS scores previously collected from usability tests.

The usability phase of the system development lifecycle often assumes a high level of cognitive ability and communication on the part of users. When developing a system to support reminiscing, it was important to choose appropriate methodologies and protocols to test the usability of the system. This section describes the usability protocols selected to assess the usability of the InspireD app. The value of these protocols to measure the usability of the InspireD app is qualitatively examined and the suitability of each protocol to assess the usability of an app by PLWD and their carers is subsequently discussed.

Task completion-based approaches

Task completion rate (TCR) refer to the percentage of users who completed the task (Sauro and Lewis, 2012). Task completion is probably the most important metric that determines the usability of a system. For example, if a user cannot accomplish a representative task using a system, then that system is poorly designed. Thus, a 100% task completion rate is the objective for any system since its intended purpose should be intuitive to its user base. The inverse of this metric is the task failure rate.

Task completion time (TCT) is the amount of time in seconds required by a user to complete a given task (Sauro and Lewis, 2012). The mean task completion time is often referred to as a usability metric within a usability test. However, the geometric mean task completion time should be calculated for smaller datasets. Nevertheless, the mean task completion time can be compared to the expert task completion time, which indicate the gap between expert and novice performance. An associated metric is the time-until failure, which is the amount of time a user is willing to dedicate before giving up on completing the task.

Study Design

The User Sensitive Inclusive Design (USID) approach (Newell and Gregor, 2000) informed the development of the InspireD app. The aim of Phase 1 was to explore and assess the value of usability protocols for a reminiscence app in the context of use by PLWD and their carers. The methods used for Phase 1 involved participants (users) engaging in meetings and workshops with the research team. The research had both quantitative and qualitative components.

Together with 7 dyads, with each dyad comprising a PLWD and their primary carer, researchers investigated the appropriateness, validity and reliability of several common usability tests and matrices. The tests and matrices for investigation in this study comprised: Concurrent think-aloud protocol (TAP) (Lewis, 1982), Video recording and audio recording devices (REC) (Lewis 1982; Sauro and Lewis, 2012), Task completion rates (TCR) (Bangor et al. *2*008), Task completion times (TCT) (Bangor et al. *2*008), Single Ease Questions (SEQ) (Sauro and Lewis, 2012) and Systematic Usability Scale (SUS) (Sauro and Lewis, 2012). The value of the tests and metrics was examined in a series of five workshops during a 6-week period.

A pilot test was conducted with the Lead User Dyad in their home to identify any problems that may have prevented PLWD and their carers from taking part in usability testing. A User Development Group (UDG) was then established and participating dyads (6 PLWD and their family carers) were recruited by collaborating with the local Alzheimer's Society Home Support Network. The 6 dyads were invited to take part in 4 workshops with members of the research team including the App Developer. Two of these workshops took place at the university campus where the study was based and the other two took place in participants' own homes. Figure 4 provides a flowchart of the sequence of events in Phase 1 of the study which will subsequently be described in greater detail.

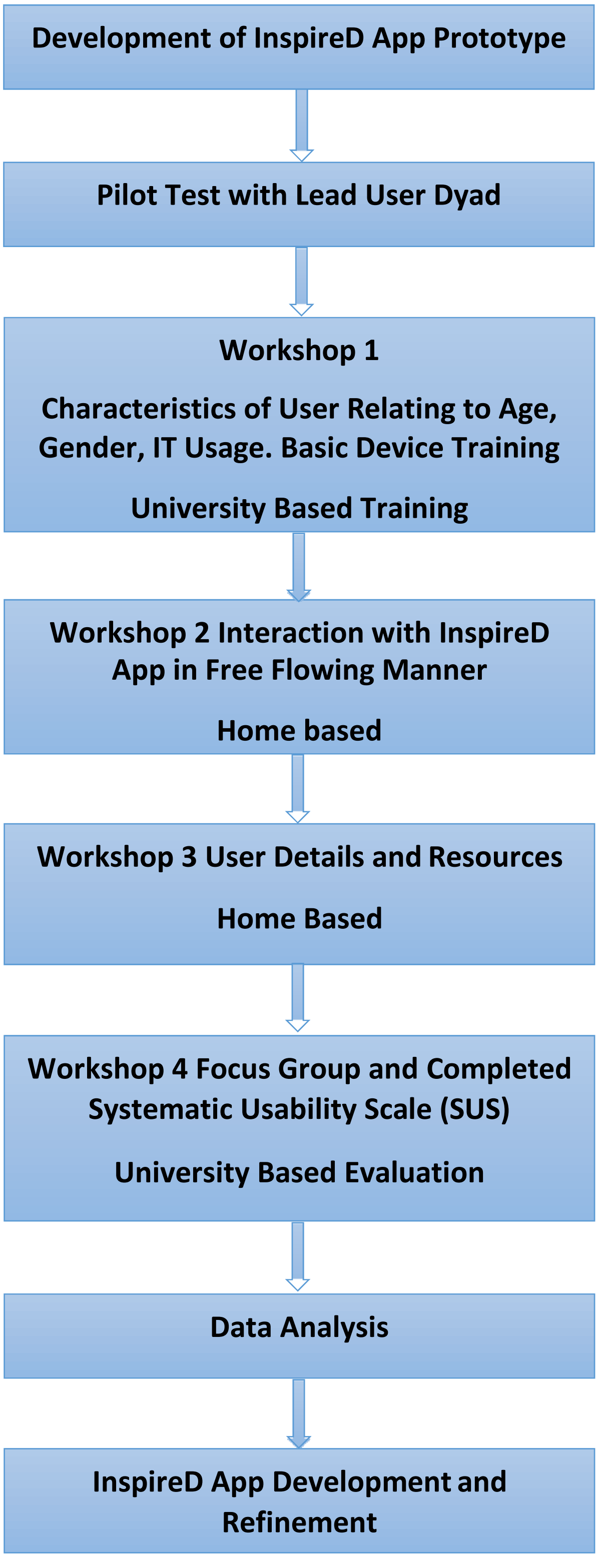


Figure 4: Phase 1 Study Design Flowchart

Recruitment

The principle 'Nothing About Us Without Us' is embedded in the global movement towards the active involvement of persons with disabilities in the planning of strategies and policies that affect their lives, and underpins the Convention on the Rights of Persons with Disabilities (United Nations, 2008). From the inception of the research idea, we recruited a Lead User Dyad comprising a person living with dementia (pseudonym 'Mike' for the purpose of this report) and his carer, to serve as expert collaborators in the research planning team. The Reminiscence Network Northern Ireland assisted in the identification of the Lead User Dyad. Both dyad members were then issued with formal invitations to join the research team as collaborators. They responded positively and subsequently, informed all aspects of the study.

The remaining 6 dyads that constituted the User Development Group were recruited through the Alzheimer's Society Home Support Network within the study site. Details of the study were outlined to the manager along with information about participant involvement and what this would entail. The research team outlined the inclusion and exclusion criteria which required participants to be diagnosed with mild to moderate dementia, able to travel to the university and able and willing to provide fully informed consent.

Letters of invitation to participate in the study were provided to the manager who distributed them to their Home Support workers (Appendix 1). The Home Support workers then selected individuals they believed would be interested or would benefit from involvement in the study. Interested individuals signed the 'Invitation to Participate' form and returned it to the Home Support workers who then sent all the forms to the research team. Receipt of this signed letter indicated permission for the lead researcher to contact interested individuals regarding their potential involvement. A member of the research team then contacted potential participants to discuss the 'Participant Information Leaflets' which outlined the voluntary nature of participation in the study and what their involvement would entail (Appendix 2).

Sample

The sample was purposive which enabled the selection of individuals who met the inclusion/exclusion criteria for the study. The sample size for this co-creative testing phase was informed by the Neilson's (1993) standard sample size requirement for usability testing in computing and technology research. In such research, with a qualitative focus, a sample size of 5 participants is deemed appropriate for reliable usability testing (Neilson 1993). Our sample exceeded this recommendation as it comprised the User Development Group, 6 PLWD and their family carers (n=12) in addition to the Lead User Dyad.

Data Collection

Lead User Dyad- Pilot Test

This Lead User Dyad informed the co-creation and design of the InspireD reminiscence app. Mike was aged 42 at the time of testing and had a high level of computing skills. He also had his own collections of digital photographs, videos and music. The Lead User Dyad, therefore, informed the initial specifications required from the system and the working version of the app. A pilot test was conducted with the dyad to establish the challenges for a PLWD to interact with the system. The dyad was requested to complete a series of tasks and their responses were observed and recorded by the App Developer and the researcher.

Mike and his carer tested the app during a 1-hour session to establish whether there would be any potential issues that could prevent PLWD from participating in the usability workshops. Mike was asked to complete a set of defined tasks and his interactions with the app were observed and recorded so that the researchers could establish a protocol for the user development workshops. Input and opinions from his carer were also recorded and these further assisted in the planning and preparation of the workshops for the user development group.

Usability testing consisted of 'think-aloud' task analysis where the dyad described what they were doing and their thinking process behind each interaction. Mike was asked to comment on the image quality, display and size of text on the user interface and on the sound. Feedback was also elicited about the size of buttons and on the 'help button' and other features of the app. Observations were made regarding how easy/difficult it was for Mike to interact with the touchscreen device.

No obvious barriers to interaction with the touch screen device were identified that that could have prevented PLWD from testing the app. The Lead User Dyad concluded that the photographs, video and sound displays and quality were suitable for interaction and further testing. Mike indicated that the image quality, display and size of text on the user interface and the sound quality were satisfactory. While he was able to use most of the buttons easily, the 'Help' and 'Exit' buttons posed some problems. Mike was able to navigate the app and complete 5/6 tasks. Both Mike and his carer were in agreement on the choice of colour and size of the main buttons and agreed that the icons were appropriate. They commented that the text in some of the messages, displayed by the system, was too small and difficult to read. Mike experienced some difficulty relating to 'thinking aloud'. He strayed off topic and could not describe the actions he was carrying out or what he was thinking as he attempted to complete the tasks. His carer had to bring him back to the actual task and steer the conversation towards the app.

User Development Group Workshops

The initial pilot test with the Lead User Dyad was followed by four User Development Group (UDG) workshops, which were undertaken with the other six dyads over a period of 2 weeks. Two of the workshops (W1 and W4) were managed as a group intervention in the university, and the two middle workshops (W2 and W3) were managed as individual dyad interventions, undertaken in the homes of participating dyads. In addition to the workshops, the dyads tested the utility of the app over a period of 1-2 weeks at home. All participants remained in Phase 1 until its completion.

The first and last User Development Group workshops (Workshop 1, 4) consisted of an introductory group meeting and a final focus group, respectively. During the home based workshops with individual dyads (W2 and W3), participants were instructed to perform a series of tasks using the app while being observed by the researchers who took notes. These tasks, for example, to 'Open Music Folder' and find the song by 'The Beach Boys' were scheduled to be completed on two separate occasions with each person being observed for around thirty minutes. It was planned that the first set of tasks would be recorded using an audio recording device and the second set of tasks would be recorded using a video recording camera.

The iPads were set up using standard settings with screen rotation and password protection enabled. No special accessibility settings were used. Excluding the camera icon and the Safari icon, all other standard icons which normally appear on the home screen were organised and put into the ‘Extras Folder’ so that users would not be distracted. The side switch was also set to lock the orientation of the user interface and auto-lock was extended to 15 minutes. Siri was switched off and auto complete was switched on. Brightness was set to approximately 75% and auto-brightness was enabled. The standard wallpaper was used for Workshop 1. For the individual workshops (W2 and W3), the InspireD app was installed on the iPad, the icon was placed in the bottom toolbar beside Safari and the wallpaper was changed to light blue.

User Development Group, Workshop 1 -User Profile and Device Training

Workshop 1 (W1) was an introductory session which took place at Ulster University. This workshop was designed to foster a cohesive group dynamic, to provide introductory training in the use of the iPad and to establish a baseline level of IT experience among the group. Advice and guidance was sought to ensure the environment was dementia friendly. Reserved and accessible parking spaces were provided and the workshops took place in a ground floor venue with café and restroom facilities close by.

Sauro and Lewis (2012) argued that product and domain experience have much more impact on usability metrics than demographics. Accordingly, in W1, the participants were introduced to the function of iPads in order to minimise a digital literacy bias. After meeting and greeting participants, the researchers explained the purpose of W1 and its context within the overall research study. Consent forms (Appendix 3) were signed and questions from the participants were answered. Participants were provided with self-report questionnaires designed to establish their previous IT experience and usage, including the use of apps and mobile devices.

The dyads were then asked to complete introductory tasks of turning on the iPad, waking it up, opening an app (Safari), closing the app and then turning off the device. The participants were encouraged to look at generic photographs on Flickr and were shown the swiping motion. This was visually demonstrated by the researcher receiving verbal instructions from the App Developer. Workshop 1 lasted 90 minutes with a 15-minute comfort break mid-way through the session.

User Development Group, Workshop 2-User Interaction with InspireD App

Workshop 2 was conducted at each dyad's home at a pre-arranged date and time agreed at the end of Workshop 1. This change of venue was important as the InspireD App was ultimately being developed for use primarily within the home setting. Workshops 2 and 3, therefore, aimed to establish how each participating dyad interacted with the InspireD App and to evaluate the usability of the app as a reminiscence aid. Each participant, irrespective of whether she/he was a PLWD or a carer was given the same tasks, and their task completion rates and task completion times were recorded. The six tasks for completion pertained to using the app to support simple reminiscing. This involved looking at photographs, watching movie clips and listening to audio clips. Participants were then asked to estimate the level of difficulty of each task using SEQ before and after they attempted it. The researcher recorded their responses on a grid. These tasks were designed by the App Developer to be realistic and to avoid confusion but, crucially, to be specific to the intended function of the app. They involved interacting with the app to view general photographs, videos or listen to music previously selected by the research team because of their relevance to the age group and locality of the User Development Group. This enabled the functionality of the app to be tested from the perspective of the PLWD and their carer. Before and after completing the tasks, the dyads were asked to rate the level of difficulty expected or experienced which was collated on a task completion grid by the researchers. The time taken to complete each task was also recorded. Workshop 2 lasted approximately 1 hour.

User Development Group, Workshop 3- User Details and Resources

The third workshop which also lasted about an hour was again conducted in the homes of participating dyads. This workshop took place one week after the second workshop and aimed to evaluate the usability of the app in terms of ease in adding users to the system and uploading reminiscence materials, e.g., photographs, videos and audio clips. Task completion rates and times were recorded. The researchers took notes at all interviews and a mobile observation device (MOD-1000, a USB macro camera) was used to record the image of the participant's tablet while it rested on the table. This small device, which was mounted on a lightweight aluminium plate with a grip-tight surface, was used to unobtrusively observe the use of the app. Similar to Workshop 2, a task completion grid was completed by the App Developer while a researcher took notes of observations and issues raised. Participants were asked to estimate the level of difficulty of each task using SEQ before and after they attempted it and the researcher recorded their responses on a grid.

This workshop enabled the App Developer and the researcher to establish the functionality of the app in relation to facilitating the process of reminiscence. The researchers noted that two of the dyads chose to complete the tasks jointly, however, in the remaining four dyads only the carer completed the task. Carers were asked to think out loud during this workshop and the researchers recorded completion rates and times. Participants were asked to rate the difficulty of each task before and after it was completed. Results were recorded on a task completion grid using a 10-point scale (10 being very difficult, 0 being very easy). Workshop 3 was also used to establish the preferences of PLWD for either an iPad or a Samsung Nexus tablet device. Each participant was shown the same picture on the two different tablet devices and was then asked to select the device with the clearest image. The general consensus was that the iPad was the device of choice.

User Development Group, Workshop 4- Focus Group and Systems Usability Testing Scale (SUS)

The final workshop was conducted at Ulster University. Hosting the final workshop at the university not only provided a conclusion to the testing phase, but also ensured that participants' feedback was related to the functionality of the InspireD app and not their ability to use it. Parahoo (2006) proposed that group interviews are effective in the exploration of general rather than personal issues. A focus group was therefore used to explore users' views on all aspect of the InspireD app.

All but one dyad (due to ill health) were able to attend the focus group in the final workshop. However, a Skype call was organised in order to receive their feedback and opinions regarding the use of the app and their involvement in the testing phase. The aim of the focus group was to ascertain if the User Development Group enjoyed using the app in their home for a period of 1-2 weeks and what difficulties, challenges or experiences they had throughout the testing process. The focus group lasted 90 minutes and involved a free flowing exchange of ideas (Parahoo, 2006). The group discussion was influenced by five questions from the Systems Usability Testing Scale (SUS) (Sauro, 2011). Each participating dyad was then asked to complete the 10 question SUS scale to measure their perceptions of the usability of the InspireD app.

Reliability and Rigour

The rigour of Phase 1 was maximised by the transparent and auditable study design displayed in Figure 1. Unstructured qualitative observations may not be as rigorous as other forms of data analysis as there is an inherent risk of selectivity bias, which could be a limitation of the study. However, the rigour of the data collection procedures used in Phase 1 was enhanced by cross comparisons with questionnaires and task completion grids. A process of peer validation whereby a second member of the research team independently transcribed and analysed transcripts to identify emergent themes enhanced the credibility of the qualitative data. The rigour of analysis was further enhanced by discussing these themes and reaching a consensus about the key issues.

Ethics

Ethical approval for this study was granted from Ulster University's Research Ethics Committee (Appendix 4). The research team sought specialist advice from the Alzheimer's Society about ways in which access, transport, parking, room selection and university facilities could be made as dementia friendly as possible. Potential participants were provided with a 'Participant Information Leaflet' one week in advance of the commencement of the study to ensure that those dyads who expressed an interest in participating had sufficient time and opportunity to fully understand what their participation would involve. This was followed by a face to face meeting where the researcher verbally explained the study and addressed any issues of concern to potential participants.

The nature of voluntariness was discussed and participants were informed that they could chose to refuse to participate or withdraw from the study at any time, without needing to provide any reason. Before that first workshop commenced, the research team was attentive to any signs of confusion or anxiety and verbally explained the consent form so each participant could provide informed consent. Workshop dates and times were determined by the User Development Group and the individual dyads arranged suitable times for home-based workshops to minimise any inconvenience to their daily lives.

There are no documented harmful effects from participating in workshops for app testing and development. Indeed, the sense of purpose generated through participation in this co-creation phase may have beneficial effects, given that Nolan et al. (2006) highlighted the significance of a sense of purpose for wellbeing in older age. The technology was non-invasive and the hardware used commercial consumer devices that had passed the appropriate safety tests. Each user was informed of the extent of information that was gathered and reassured that it would be stored anonymously. Participant data was only accessible to members of the research team employed by Ulster University and stored on password protected computers.

Data Analysis

Phase 1 had both quantitative and qualitative components and data were analysed accordingly.

Workshops 1-3

Workshop 1, nominal data such as age, gender and IT experience of the user was collected for the purpose of highlighting user demographics. The tests and matrices for investigation in Workshops 2 and 3 included the following:

- Concurrent think-aloud protocol (TAP) (Lewis, 1982)
- Video recording and audio recording devices (REC) (Lewis, 1982; Sauro and Lewis, 2012)
- Task completion rates (TCR) (Bangor et al. 2008)

- Task completion times (TCT) (Bangor et al. 2008)
- Single Ease Questions (SEQ) (Sauro and Lewis, 2012)
- Systematic Usability Scale (SUS) (Sauro and Lewis, 2012).

As previously stated, each dyad participated in the two usability workshops (Workshop 2, 3) in their own home, where each dyad member was instructed to perform a series of tasks using the app while being observed by the researchers who observed and took notes. These tasks, described in Table 1 were scheduled to be completed on two separate occasions with each person being observed for around thirty minutes. Twelve typical tasks were identified for the users to complete in Workshops 2 and 3. These tasks were carefully written so they would be realistic, actionable and avoid unnecessary prompting from the carers or the researchers. The tasks in Workshop 2 related to using the app to do simple reminiscing – interacting with photographs, watching movie clips and listening to audio clips. The tasks in Workshop 3 focused on selecting, uploading and recording materials to the app for use in reminiscence.

Table 1: Tasks Observed in W2 and W3

Task Description	Completed	Ref
Select a photo from personal collection and make it full size.	Individually	W2
Go back to photo collections, scroll through, find steam engine and select.	Individually	W2
Go back to home screen. Select video of Gerry Anderson and play	Individually	W2
Stop the video and go back to home.	Individually	W2
Open Music folder and find the song by The Beach Boys.	Individually	W2
Go back to the Home screen and Exit the app.	Individually	W2
Add a new user: name and photo.	As a dyad	W3
Upload a photo to the app and add tags and a description.	As a dyad	W3
Upload a photo to the app and add a short narrative.	As a dyad	W3
Take a picture of an object and save it to the app.	As a dyad	W3
Add a video to the app.	As a dyad	W3
Add a sound clip to the app.	As a dyad	W3

A task completion grid was printed for the researchers to record the metrics for time taken by each participant to complete each task. The Single Ease Question scale was used to record and assess how difficult users found each task. An audio recording device and video recording software and hardware (point-to-view) were selected to record the tasks and the verbalisation of the think-aloud data. The device used was the Mobile Observation Device (or MOD-1000) which is a popular mobile testing unit (Sauro and Dumas, 2009). A post-test SUS questionnaire was used to obtain feedback on the users' perception of the app to be administered at the final focus group.

Workshop 4

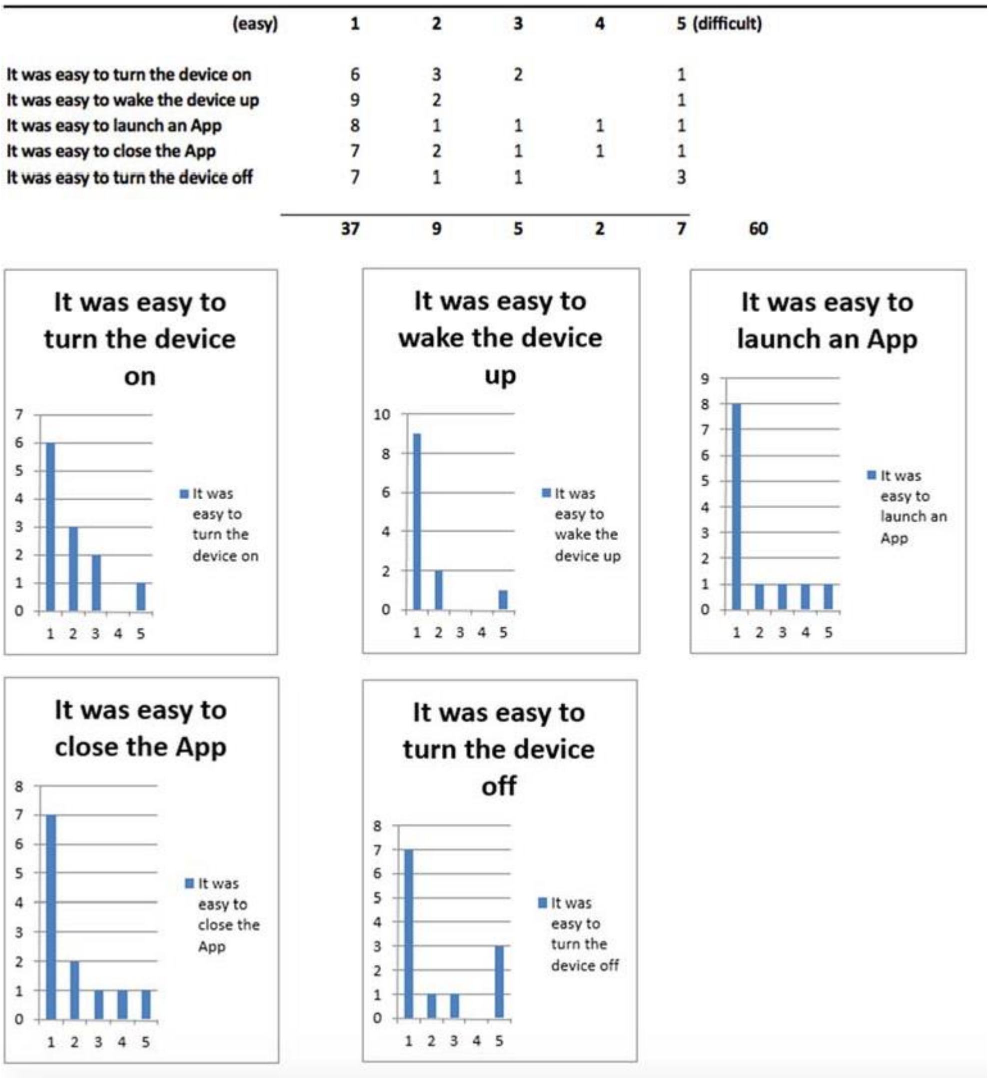
Workshop 4 involved a focus group interview using a topic guide based on the key components of Sauro's (2011) Systematic Usability Scale {SUS}. This semi-structured interview facilitated the free flow of information and feedback between members of the User Development Group and the researchers. The focus group interview was audio recorded on a digital recorder and transcribed verbatim by the researcher. The App Developer also listened to the recording and independently transcribed a section for comparison to ensure the reliability of transcription. Observational recordings and field notes allowed the researchers to reflect on their immediate feelings, facilitating the contextualisation of the data through analysis. Braun and Clarke's (2006. P.86) six step method of thematic analysis was used to identify "*repeated patterns of meaning*"

Results Phase 1

Workshop 1 - User Profiles

In the first User Development Group workshop, a typical user profile was established for the participants. Five of the six PLWD were male and all of the caregivers were female. The ages of participants ranged between 55 to 77 years. There was considerable variation in the group's experience of technology. One-third of the participants had never used a computer. Two-thirds had used a touch screen device in the past (this included touch screen tills in supermarkets and cash machines). Only half of the participants had used audio devices such as an iPod to listen to music and fewer than half had access to a tablet device at home. However, 11/12 of the participants had experience of using a mobile phone. Three PLWD quickly learned how to use the device and they said they had 'no difficulty' using the iPad. Two PLWD were easily able to carry out the tasks with simple instructions from their carer. One person found it very difficult to press the buttons. Five of the 6 carers had no difficulty using the iPad, while one carer was confident using it with help from the PLWD. Both the

PLWD and their carer were comfortable using the app and completed all of the tasks described in Table 1 without additional support from the researcher. Some prompts from the carer were given to the PLWD to keep them focused on the task in hand but no significant issues were identified during this session to indicate that PLWD would be unable to participate in the testing of the app (Figure 5).



(easy)	1	2	3	4	5 (difficult)	
It was easy to turn the device on	6	3	2		1	
It was easy to wake the device up	9	2			1	
It was easy to launch an App	8	1	1	1	1	
It was easy to close the App	7	2	1	1	1	
It was easy to turn the device off	7	1	1		3	
	37	9	5	2	7	60

Figure 5: Degree of difficulty of each task from the perspective of the PLWD

Workshop 2 - Interaction with the App

In Workshop 2, it was evident that all of the caregivers could interact comfortably with the app when using it to browse reminiscence materials. The task completion rate for the carers was 100% (Figure 6). Task 2 (scrolling through a group of images) presented challenges for all but one of the PLWD. Only two of the PLWD were able to complete task 6 (going back to the previous screen and exiting the app). All of the other tasks were completed by at least three of the PLWD. One PLWD was unable to complete any of the tasks although it is noteworthy that this participant appeared to be at a more advanced stage of dementia than the others.

Task	1	2	3	4	5	6
	Completed	**Completed**	**Completed**	**Completed**	**Completed**	**Completed**
Dyad 1						
PWD	Y	N	Y	N	N	N
CARER	Y	Y	Y	Y	Y	Y
Dyad 2						
PWD	Y	Y	Y	Y	Y	Y
CARER	Y	Y	Y	Y	Y	Y
Dyad 3						
PWD	N	N	N	N	N	N
CARER	Y	Y	Y	Y	Y	Y
Dyad 4						
PWD	Y	N	Y	Y	Y	N
CARER	Y	Y	Y	Y	Y	Y
Dyad 5						
PWD	N	N	Y	Y	N	N
CARER	Y	Y	Y	Y	Y	Y
Dyad 6						
PWD	Y	N	Y	Y	Y	Y
CARER	Y	Y	Y	Y	Y	Y

Figure 6. Workshop 2 task completion for each participating dyad

Workshop 3 - User Details and Resources

In Workshop 3, the tasks were completed in pairs comprising the PLWD and his/her carer. It was found that 96% of the tasks in Workshop 3 were successfully completed in this mutually supportive approach. The researchers incorporated the ‘think-aloud’ approach to illuminate participants’ experiences of using the app. However, it became apparent in the workshops that PLWD had difficulty in verbalising and narrating what they were doing, even when prompted and reminded to do.

In Workshop 3, the MOD-1000 mobile observation device was used to record the image of the participants’ tablets. Mobile observation is a tried and tested method for measuring usability. The original plan was to record each dyad uploading materials onto the app. It became apparent after only 15 minutes that the device presented a distraction which was interfering with participants’ ability to complete the specified tasks. Consequently, a decision was taken not to use the camera device in the subsequent workshops. The task completion times for Workshop 3 varied slightly depending on the age and experience of participants. Researchers had estimated that it would take approximately 30 minutes to complete all six tasks. The participant that identified himself as most experienced in the use of IT systems completed all six tasks in 25 minutes. In contrast, the slowest completion rate was 34 minutes. The difficulty ratings in the six tasks completed as a mutually supportive dyad in Workshop 3 were recorded and analysed (see Table 2). A negative Delta value indicates the task was easier than expected, while a positive value means that the task was harder than anticipated by the user. In this study, although most of the tasks were actually easier than the dyads had anticipated, the results are insignificant given the small number of dyads in the study (see p-values in Table 2).

Table 2: Results of SEQ for Workshop 3

Task	Expected difficulty rating (edr)	Actual difficulty rating (adr)	Delta (edr - adr)	p-values
1	4.17 (2.93)	3.00	-0.03	0.59
2	3.50 (2.88)	3.67	-1.02	0.92
3	3.33 (2.94)	2.67	-2.13	0.59
4	3.67 (2.58)	2.83	-1.25	0.86
5	2.33 (1.03)	2.67	0.33	0.58
6	3.50 (2.43)	3.83	0.05	0.47

Table 3 illustrates the range of usability protocols and metrics and their employment with the Lead User Dyad (DLU), group workshops (W1, W4) and individual dyad workshops (W2, W3).

Table 3: Engagement matrix with usability measures

	DLU	W1	W2	W3	W4
TAP	X		X	X	
REC			X	X	
TCR			X	X	
TCT				X	
SEQ		X			
SUS					X

Workshop 4 - *Usability Testing Scale (SUS)*

The systematic usability scale for post-test survey has become an industry standard questionnaire for measuring perceptions of usability. The mean rating given to the InspireD app by carers was 67.5% (SD=11.55) and the four PLWD who completed the SUS questionnaire awarded the app 78.75%. These results indicate that the app is usable, as a mean SUS score greater than 68 is considered above average (Bangor et al. 2008). However, the task completion rates (TCR) observed indicate that the app was more usable for carers than for PLWD. This challenges the widely accepted reliability and validity of the SUS methodology of measuring usability. The most plausible reason for these discrepancies is that PLWD had a different perception of difficulty than that of the carers. Their replies indicated that they enjoyed using the app, that they would recommend it to a friend and that it was a pleasant experience. However, it is possible that PLWD found the questions in SUS difficult to understand or perhaps they could not fully recall the issues they encountered when using the app, after the task. This has implications for future research, given the understanding that short-term memory is adversely affected in the common dementias.

Focus Group Findings

Five key themes emerged from the analysis of focus group transcripts:

- Usability and familiarity
- Convenience
- Another facet of the condition
- Facilitating interaction
- Capturing connectedness

Usability and familiarity

Participants discussed the challenges of using the system and the support that would be required for the dyad to regularly use it. All participants felt that individuals may need to have previous experience of using computers and all recommended that formal IT training would be a supportive measure:

> *"…I don't think it would be for people who don't have…ye know any formal training in IT or have any experience in computers…"* (C 1)

All the family carers agreed that training would provide them with the confidence to use the device with their relative. However, a small number of PLWD felt that once they were shown how to use the system they would be able to use confidently:

> *"Aye but once ye would know how to use it then you would be alright…"* (PLWD 3)

The group discussed specific features which needed to be amended in the system to ensure the ease of use for PLWD and two key format issues arose. The first concerned the size of icons and written text relating to directions and descriptions on the touch screen:

> *"Well I do think that if it was large instead of wee small…icons that that would help because eyesight is such a big thing with dementia sufferers as well"* (C 10)

The second issue related to participants' comprehension of written directions and descriptions which they felt impacted on their usability of the system:

> *…the other thing is …mmm…that sometimes people with dementia have difficulty reading even if no matter how big the words are…like comprehension difficulties and…mmm… instead could you have maybe…a facility of recording who the person is and saying it…"* (C 1)

All participants discussed how they enjoyed the photographs, music and videos that the researchers had chosen, but stressed that familiarity was key to usage of the InspireD app. There was a consensus among participants that the reminiscence materials should be as specific and familiar to the individual as possible:

> "*Well I think it is better to use photos of things that you are used to…because looking at a photo of another town…I wouldn't have a clue…"* (PLWD 3)

> *"… It would have to be something familiar…"* (C 4)

Convenience

When the group discussed the use of an app to facilitate the process of reminiscence, they outlined their key expectations. These were, to make their current life situation slightly easier and for the app to be totally accessible for the PLWD:

> *"Aye to make it that wee bit easier and it should be if they are going to design an App…for people it should be really easy for them to access"* (PLWD 1).

Some participants stated that they currently stored photographs and music on desktop computers and laptops and had previously used these as a source of family memorabilia. However, the carers explained that this was too time consuming and the use of an app would be more convenient:

> *"See to me to take out a laptop or a computer would be…just…just too much time…So the convenience of it…for us…"* (C 6)

The theme of convenience was again referenced from the perspective of the PLWD. The use of an app was seen as a more realistic option as the mobility of the tablet device enabled the system to be with the them at all times and required minimum effort or strain:

> *"It's just for people to keep beside them…ye know on the arm of their chair so all they have to do is pick up the wee iPad…like I couldn't imagine X…. (*name of relative living with dementia*) going to computer desk and trying to turn it on or whatever…* (C 4*)*

Another facet of the condition

Carers discussed the challenges they faced when conveying to health and social care practitioners the impact of their relative's diagnosis on their everyday life. It was their view that the InspireD app could provide an alternative perspective on living with dementia:

> *"It is a whole other facet to this condition…like you can get medical people and they are not in…they are not really in there…dya know what I mean? they will say it is a wide spectrum and you need to be taking so many milligrams of that and whatever but…the actual day to day work…that it involves…"* (C 10)

The PLWD viewed the Inspired app very positively. It was their view that it was enjoyable to use as it not only enabled them to remember specific or significant life events but the process itself was seen as hugely beneficial:

> *"I would like to say something…for dementia people I think it is fantastic idea because they can remember things…whether…the app is…doing…its right thing or not…for the photographs an all…it is EXCELLENT for the people to look back and remember things (Participant stresses word) ye know?"* (PLWD 3)

The carers discussed how they were aware that the app had become something important for their relative. They gauged this by their relative's ability to remember using it and recalling this to friends and family:

> *"You know what is good, is the fact that X can talk about the app to other people, you know. So that it has obviously…got embedded somewhere. So it has become something of a level of importance. We were talking to her friend about it on Saturday".* (C 10)

While carers acknowledged that they too enjoyed looking at photographs, it was seeing their relative appearing calmer and showing an improvement in mood as a result of using the App that informed their perspective:

> *"Well, I think that if your partner is settled and you see them relaxed and just being in good form, obviously that is positive" (C* 6).

Capturing Connectedness

Participants stressed that the convenience and usability of the system facilitated interaction within a broader social context of family and friends. Carers described how the app enabled their relative to re-engage with family and friends and in doing so to remain recognised as part of the family:

> *"But… I find see the convenience of it like see when you have company coming into the house who are a wee bit lost with dementia sufferers…they just don't know…they dry up and they don't know what to do. So something as convenient as that that I can say "why don't you go and have a look through a few photographs? And generally most people can lift up an iPad and …it fills that gap!* (C 6)

Participants felt that the PLWD would find independent use of the app challenging and would therefore be less likely to use it on a regular basis. This invariably meant that the responsibility of initiating usage would fall to the carers:

> *"I would doubt that someone would actually go themselves and say…the carer would have to introduce and say "will we have a session" and go and get the device and start it up on their own I can't see that happening…ye know…" (C 10)*

However, this was not viewed negatively as carers felt that this ensured that the reminiscence process was a shared activity. One carer described the profound and unexpected impact this process had on her personally and her feelings towards her relative with dementia:

> *"I…I don't, we don't get to do a lot together and if, to me, even watching (pause, due to being very emotionally affected) just seeing* X *with our wee boy I mean…just changed in my heart, just something happened on Friday night, you know… It brought something up on me that I didn't have… for quite a while…it's been quite a while since I felt that"* (C 6)

Summary

The InspireD app was designed and developed with input from a Lead User Dyad and a User Development Group. This app, created to facilitate the process of reminiscence, was tested using standard usability metrics and methods by PLWD and their family carers over a period of approximately 6 weeks. Phase 1 results indicate that the InspireD app is usable for some PLWD. Carers found the app easy to use and could support their relative living with dementia to use it to reminisce. Our results indicate that common usability testing protocols such as the SUS instrument, think-aloud protocols and external mobile macro cameras attached to the mobile testing device may not be suitable for evaluating apps whose target users have been diagnosed with a progressive cognitive disease such as dementia. Phase 1 has demonstrated the importance of working with PLWD and their carers in the co-creation of technology to positively impact quality of life and relationship. Findings have indicated that IT training, ease of use, convenience and familiar memorabilia are key factors which enhance user engagement with the InspireD app. Findings further suggest that participating dyads viewed the InspireD app as potentially offering a different facet to the condition facilitating interactions with PLWD in their social network and, crucially, within the dyadic relationship.

Table 4: Summary of findings on the suitability of usability measures

Usability Measures	Summary of findings
Thinking Aloud Protocol (TAP)	Requires intensive facilitator and/or carer interaction and management, supporting prospective memory of person living with dementia
Recording – Video analysis (REC)	The MOD-1000 camera device was removed as it was found to distract users when they were completing assigned tasks. In addition, it was perceived by the users to be an additional component of the reminiscence device.
Task Completion Rates (TCR)	This was found to be a reliable usability metric for all usability tests independent of user profile.
Task Completion Times (TCT)	This was found to be a reliable usability metric for all usability tests independent of user profile.
Single Ease Question (SEQ)	Not useful for persons living with dementia as they find it difficult to estimate how difficult a task should be, perhaps exposing a lack of experience with digital technology.
Systematic Usability Scale (SUS)	The SUS was an invalid instrument in this study. The scores from users living with dementia were not reliable, as they did not concur with task completion rates. This may be because any post-test survey relies on reflection and short-term memory. An additional challenge presented to users living with dementia, is alternating negatively and positively worded questions.

Chapter 4 - Phase 2:

An Overview

Introduction

This chapter presents an overview of Phase 2 of this feasibility study which aimed to investigate the outcomes of a home based, individual specific reminiscence intervention facilitated through the use of an iPad app for PLWD and their family carers. Phase 2 comprised complex data collection processes and procedures which will be presented separately in four discrete parts over the next four chapters. Part 1 (Chapter 5) describes the use of event logging and behavioural analysis to establish patterns of user engagement. Part 2 (Chapter 6) examines the impact of the intervention on primary and secondary outcome measures related to mutuality, well-being and quality of the relationship between PLWD and their carers. Part 3 (Chapter 7) outlines a novel component of the analysis in which 'in the moment' questions, derived from the primary outcome measure (Mutuality Scale) were programmed during usage and correlated to the data generated at baseline, midpoint and endpoint. Although this was *not* a specific study objective, the research team felt that it would have been a missed opportunity not to try and explore this type of data collection, particularly for people living with dementia, who may be best able to describe their feelings 'in the moment' rather than through recollection of short term memories which may be compromised as a result of their dementia diagnosis. Finally, Part 4 (Chapter 8) presents the health economic analysis for the delivery of this intervention and its potential implications.

Aim and Objectives

The overall aim of Phase 2 was to investigate the feasibility of individual specific reminiscence, facilitated through the use of bespoke software (InspireD App) on persons living with dementia and their family carers.

The objectives were to:

1. implement an intervention comprising home-based reminiscence training, IT support and use of the app in the home of people living with dementia;
2. establish the pattern of user interactions with the app and its three functionalities
3. examine the impact of the intervention on mutuality, wellbeing and on quality of the relationship between PLWD and their family carers;
4. undertake preliminary costing to inform a potential cost effectiveness analysis.

Design and Method

This was a quasi-experimental study incorporating a repeated measures design, with each participant serving as his or her own control. Similar to Phase 1, the study focused on dyads comprising a PLWD and his/her family carer. The intervention was three pronged and consisted of reminiscence training, IT training and thirdly, independent use of the InspireD app to support individual specific reminiscence in the homes of participating dyads. All participants received a package of 4 reminiscence training sessions and a 5th session on compiling memorabilia for use with the app. The training was provided on a one-to-each basis to participating dyad in their own homes by a Reminiscence Facilitator from the Reminiscence Network Northern Ireland (RNNI). At the close of reminiscence training, an IT assistant supported the dyads to upload their personal memorabilia onto the app and then provided 2 one-hour sessions, in order to ensure that the PLWD and his/her carer had developed the confidence and skills to use the app independently. A contact phone number for further IT assistance was also provided. Participants were encouraged verbally and in writing to use the app for a minimum of three times a week for the following 3 months. Data pertaining to the primary (mutuality) and secondary outcome measures (well-being and quality of the relationship between the PLWD with dementia and their carers) were collected at baseline, mid-point and at the end of the intervention. Table 5 summarises the intervention activities and data collection time-points.

Table 5: Intervention activities and data collection time-points

	Pre-intervention	Intervention					
Timescale	**Baseline**	**Weeks 1-6 Training**			**Week 7-19 Home Reminiscence using iPad App**		
Activities		Rem Training Session 1- 4	Rem Training session 5 IT Training 1	IT Training 2	Home Rem begins	Home Rem continues IT training 3	Home Rem ends
Data collection Time-points	Baseline T_0					Mid-point Home Rem (week 13) T_1	End-point Home Rem (week19) T_2
Repeated measures	Mutuality WHO-5 QCPR CSRI EQ-5D DEMQOL DEMQOL (Carer)					Mutuality WHO-5 QCPR EQ-5D DEMQOL DEMQOL (Carer)	Mutuality WHO-5 QCPR CSRI EQ-5D DEMQOL DEMQOL (Carer)

Abbreviations: Reminiscence [Rem], Information Technology [IT]

The CSRI, EQ-5D, DEMQOL and DEMQOL (Carer) were used in the health economic analysis and will be explained in detail in Chapter 8.

Recruitment

The study was based in a large health and social care trust in the United Kingdom. A purposive sampling strategy was used to recruit a total of 60 individuals, i.e. 30 dyads (person living with dementia and their carer). Recruitment was supported by the Trust's community mental health team for older people and in particular through the Trust's Cognitive Rehabilitation Team who issued letters of invitation to potential participants (Appendix 5). As memory testing is routinely assessed through the Trust's memory assessment services referral pathway, a referral to the Memory Rehabilitation Programme is indicative of a diagnosis of mild to moderate dementia. Further support was provided by the specialist dementia nurse within the Trust's Memory Clinic and engagement with the Alzheimer's Society Dementia

Cafes within the locality. The sample size was deemed to be sufficient to meet the objectives of a feasibility study and represents a significant increase on previous reminiscence studies in the context of dementia.

All persons living with dementia who met the study's eligibility criteria were potentially suitable for inclusion in the study.

Inclusion criteria:

- Person living with dementia: A person who (1) met the criteria for mild to moderate dementia following assessment by the WHSCT Community Mental Health Team for Older People/Memory Clinic, (2) was able to communicate and understand communication and (3) was aware of his/her dementia diagnosis.
- Family carer: A person who was (1) aged 18 or over, (2) caring for a family member living with dementia meeting the above criteria (either co-habiting or non-co-habiting) and (3) aware of his/her relative's dementia diagnosis.

An exclusion criteria was applied: Persons who 1) had a major illness or disability preventing their participation in the study or 2) could not speak English.

Reminiscence Facilitator Training

The three pronged intervention used in this study intervention consisted of reminiscence training, IT training and thirdly, independent use of the InspireD reminiscence app in the homes of people living with dementia. The model of reminiscence that was utilised to underpin the training intervention was that of simple reminiscence (Webster et al. 2010) which encompassed mainly unstructured autobiographic storytelling and triggers that generated spontaneous reminiscence, often within a relational context, such as special days or events shared by friends and family. The goal of this approach is to enhance social contacts and short-term well-being while also supporting intergenerational bonding (van Kordelaar et al. 2007; Webster et al. 2010). Given the individual and specific nature of the reminiscence approach employed in this study, the research team worked in close consultation with co-investigators from the Reminiscence Network Northern Ireland (RNNI) to amend their training programme in order to ensure a more bespoke and individualised intervention (Appendix 6). This training was underpinned by a number of key values:

- Individual specific reminiscence recognises the person living with dementia as a unique individual.
- The relationship between the person living with dementia and his/her carer is central. Both parties have individual and relational needs which should be recognised and valued.
- Individual specific reminiscence values freedom of choice, sharing and working together, effective communication, building good relationships, focusing on a person's strengths and recognising the importance of a person's biography in shaping and influencing their current presentation (Subramaniam and Woods, 2012).
- An individualised or personalised reminiscence approach that caters for specific needs, preferences and interests, is more likely to support personhood and well-being. (Subramaniam and Woods, 2012).
- The reminiscence approach advocated in this study is aligned to Cooney et al's. 2014 theory of *"seeing me (through my memories)"* in which reminiscing with another, learning their stories and understanding their personal meaning, allows the person to be revealed to us in unexpected ways as a unique human being. It is not simply the act of reminiscing but the resulting interaction and connectedness it fosters which helps us to truly "see" the other.

Preparatory meetings were conducted with the RNNI in October 2015, when it was agreed that three facilitators would be recruited from the Western Health and Social Care Trust area where the study was based. Initial training with facilitators took place in November 2015 and continued over a period of 5 sessions until March 2016. In response to the need to recruit from a wider geographical area without adding to the travel burden of the existing facilitators, a further three facilitators were recruited and trained within this timeframe. This represented a significant capacity building from the study's perspective. However, due to personal circumstances one facilitator could no longer work on the research study, resulting in a final team of five facilitators.

All five facilitators were asked to provide a brief biography of themselves, which was subsequently given to participating dyads. In turn, the researchers prepared a short biography of each dyad, which was given to their facilitator in advance of the first reminiscence session. This arrangement was endorsed by both the facilitators and the dyads and was primarily designed to aid the establishment of a rapport between both parties. Reminiscence Facilitators from the RNNI then worked with the 30 dyads in their own home to demonstrate how to identify and use specific memorabilia to stimulate their personal memories. Once identified, the personal memories in the form of photographs, music or videos were uploaded onto the on the iPad using the InspireD app.

IT Training

Each dyad was given three IT training sessions. Each of these sessions lasted approximately one hour. The first training session took place during the final (5th) reminiscence session, with the reminiscence trainer and participants selecting the resources they felt were most conducive to reminiscing. During this session, the IT trainer uploaded pictures and videos to the app while also teaching participants how to use the device, from the basics of turning it on to taking pictures, videos and connecting to the internet. The IT trainer used a training booklet, specifically designed for the study, to assist the dyads to familiarise themselves with the Inspired app. They were shown how to login to the app and introduced to the various photo, music and video screens. At this session, carers were usually shown how to add photos and also audio/ video files. In addition to the training booklet, some of the participants took their own written notes about things they were unsure about. At the end of the first session, participants were advised to explore the iPad and use the multimedia apps to take pictures, add videos and music over the course of the following week. They were asked to practise adding resources to the InspireD app and to select a photo of themselves and have it ready for IT session 2 so it could be added to the login screen of the app.

The second IT training session took place one week after the initial one. This session also lasted approximately one hour and gave participants the opportunity to ask questions and add any more pictures or materials they wanted to store on the app. Their photos were added to the login screen of the app and this gave it a more personalised feel. Again at this session, carers were shown how to add resources and how to link to their iTunes account to select their choice of music to enable a more personalised reminiscence experience. For a few dyads, this session was slightly longer than anticipated, especially if the dyad had a lot of questions or materials to add. Sometimes during this session, people wanted to create a Flickr account or go over how to use YouTube to listen to/watch generic music/ videos online. Sometimes they had experienced problems with the iPad or the app and the IT trainer spent time resolving these issues. At the end of this session, participants were advised to use the app independently and were provided with contact details for the research team if a problem arose.

After approximately 6 weeks of independent app usage, the third IT session took place. This time frame had been agreed with participants who wanted to try things out themselves before the final IT support session. This final session lasted between 30 and 60 minutes. During this session, the IT trainer loaded some more pictures onto the app and also helped people if they had experienced any problems. If dyads had not yet used the generic photos/ videos/ music at this stage, they were shown how to set up a Flickr account and also how to use YouTube to listen to/ watch generic music/ videos online. This session was often a general question and answer session to give participants another opportunity to ask questions or give them more information about how to use the app to reminisce. At this stage, most people knew how to use the InspireD app and questions often related to adding/ deleting photos or music or using online resources. Dyads were encouraged to use the multimedia apps on the iPad to store all of the pictures/ videos/ music they wanted to store and to regard the InspireD app as a place to upload the pictures/videos and songs that were most meaningful to them while engaging in joint reminiscence.

Ethical Issues

Phases 2 and 3 of this study were approved by the University's Research Ethics Filter Committee, the regional ORECNI and the Trust's Research and Development office (Appendix 7). The ethical principles of beneficence and non-maleficence applied. In their seminal systematic review of individual reminiscence therapy for people living with dementia, Subramaniam and Woods (2012) concluded that there were some immediate and longer-term psychosocial benefits if the intervention involved a life review process or was personalised and specific to the individual. Pertaining to the principle of non-maleficence, the researchers were cognisance that evidence was accumulating to suggest that older people experience no negative effect in using touchscreen devices such as tablet devices versus paper for reminiscing (Upton et al. 2011, Wright and Mulvenna, 2012). Other ethical considerations included voluntariness and to this end, separate Participant Information Leaflets (Appendix 8 and 9) and Consent Forms (Appendix 10 and 11) were prepared for the person living with dementia and their carer. Participants were reminded of their right to withdraw from the study at any time and the research team were very mindful of the need to use sensitive language about dementia in all verbal and written documentation. The researchers did their utmost to limit burden and inconvenience by ensuring that reminiscence and IT training sessions and data collection procedures occurred at times and dates convenient for participants. A distress protocol was prepared to enable the team to manage distress caused by the recollection of painful memories and participants were also made aware of the duty of the research team to report any potential safeguarding concerns.

Summary

This chapter has provided an overview of Phase 2 including the overall aim, objectives and study design. The programme of reminiscence and IT training was described in detail. Phase 2 comprises four discrete parts: 1) event logging and behavioural analysis, 2) primary and secondary outcome measures, 3) in the moment data and 4) health economics analysis. These four component parts of Phase 2 will be described in detail in the following four chapters.

Chapter 5 - Phase 2:

Part 1

Event Logging and Behavioural Data Analysis and Results

Introduction

This chapter presents data and results pertaining to Phase 2 Part 1, which focused on participants' interaction with the InspireD app that was specifically developed within and for this project.

Interaction with the InspireD app

In keeping with the individual specific nature of the home based reminiscence intervention, the researchers offered a flexible approach to the frequency with which each dyad should use the iPad app. The written and verbal advice that was offered to each dyad was to use the app on three different occasions, if possible, each week. The app was designed to capture data pertaining to patterns of usage by the 30 participating dyads. Unfortunately, usage data was found to be corrupted in the iPad software used by two dyads (a total of four participants). Therefore, only the tracking data of 28 dyads (56 participants) has informed the analysis and findings in relation to app interaction days (Table 6). A total of three (10%) dyads interacted with the app on 36 days or more over the 12-week period (equivalent to at least three days per week). Six (20%) dyads interacted with the app on 24 – 35 days (equivalent to two to three days each week), 15 (50%) dyads interacted with the app on 12 – 23 days (equivalent to one to two days each week), and four (13%) dyads had interacted with the app on less than 11 days over the 12 weeks (Table 6).

Table 6: App interaction days by dyads over the 12-week period

Interaction days	N (%) of dyads	Mean days	Range of days
≥36	3 (10%)	47.3	39 – 59
24 – 35	6 (20%)	29.3	25 – 34
12 – 23	15 (50%)	17.3	12 – 23
≤11	4 (13%)	7.5	6 – 10
Corrupted tracking data	2 (6.6%)	---	---

An independent samples T-Test was conducted to compare the mean number of days that the PLWD was interacting when logged in with the mean number of days that the carer was interacting when logged in. The PLWD had interacted with the app on an average of 12.36

(SD = 8.56) which was higher than the average number of days that carers had interacted with the app (mean 9.11 days, SD = 5.8). This difference was not statistically significant (p =.10).

Table 7 shows that the mean number of days that there was interaction with the app over the 12-week period of home use was 10.22 (SD = 7.8) for co-habiting dyads, and higher for non-co-habiting dyads (mean = 12.82, SD = 5.36). The difference was not statistically significant (p = .30)

Table 7: Interaction with the iPad app for co-habiting and non-co-habiting dyads.

	Dyad together	N	Mean	Std. Deviation
App Interaction days	Yes	45	10.22	7.822
	No	11	12.82	5.363

We had not anticipated that non-cohabiting dyads would use the app more frequently than cohabiting dyads. We then compared end point measurement scores between co-habiting and non-co-habiting dyads. There were no statistical differences between the mean primary and secondary outcome measures (Mutuality, WHO-5 and QCPR) scores of cohabiting and non-co-habiting dyads. More detailed results of the primary and secondary outcome measures are presented in the next part of this chapter.

Event Logging Design

The goal of incorporating event logging into the InspireD app was to help understand behaviour and usage about how PLWD and their family carers actually reminisced when presented with video, audio and images that may be personal or generic artefacts. The results show promise in understanding the behaviour of users of interactive assistive technologies, and indicate relatively strong engagement by PLWD and their carers in using the InspireD app.

During IT training, PLWD and their carers were provided with a method of personalised access, which was set up as a photograph of themselves, which, when clicked, logged them into InspireD. The InspireD app was designed to incorporate a logging facility for five canonical events, namely 1) Entry (Logging in), 2) Admin (Adding a photo, deleting an audio, etc.), 3) Reminiscing (Viewing a video, viewing a photo, etc.) 4) Exit (Logging out) and 5) 'In the Moment'. The results of the first four canonical events pertaining to the behaviour of participants within and across each usage session over the 3-month period of home use will now be described in detail. The fifth event pertaining to the 'In the Moment' data will be analysed in-depth in Part 3 of this chapter.

Results

Event Logging and Behavioural Analysis

User events were classified into the five canonical events as shown in Figure 7. As demonstrated, the InspireD app was primarily used for reminiscing. A total of 71% of interactions from PLWD were reminiscing events whereas only 47% of interactions from carers were reminiscing events and this difference was statistically significant ($p<0.001$). It is reassuring that PLWD mainly used the system for reminiscing as this was the intended study outcome. The data indicates that the training provided at the beginning of the home-use phase where the carer was trained in being a *de facto* administrator for the management of reminiscing material on the app held true throughout the trial period. Fewer exit events were logged than enter events. In explanation, part of the training was helping users to understand how to exit the app by arbitrarily closing it ('swiping up') which resulted in the non-recording of an exit event. Power running out and other practical issues also explain this 'enter-exit' difference. Only carers could carry out 'Admin' events such as adding a photo, as mandated by their access rights set at login. It can perhaps be seen as a positive sign that carers generally chose to put into action their training and use the administrative features and add to the music, pictures and videos that were uploaded to the app prior to the intervention beginning, rather than simply browsing those already there.

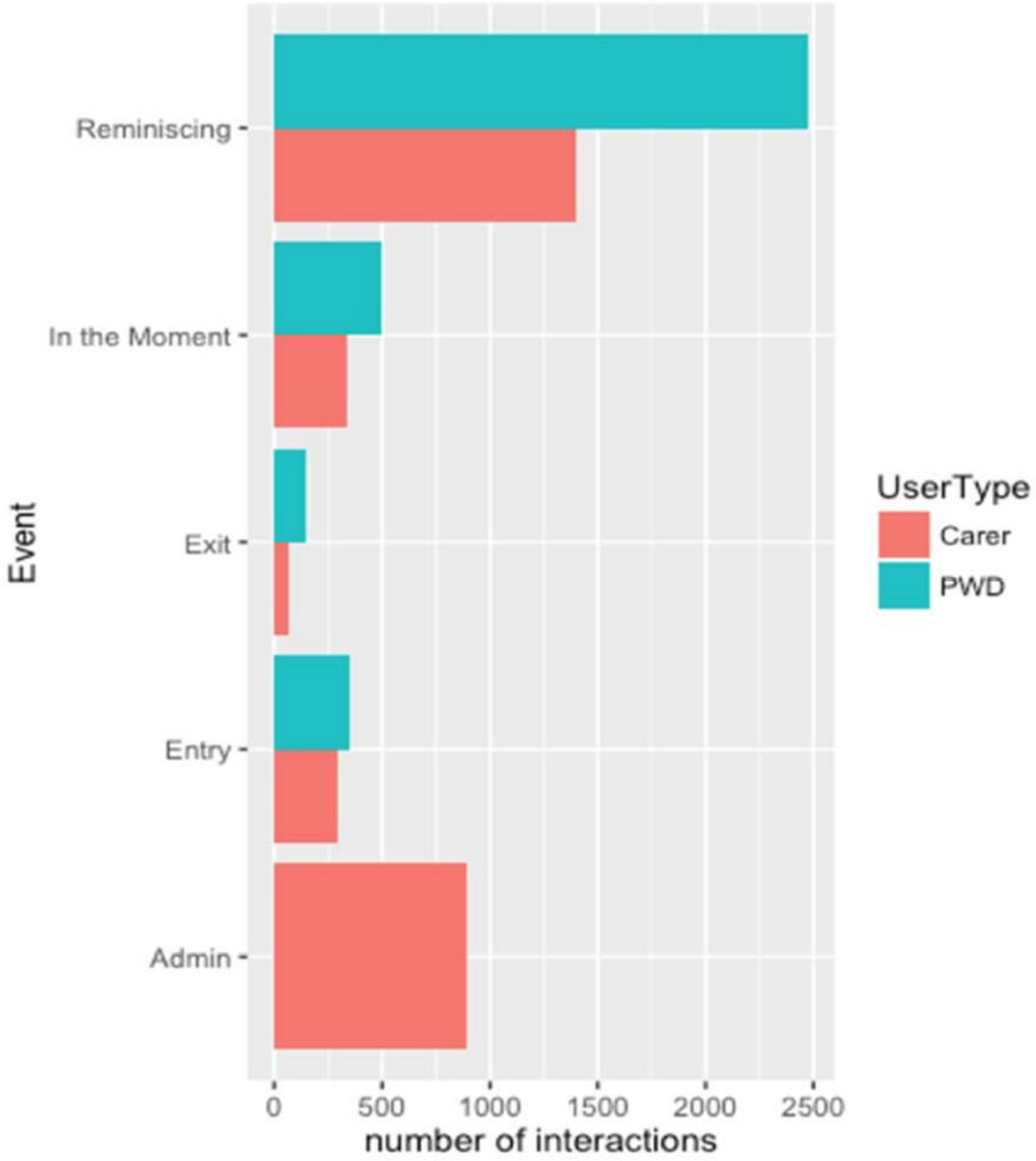


Figure 7: Number of interactions by carers and persons living with dementia in each of the classified events

In exploring the reminiscence data, it was interesting to observe that there were more interactions with photographs in comparison to music and video (Figure 8).

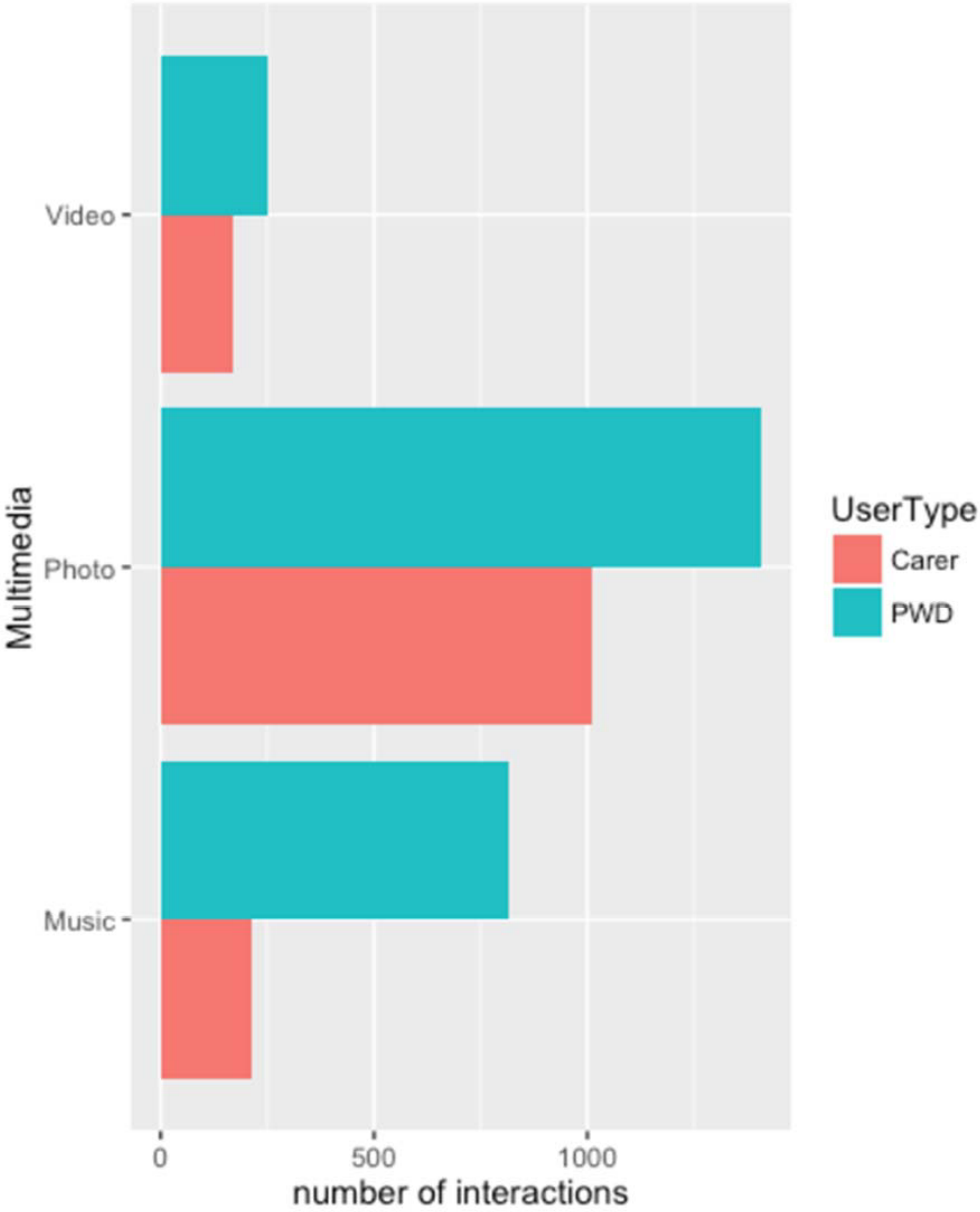


Figure 8: Number of interactions by carers and persons living with dementia in each of the multimedia features used to facilitate reminiscing

The IT training provided step-by-step instructions for uploading personal reminiscing material as well as explaining how to access non-personal material via the InspireD app's access to third-party media sources including Flickr and YouTube. Therefore, both personal and generic media were accessible in the app for reminiscing. However, Figure 9 shows that the app was primarily used for reminiscence using personal multimedia content as opposed to generic photos and videos.

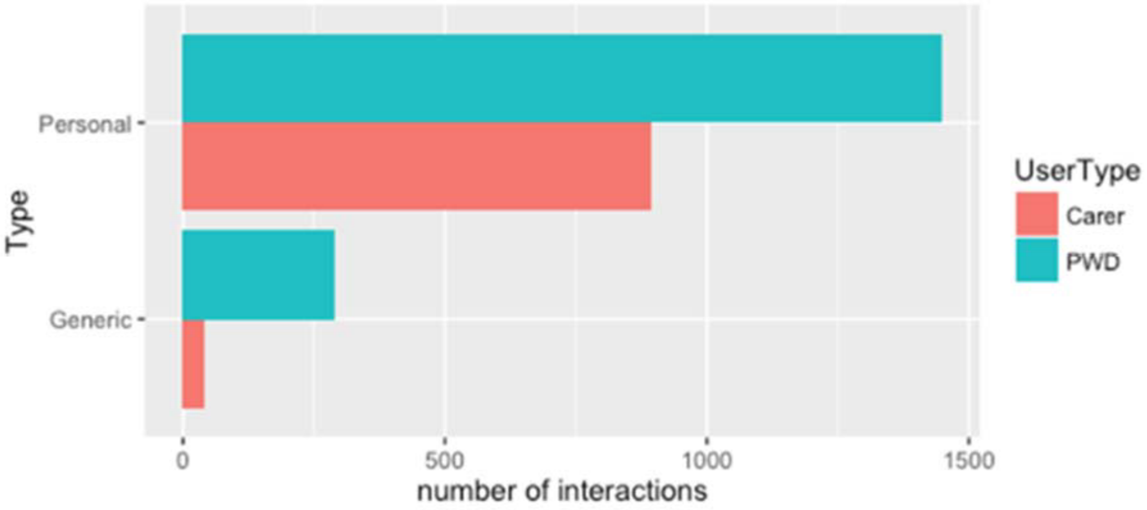


Figure 9: Number of personal and generic interactions by carers and people living with dementia

Figure 10 clearly shows the most popular times that PLWD and their caregivers prefer to use the app, which was around peaks at 11am, 3pm and 8pm. These times correspond to post-breakfast, post-lunch and post-evening meal times.

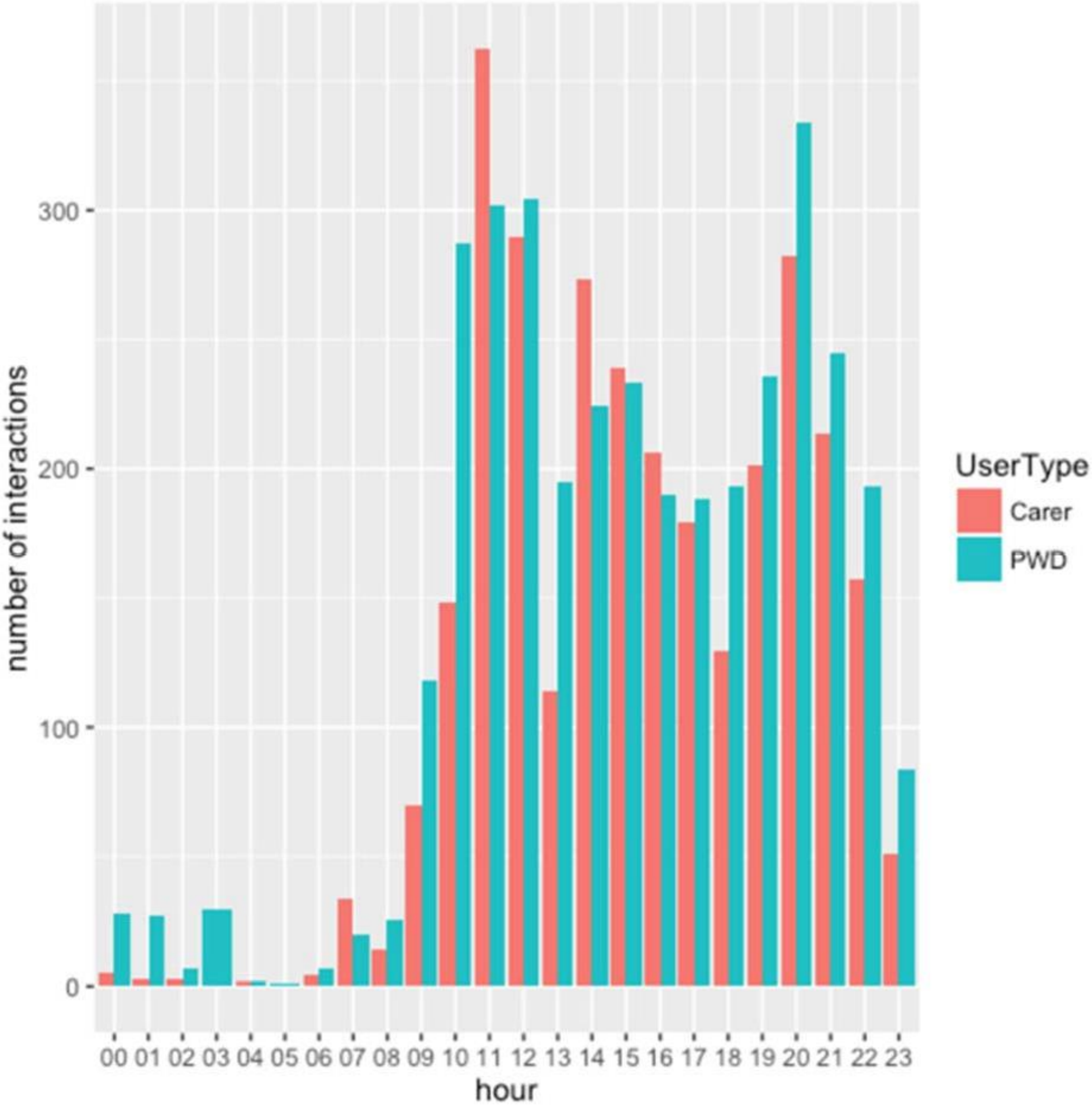


Figure 10: Number of event interactions by carers and persons living with dementia per hour

Figure 10 also shows the correlation between hours of usage by both PLWD and carers. Moreover, we calculated the number of unique days in which users interacted with the system (Figure 11) and there was a significant statistical correlation between the number of days the PLWD and their carers interacted with the system ($r=0.577$, $p<0.001$). The PLWD showed some independence as they had slightly more unique day interactions than carers as indicated in Figure 11.

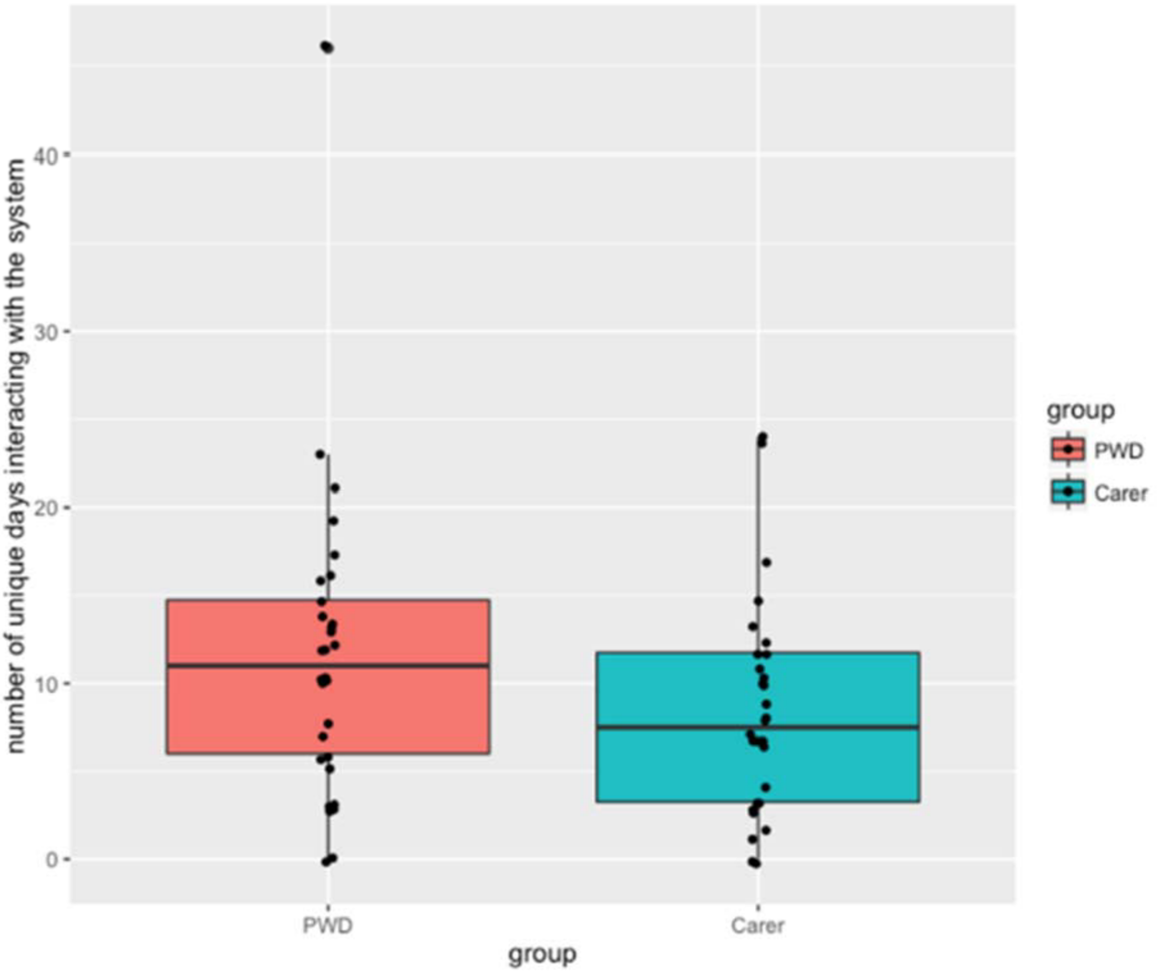


Figure 11: Number of unique day interactions by carers and people living with dementia

Over the 12 weeks, on average, a PLWD interacted with the system on 13.73% of the days which is equivalent to one reminiscence session per week. We also calculated the median frequency of exclusive day usage (or median interval between each usage day), which was 7.10 days - in other words, if a PLWD engaged in reminiscing on the app on a given day they were not likely to use it again until one week later. However, this is an average statistic that may not reflect the uniquely different patterns of users. A full picture of each individual's app interactions is shown in Figure 12.

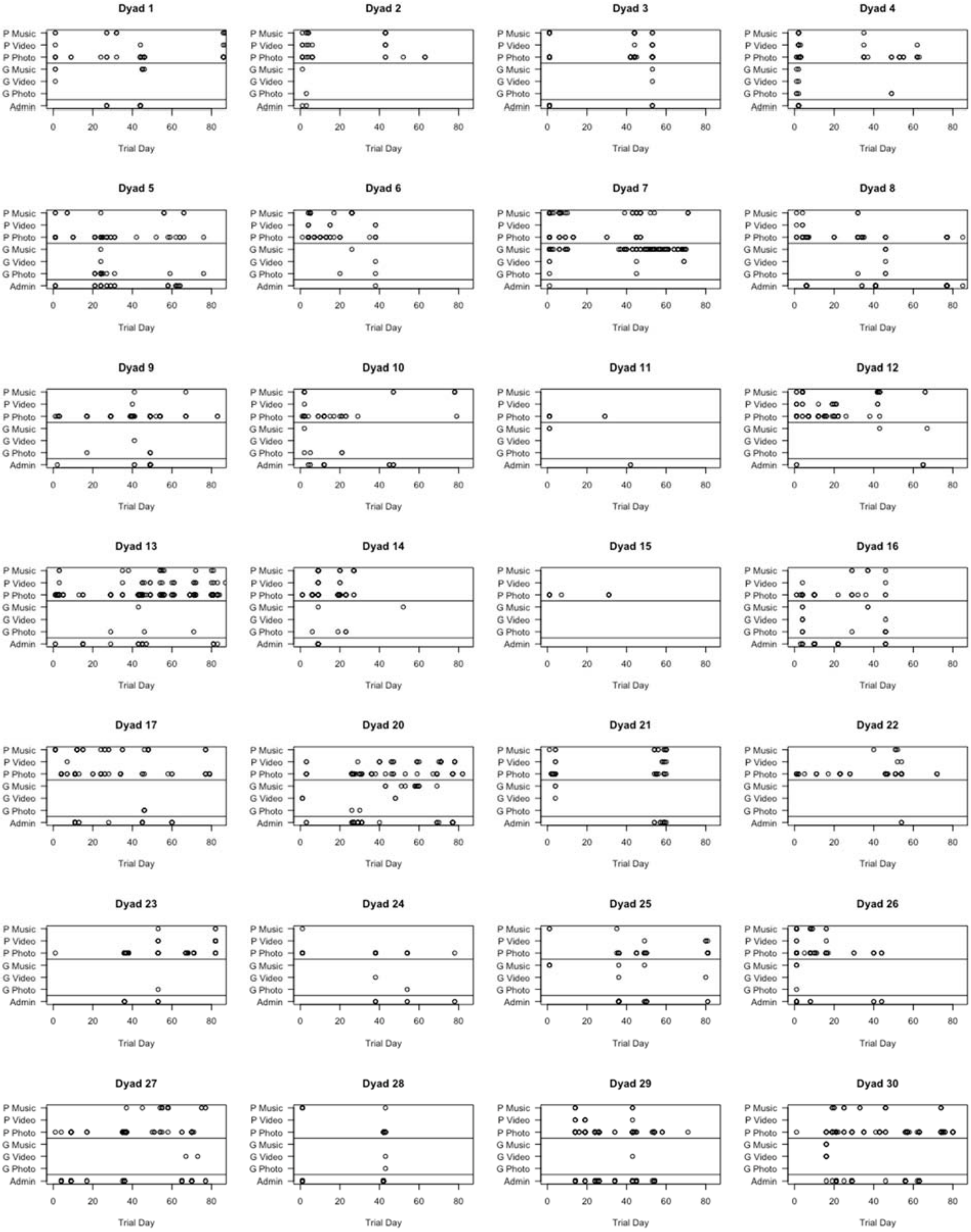

Dyad 1
Dyad 2
Dyad 3
Dyad 4
Dyad 5
Dyad 6
Dyad 7
Dyad 8
Dyad 9
Dyad 10
Dyad 11
Dyad 12
Dyad 13
Dyad 14
Dyad 15
Dyad 16
Dyad 17
Dyad 20
Dyad 21
Dyad 22
Dyad 23
Dyad 24
Dyad 25
Dyad 26
Dyad 27
Dyad 28
Dyad 29
Dyad 30

Figure 12. Usage patterns of Dyad's interacting with the Inspired App (G= reminiscing using generic media, P= reminiscing using personal media, Admin= Carer interactions).

Summary

In summary, we analysed the user log data which comprised of time stamped user interactions from both PLWD and their carers. The IT training provided appears to have been effective as both PLWD and carers were able to use the InspireD app for reminiscing. Moreover, the interactions from PLWD were mostly reminiscing events, which is of no surprise given that this was the main purpose of the app. Our data confirmed that reminiscence of personalised media was preferred over generic media and that carers played a crucial role in adding personalised media to the app.

The use of event logging in our study provided insights into carer and PLWD behaviour in all the dyads. The event log data indicated relatively strong engagement by PLWD and carers in using the InspireD app. Most positively, the primary users were PLWD and their primary use was reminiscing using personal photographs added to the InspireD app. Overall, over the 12 weeks, on average, a PLWD used the InspireD app for around one session of reminiscing per week and usage peaked at 11am, 3pm and 8pm. Note that this is an average statistic that may not reflect the uniquely different patterns of PLWD users of the app. This 'once per week' reminiscence session may seem relatively low, but the log data indicates independence of use of the app by the PLWD and sustained use of the app over the 12 week period.

Chapter 6 - Phase 2: Part 2

Primary and Secondary Outcome Measures Analysis and Results

Introduction

This chapter provides a detailed description of the primary and secondary outcome measures used in the study and the rationale for their selection. It also includes details on data collection and analysis and presents the results of this part of the study. As this was a feasibility study, our data collection and analysis processes and procedures were tested in order to inform a future RCT. Recruitment, compliance and drop-out rates of participants are presented in Table 8.

Table 8: Recruitment, Compliance and Drop Out rates of Participating Dyads

Recruitment/Involvement Rates	**Number of Dyads**
Dyads invited for involvement	44
Unsuitable referrals	8
Declined involvement	6
Participated	30
Withdrew	1 dyad withdrew after baseline and was immediately replaced
Lost to follow up	1 PLWD died prior to end-point data collection

Outcome Measure Instruments

Primary Outcome Measure- The Mutuality Scale (Mutuality)

The primary outcome measure used in this study was mutuality, defined as the positive quality of the relationship between caregiver and care receiver (Archbold et al. 1990). *The Mutuality scale* consists of 15 items that ask about the relationship between a caregiver and care receiver (Appendix 12). A sample item asks 'How attached are you to him or her?' to which respondents reply using a five-point scale ranging from 0 (not at all) to 4 (a great deal). Higher scores indicate higher mutuality, which may support relationships in difficult circumstances (Archbold et al. 1990). Consistent with other studies (Tetz et al. 2006;

Schumacher et al. 2007), the Mutuality scale was scored by calculating the mean across items. Validity has been shown in hypothesised relationships with other variables (Carter et al. 1998) and the Mutuality Scale has exhibited high Cronbach's alpha values (.91 to .95) in studies of family caregiving (Lyons et al. *2*007). The Mutuality scale has been tested in studies involving people living with dementia. Gallagher-Thompson et al. (2001) used the scale to measure the differences in social interactions between husbands and wives where the husband had a diagnosis of dementia and a comparison group where the husband did not have a dementia diagnosis. Lyons et al. (2007) used the scale to investigate changes in mutuality over the course of a 20-month period among 103 caregiving dyads, where care recipients were older adults, a significant percentage of whom had a diagnosis of dementia.

Secondary Outcome Measure –The WHO -5 Well-Being Index (WHO-5)

The WHO-5 Well-Being Index (Bech et al. 2003) comprises five questions that tap into the subjective well-being of participants (Appendix 13). The WHO-5 index has been extensively tested for validity (Henkel et al. *2*004; Liwowsky et al. *2*009) and reliability with coefficients ranging from 0.82-0.95 (Lowe et al. *2*004; deWit et al. *2*007). WHO-5 has been shown to be a better screening test for depression than the 12-item General Health Questionnaire (Henkel et al. 2004) and the Hospital Anxiety and Depression Questionnaire (Lowe et al. *2*004). A systematic review conducted by Topp et al. (2015), reported that WHO-5 is particularly useful in studies that seek to assess well-being over time or to compare well-being between groups. The WHO-5 scale items are scored from 0 – 5, and then totalled, giving a potential raw scores ranging from 0 – 25. Several studies (World Health Organisation, 1998; Snoek, 2006; Topp et al. 2015) recommend transforming the raw scores by multiplying by 4 in order to attain percentage scores ranging from 0 to 100 and we chose to adopt this strategy. A percentage score of 0 represents the worst possible result whereas a score of 100 represents the best possible measure of emotional well-being over a 14-day period. A percentage score of 50 or less is an indication of low mood, and a score of 28 or less is an indication of likely depression warranting further assessment and diagnosis (Snoek, 2006).

Secondary Outcome Measure- Quality of the Carer Patient Relationship (QCPR)

The *Quality of the Carer Patient Relationship* (QCPR) developed by Spruytte et al. (2002) is a 14-item scale measuring relationship quality, including level of warmth and level of criticism, rated separately by the person living with dementia and the family carer (Appendix 14 and 15). The QCPR scale has shown good internal consistency for carers (a=0.85) and for people living with dementia (a=0.80) and concurrent validity with other measures of relationship quality and carer stress (Woods et al. *2*012). Responses are rated using a 5-point Likert scale, scored from 1 – 5, ranging from totally disagree to totally agree. The six items measuring criticism and conflict (items 2, 3, 8, 10, 11, and 13) were reverse scored in computation, as guided by Spruyette et al. (2002). The minimum potential total score is 14 and the maximum potential total score is 70. A score >42 indicates a good relationship, and a score of less than or equal to 42 indicates a poor relationship.

Data Collection

In our **repeated measures** design, these three measurement tools were used to collect data at 3 time points during home visits to participants. As the intervention constituted the reminiscence training, IT training and use of the InspireD app, baseline data were collected prior to the reminiscence and IT training sessions. Mid-point data were collected mid-way through participants' 12-week period of home use and the final data collection took place at the end of this 12-week period of home use. (Table 5, page 63).

Data Analysis

Independent sample t-tests were undertaken to compare measurement scores across gender and dyad relationship (person living with dementia and carer) at baseline, mid-point and at end-point. Paired sample t-tests investigated difference in scores across two time-points. Within and between repeated measures analysis of variance investigated the impact of the intervention over time. Correlational tests were used to investigate the relationship between number of app interaction days and endpoint measurement scores.

Missing Data

Missing data analysis is an integral component in the testing of data collection methods and the appropriateness of the selected measurement tools (Bannon, 2015), as it enables patterns and challenges to be discerned. There were no missing values in the descriptive data that informed the characteristics of the participants. Data were collected at baseline, mid-point and end-point using the Mutuality, WHO-5 and QCPR scales. Missing data analysis revealed no missing data in any of the three measurement scales at baseline (time point 0). However, at time-point 1, three (5%) participants had missing data. Participant 44 was unavailable due to a hospital admission. Participant 50 had 2.9% missing data, which constituted one missing value (WHO-5 item 3) and Participant 11 had 5.9% missing data, which constituted two missing values (Mutuality items 6 and 9). At time-point 2 (endpoint), four (6.6%) participants had missing data. Of these, Participant 20 had 2.9% missing data, which constituted one missing value (WHO-5 item 5) and Participants 3, 4 and 43 had 100% missing data. Participant 3 had died and her carer (Participant 4) withdrew from the study. Participant 43 was unavailable due to a hospital admission. On an intention to treat basis, the missing data for Mutuality, WHO-5 and the QCPR across the three time points were managed using expectation-maximization Imputation in SPSS in line with Bannon (2015) and Pallant (2010). This enabled the missing data values to be effectively estimated based on participant responses to other variables. Following on from this, mean values were computed for the Mutuality item scores, percentage values were computed for WHO-5 and total values were computed for QCPR for each of the three time points in accordance with the recommendations of other studies (Spruyette et al. *2*002; Schumacher et al. *2*007; Topp et al. *2*015).

Results

A total of 60 participants, in thirty dyads, were recruited to Phase 2 of the study. Of these, a total of 56 participants (28 dyads) were retained in the study at completion.

Characteristics of the sample

The participants in twenty-three of the dyads were co-habiting. The characteristics of the participants, and baseline measurement scores are presented in Table 9.

Age and gender

The age range of PLWD was 61 - 94 years, mean 79 years and median 80 years. An independence samples t-test revealed that the mean age of carer participants was significantly lower than that of the PLWD, ranging from 31 - 91 years, mean 67 years and median 66 years (P < .001). The majority of PLWD (n=20; 67%) were men. A chi-square test for independence indicated that this was significantly different to the gender composition of the carers who were predominantly women (n=24; 80%; p = .001).

Marital status

Twenty-two of the PLWD (73%) were married, and eight (27%) were widowed. Twenty-five of the carers (83%) were married, one was widowed, and four were either separated or single.

Previous Information technology experience and home internet access

Only six of the PLWD (20%) had some or a lot of IT experience. In contrast, the majority of carers (n=19; 63%) had some or a lot of IT experience. In relation to internet access, the majority of PLWD (n=25; 83%) and carers (n=27; 90%) had access to the internet at home.

Hobby engagement

The majority of PLWD (n=19; 64%) and carers (n=29; 97%) sometimes engaged or were fully engaged in hobbies. Hobby choices were explored, indicating a preference for social hobbies, followed by physical fitness.

Baseline measurement scores

Mutuality

The mean Mutuality score at baseline was 3.13 (SD = .68), indicating a moderately high level of mutuality. Tests of normality of the distribution generated a Kolmogorov-Smirnov statistic of .006, and a Shapiro-Wilk statistic of .000, suggesting violation of the assumption of normality. However, from visual inspection of the histogram and Q-Q Plots, the distribution was observed to be reasonable although positively skewed. An independent samples t-test was performed to compare Mutuality scores at baseline between PLWD and carers. The mean score for PLWD was 3.24 (SD= .54) and for carers, it was 3.02 (SD = .79). There was no significant difference in the scores between the two groups at baseline (p = .218).

An independent samples t-test was undertaken to compare baseline mutuality scores between men and women. There was a significant difference between the scores of men (M = 2.9, SD = .78) and women (M = 3.3, SD = .56, t (43.4) = 1.6, p = .036), with women having higher scores. The relationship between age and baseline mutuality scores was investigated using Pearson rho. The correlation value of .09 is indicative of no relationship (p = .459).

WHO-5 Well-Being Index

The mean percentage WHO-5 score at baseline was 61.0 (SD = 23.9), indicating a moderate level of emotional well-being. Tests of normality of the distribution generated a Kolmogorov-Smirmov statistic of .017, indicating a violation of the assumption of normality. The Shapiro-Wilks statistic is an appropriate alternative in a small sample. The result of .052 is non-significant which, together with visual inspection of the histogram and Q-Q plots, suggested a reasonable although positively skewed distribution. An independent samples t-test was performed to compare WHO-5 scores at baseline between PLWD and their carers. The mean score for PLWD was 60.8 (SD = 26.2) and for carers, 61.2 (SD = 21.8). There was no significant difference in the WHO-5 scores between these two groups at baseline (p = .94).

An independent samples t-test was undertaken to compare baseline WHO-5 scores between men and women. The difference between the scores of men (M = 58, SD = 25.0) and women (M = 63.3, SD = .23.2, t (58) = -.846), was not significant (p = .401). The relationship between age and baseline WHO-5 scores was then investigated using Pearson rho. The correlation value of -.041 was indicative of no relationship (p = .755).

Quality of the Carer Patient Relationship (QCPR)

The mean QCPR score at baseline was 57.4 (SD = 7.9), indicative of a good relationship. The Kolmogorov-Smirmov statistic was .057, which suggested normality. Visual inspection of the histogram (Graph 3) and Q-Q plots confirmed a reasonable distribution. An independent samples t-test was performed to compare QCPR scores at baseline between PLWD and their carers. The mean score for PLWD was 58.1 (SD = 7.1), and for carers was 56.7 (SD = 8.6). There was no significant difference in the scores between the two groups (p = .52).

Next, mean baseline QCPR scores were compared between men and women. There was no significant difference in QCPR between men (M = 57.5, SD = 7.74) and women (M = 57.31, SD = 8.1, t (58) = .108, p = .914). The relationship between age and baseline QCPR scores was investigated using Pearson rho. The correlation value of .123 is indicative of weak positive relationship, however, the relationship failed to reach statistical significance (p = .349).

Table 9: Characteristics of participants and baseline measurement scores

Characteristic	**Total (N=60)**	**Person Living with Dementia (N=30)**	**Family Carers (N=30)**	**P values**
Age (years):				
Range; mean ± SD	31-94; 73 ± 13	61-94; 79 ± 8.9	31-91; 67 ± 14.8	<.001
Gender:				
Male	26 (43%)	20 (66.7%)	6 (20%)	.001
Marital status				
Married	47 (78%)	22 (73%)	25 (83%)	
Widowed	9 (15%)	8 (27%)	1 (3%)	
Single	3 (5%)	0 (0%)	3 (10%)	
Separated	1 (1.7%)	0 (0%)	1 (3%)	
Previous IT experience				
Little or none	35 (58%)	24 (80%)	11 (37%)	
Some	21 (35%)	5 (17%)	16 (53%)	
A lot	4 (7%)	1 (3%)	3 (10%)	
Home Internet Access				
Home internet access	52 (87%)	25 (83%)	27 (90%)	
Engagement in hobbies				
Rarely engaged	12 (20%)	11 (37%)	1 (3%)	
Sometimes engaged	38 (63%)	17 (57%)	21 (70%)	
Fully engaged	10 (17%)	2 (7%)	8 (27%)	
Hobby choices				
No hobby	5 (8.3%)	4 (13%)	1 (3%)	
Social	29 (48%)	14 (47%)	15 (50%)	
Creative	7 (12%)	4 (13%)	3 (10%)	
Physical fitness	19 (32%)	8 (27%)	11 (37%)	
Baseline measurements				
Mutuality mean ± SD	3.13 ± .68	3.24 ± .54	3.02 ± .79	.22

WHO-5 mean ± SD	61.0 ± 23.9	60.8 ± 26.2	61.2 ± 21.8	.94
QCGR mean ± SD	57.4 ± 7.9	58.1 ± 7.1	56.7 ± 8.6	.52

Effect of Intervention Over time

Mutuality Scores over Time

A paired samples t-test was conducted to investigate if there was a change in Mutuality scores for the participants from baseline (T_0) to mid-point (T_1) of the intervention. There was a statistically significant increase in Mutuality from baseline (M = 3.13, SD = .687) to midpoint (M = 3.39, SD = .55), t (59) = -3.79, p < .0005 (two-tailed). A paired samples t-test involving only PLWD confirmed a statistically significant increase from baseline (M = 3.24, SD = .545) to midpoint (M = 3.63, SD = .455), t (29) = -4.69, p < .0005 (two-tailed). A paired samples t-test involving only carers revealed no significant difference in Mutuality scores from baseline (M = 3.02, SD = .798) to midpoint (M = 3.15, SD = .673), t (29) = -1.22, p = .232.

Next, a paired samples t-test was conducted to investigate if there was a change in participants' Mutuality scores from mid-point (T_1) to end-point (T_2) of the intervention. This revealed that there was no significant difference in Mutuality scores from midpoint (M = 3.39, SD = .55) to endpoint (M = 3.36, SD = .54), t (59) = .804, p = .425. A paired samples t-test was then conducted with PLWD only. There was no significant difference in the Mutuality scores of PLWD from midpoint (M = 3.63, SD = .202) to endpoint (M = 3.64, SD = .274), t (29) = -.125, p = .901. A paired samples t-test with only the carers revealed no significance difference in the Mutuality scores from midpoint (M = 3.15, SD = .673) to endpoint (M = 3.07, SD = .600), t (29) = 1.04, (p = .307).

Next, a paired samples t-test was conducted to investigate the change in participants' mutuality scores from baseline (T_0) to end-point (T_2) of the intervention. There was a statistically significant increase in the Mutuality scores of the participants from baseline (M = 3.13, SD = .687) to endpoint (M = 3.36, SD = .542), t (59) = -3.61, p < .005 (two-tailed). When the paired samples t-test was then repeated for PLWD, there was a statistically significant increase in the Mutuality scores from baseline (M = 3.24, SD = .545) to endpoint (M = 3.64, SD = .274, t (29) = -4.90, (p < .0005). The mean increase in Mutuality scores was .40, with a 95% confidence interval ranging from -.56 to -.23. The eta squared statistic (.45) indicated a large effect size. A paired samples t-test involving only the carers found no significance difference in Mutuality scores from baseline (M = 3.02, SD = .798) to endpoint (M = 3.07, SD = .600), t (29) = -.645, p = .524).

In a further exploration of the Mutuality data, a mixed between-within subjects analysis of variance was conducted to assess if there was a difference in the impact of the reminiscence intervention on the Mutuality scores across the three time points between PLWD and the carers. For PLWD, the mean Mutuality score at baseline was 3.24, increasing to 3.63 at mid-point and rising further to 3.64 at end-point. For the carers, the mean Mutuality score at baseline was 3.02, increasing to 3.15 at mid-point and decreasing to 3.07 at endpoint (Table 10).

Table 10: Mutuality scores over time.

	Dyad role	Mean	Std. Deviation	N
T0 Mutuality	Person living with dementia	3.2444	.54592	30
	Carer	3.0244	.79875	30
	Total	3.1344	.68731	60
T1 Mutuality	Person living with dementia	3.6350	.20296	30
	Carer	3.1517	.67384	30
	Total	3.3933	.55029	60
T2 Mutuality	Person living with dementia	3.6406	.27475	30
	Carer	3.0798	.60080	30
	Total	3.3602	.54266	60

The Levene’s Test of Equality of Error Variances was undertaken and significant values less than .05 indicated a violation in the assumption of homogeneity at time points 1 and 2. Stevens (1996) has pointed out that analysis of variance is sufficiently robust to violations of equality, provided that the two groups are of reasonably similar size. In our study, there were 30 PLWD and 30 carers; two groups of equal size. Box’s M Sig. value less than .001, indicated a violation of homogeneity. Box's Test of covariance is highly sensitive. Given our sample size it is still justifiable to interpret analysis of variance (Pallant, 2010).

Overall, a statistically significant effect of the intervention was demonstrated over time using the Mutuality scale, Wilks' Lambda = .77, F (2, 57) = 8.17, p = .001, partial eta squared = .22. The value obtained for time (.22) is indicative of a large effect. There was also a statistically significant difference in patterns of scores across the time-points between PLWD and their carers, Wilks' Lambda = .87, F (2, 57) = 4.23, p = .019, partial eta squared = .129, with PLWD attaining significantly higher scores (Table 11). Figure 13 show the trends in mutuality scores across the three time-points.

Table 11: Multivariate Tests- Mutuality

Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
Mutuality Time	Pillai's Trace	.223	8.168[b]	2.000	57.000	.001	.223
	Wilks' Lambda	.777	8.168[b]	2.000	57.000	.001	.223
	Hotelling's Trace	.287	8.168[b]	2.000	57.000	.001	.223
	Roy's Largest Root	.287	8.168[b]	2.000	57.000	.001	.223
Mutuality Time * Dyad role	Pillai's Trace	.129	4.233[b]	2.000	57.000	.019	.129
	Wilks' Lambda	.871	4.233[b]	2.000	57.000	.019	.129
	Hotelling's Trace	.149	4.233[b]	2.000	57.000	.019	.129
	Roy's Largest Root	.149	4.233[b]	2.000	57.000	.019	.129

a. Design: Intercept + Dyad role, Within Subjects Design: Mutuality Time

b. Exact statistic

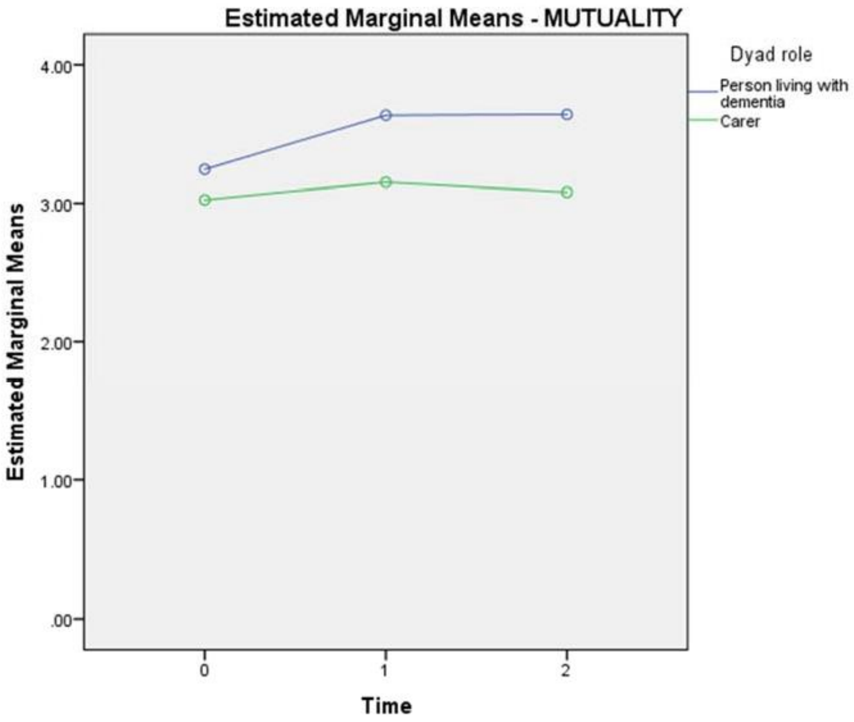


Figure 13: Mutuality scores across the three time points.

WHO-5 Scores over Time

A paired samples t-test was conducted to investigate if there was a change in participants' WHO-5 well-being scores from base line (T_0) to mid-point (T_1) of the intervention. There was no significant difference in the WHO-5 scores of the participants from baseline (M = 61.0, SD = 23.9) to midpoint (M = 63.2, SD = 23.9), t (59) = -.784, p = .43. Next, a paired samples t-tests was conducted for PLWD only. There was a statistically significant increase in their WHO-5 scores from baseline (M = 60.8, SD = 26.2) to midpoint (M = 69.8, SD = 18.18), t (29) = -2.51, p < .05 (two-tailed). A paired samples t-tests involving only the carers revealed no significant difference in WHO-5 scores from baseline (M = 61.2, SD = 21.8) to midpoint (M = 56.5, SD = 27.2, t (29) = 1.17, p = .25).

A paired samples t-test was conducted to investigate if there was a change in participants' mean percentage WHO-5 scores from mid-point (T_1) to end-point (T_2) of the intervention. There was no significant difference in the WHO-5 scores of the participants from midpoint (M = 63.2, SD = 23.9) to endpoint (M = 65.4, SD = .22.9), t (59) = -.96, p = .337 (two-tailed).

Similarly, when a paired samples t-test was conducted to investigate if there was a change in the WHO-5 scores from mid-point (T_1) to end-point (T_2) for PLWD only, we found no significant difference in the WHO-5 scores from midpoint (M = 69.8, SD = 18.2) to endpoint (M = 70.6, SD = .21.4), t (29) = -.283, p = .779). There was also no significant difference in the WHO-5 scores of carers from midpoint (M = 56.5, SD = 27.2) to endpoint (M = 60.2, SD = 23.4), t (29) = -.991, p = .330).

A paired samples t-test was conducted to investigate if there was a change in participants' mean percentage WHO-5 scores from baseline (T_0) to end-point (T_2) of the intervention. There was a statistically significant increase in the WHO-5 scores of the participants from baseline (M = 61.0, SD = 23.9) to endpoint (M = 65.46, SD = 22.9), t (59) = -2.26, p < .05 (two-tailed). A paired samples t-test involving PLWD only, confirmed a statistically significant increase in their WHO-5 scores from baseline (M = 60.8, SD = 26.2) to endpoint (M = 70.6, SD = 21.4), 95% CI: -14.8 - -4.84; t (29) = -4.02, p < .05 (two-tailed). The mean increase in WHO-5 scores was 9.8, with a 95% confidence interval ranging from -14.8 to -4.84. The eta squared statistic (.35) indicated a large effect size. A paired samples t-test involving carers only, indicated no significant difference in their WHO-5 scores from baseline (M = 61.2, SD = 21.8) to endpoint (M = 60.2, SD = 23.4), t (29) = .334, p = .741).

In a further exploration of the WHO-5 data, a mixed between-within subjects analysis of variance was then conducted to assess if there was a significant difference in the impact of the reminiscence intervention on the WHO-5 scores across the three time points between the PLWD and the carers. For the PLWD, the mean WHO-5 score at baseline was 60.8, increasing to 69.8 at mid-point and rising further to 70.66 at end-point. For the carers, the mean WHO-5 score at baseline was 61.2, decreasing to 56.5 at mid-point and then increasing to 60.2 at end point (Table 12).

Table 12: WHO -5 scores over time.

	Dyad role	Mean	Std. Deviation	N
T0 WHO-5	Person living with dementia	60.8000	26.26969	30
	Carer	61.2000	21.83701	30
	Total	61.0000	23.95051	60
T1 WHO-5	Person living with dementia	69.8667	18.18626	30
	Carer	56.5333	27.24567	30
	Total	63.2000	23.92984	60
T2 WHO-5	Person living with dementia	70.6667	21.43367	30
	Carer	60.2667	23.48724	30
	Total	65.4667	22.90102	60

Levene's Test of Equality of Error Variances indicated a violation of the assumption of equality of variances at time point 1 only. A Sig. value greater than .001, in our case .088, in Box's test of equality of covariance indicated that we had not violated the assumption of homogeneity in respect of the WHO-5 data.

Overall, a significant effect of the intervention was not demonstrated over time using the WHO-5 scale, Wilks' Lambda = .90, F (2, 57) = 2.94, p = .06, partial eta squared = .09. The value obtained for time (.09) however, is indicative of a moderate effect, and perhaps a larger sample size would have generated a significant difference in scores over time. A statistically significant difference was found in the pattern of scores across time between PLWD and their carers, Wilks' Lambda = .85, F (2, 57) = 4.90, p = .011, partial eta squared = .147. The intervention was associated with significantly higher scores for the PLWD (Table 13). Figure 14 show the trends in WHO-5 scores across the three time-points.

Table 13: Multivariate Tests – WHO-5

Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
Time	Pillai's Trace	.094	2.944[b]	2.000	57.000	.061	.094
	Wilks' Lambda	.906	2.944[b]	2.000	57.000	.061	.094
	Hotelling's Trace	.103	2.944[b]	2.000	57.000	.061	.094
	Roy's Largest Root	.103	2.944[b]	2.000	57.000	.061	.094
Time * Dyad role	Pillai's Trace	.147	4.906[b]	2.000	57.000	.011	.147
	Wilks' Lambda	.853	4.906[b]	2.000	57.000	.011	.147
	Hotelling's Trace	.172	4.906[b]	2.000	57.000	.011	.147
	Roy's Largest Root	.172	4.906[b]	2.000	57.000	.011	.147

a. Design: Intercept + Dyad role

Within Subjects Design: Time

b. Exact statistic

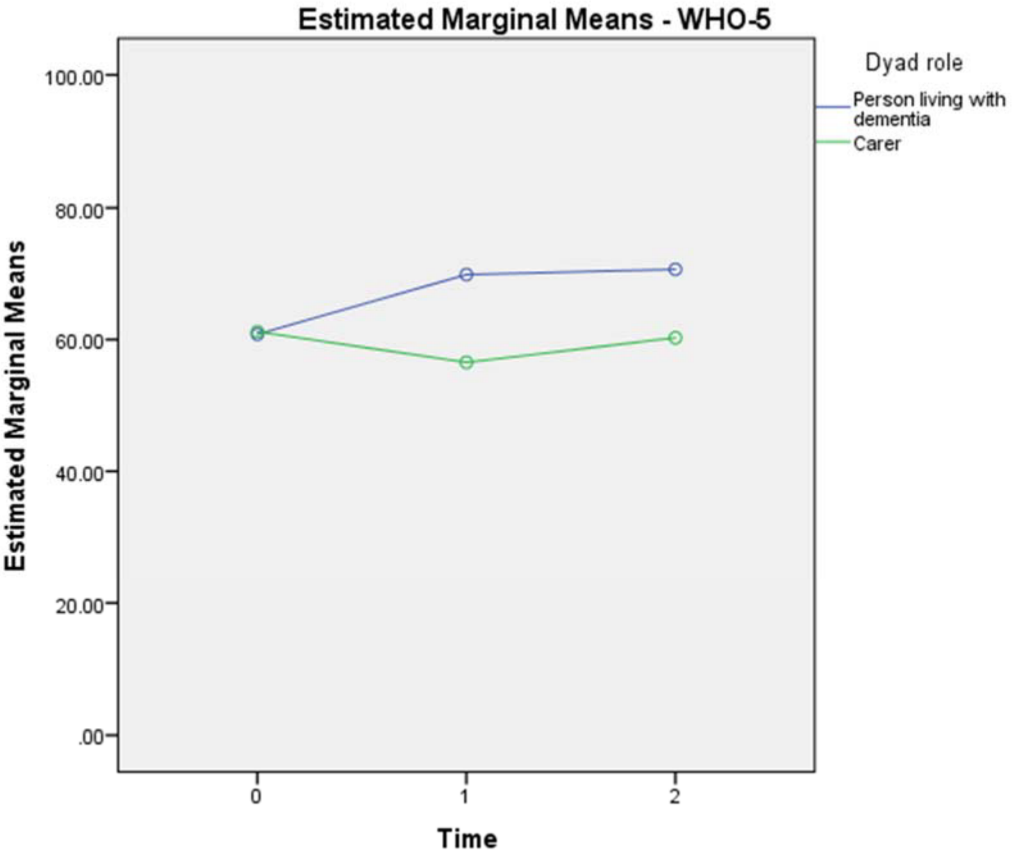


Figure 14: WHO-5 scores across the three time points.

'Quality of Carer Patient Relationship' Over Time

A paired samples t-test was conducted to investigate if there was a change in participants' QCPR scores from baseline (T_0) to mid-point (T_1) of the intervention. There was a statistically significant increase in the QCPR scores of participants from baseline (M = 57.4, SD = 7.89) to midpoint (M = 59.9, SD = 6.49), t (59) = -3.23, p < .005 (two-tailed). A paired samples t-test was conducted with PLWD only and confirmed a statistically significant increase in QCPR scores from baseline (M = 58.07, SD = 7.12) to midpoint (M = 61.3, SD = 5.17), t (29) = -3.37, p < .005 (two-tailed). When a paired samples t-test was conducted involving the carers only, there was no significant difference in QCPR scores from baseline (M = 56.7, SD = 8.66:) to midpoint (M = 58.5, SD = 7.42), t (29) = -1.46, p = .153).

Next a paired samples t-test was conducted to investigate if there was a change in participants' QCPR scores from mid-point (T_1) to end-point (T_2) of the intervention. There was no significant difference in the QCPR scores during this time period (M = 59.9, SD = 6.49) to endpoint (M = 60.58, SD = 7.05), t (59) = -1.049, p = .289 (two-tailed). When a paired samples t-test was conducted involving PLWD only, a statistically significant difference was revealed in the QCPR scores from midpoint (M = 61.3, SD = 5.17) to endpoint (M = 63.1, SD = 4.32), t (29) = -2.84, p < .05 (two-tailed). When a paired samples t-test was conducted with carers only, there was no significant difference in the QCPR scores from midpoint (M = 58.5, SD = 7.42) to endpoint (M = 57.9, SD = 8.26), t (29) = .587, p = .56 (two-tailed).

Next a paired samples t-test was conducted to investigate if there was a change in participants' QCPR scores from baseline (T_0) to end-point (T_2) the intervention. There was a statistically significant increase in the QCPR scores of the participants from baseline (M = 57.4, SD = 7.89) to endpoint (M = 60.58, SD = 7.05), t (59) = -3.86, p < .0005 (two-tailed). When a paired samples t-test was conducted involving PLWD only, a statistically significant increase in their QCPR scores from baseline (M = 58.07.4, SD = 7.12) to endpoint (M = 63.2, SD = 4.32), 95% CI: -7.42- -2.84; t (29) = -4.58, p < .0005 (two-tailed) was confirmed. The mean increase in QCPR scores was 5.13, with a 95% confidence interval ranging from -7.42 to -2.84. The eta squared statistic (.42) indicated a large effect size. When a paired samples t-test was conducted involving carers only, the difference in QCPR scores from baseline (M = 56.7, SD = 8.66) to endpoint (M = 57.9, SD = 8.26), t (29) = --1.09, was not found to be significant (p = .281).

In a further exploration of QCPR data, a mixed between-within subjects analysis of variance was then conducted to assess if there was a difference in the impact of the reminiscence intervention on the QCPR scores across the three time points between PLWD and their carers. For the PLWD, the mean QCPR score at baseline was 58, increasing to 61.3 at mid-point and rising further to 63.2 at end-point. For the carers, the mean QCPR score at baseline was 56.7, increasing to 58.5 at mid-point and decreasing to 57.9 at end point (Table 14).

Table 14: QCPR scores over time.

	Dyad role	Mean	Std. Deviation	N
T0 QCPR	Person living with dementia	58.07	7.119	30
	Carer	56.76	8.668	30
	Total	57.41	7.892	60
T1 QCPR	Person living with dementia	61.30	5.174	30
	Carer	58.56	7.426	30
	Total	59.93	6.494	60
T2 QCPR	Person living with dementia	63.19	4.327	30
	Carer	57.97	8.265	30
	Total	60.58	7.052	60

Levene's test of equality of error variances was undertaken, and significant values of .036 and .005 indicated a violation of the assumption of equality of variances at time points 1 and 2. A Sig. value greater than .001, in our case .010, in Box's test of equality of covariance matrices, indicated that our data did not violate the assumption of homogeneity in respect of the QCPR.

Overall, a significant effect of the intervention was demonstrated over time using the QCPR scale, Wilks' Lambda = .777, F (2, 57) = 8.15, p = .001, partial eta squared = .223. The value obtained for time (.223) is indicative of a large effect size. There was also a statistically significant difference in patterns of scores across the time points between PLWD and their carers, Wilks' Lambda = .88, F (2, 57) = 3.72, p = .03, partial eta squared = .116, with PLWD having higher scores (Table 15). Figure 15 show the trends in QCPR scores across the three time-points.

Table 15: Multivariate Tests – QCPR

Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
QCPR Time	Pillai's Trace	.223	8.156[b]	2.000	57.000	.001	.223
	Wilks' Lambda	.777	8.156[b]	2.000	57.000	.001	.223
	Hotelling's Trace	.286	8.156[b]	2.000	57.000	.001	.223
	Roy's Largest Root	.286	8.156[b]	2.000	57.000	.001	.223
QCPR Time * Dyad role	Pillai's Trace	.116	3.725[b]	2.000	57.000	.030	.116
	Wilks' Lambda	.884	3.725[b]	2.000	57.000	.030	.116
	Hotelling's Trace	.131	3.725[b]	2.000	57.000	.030	.116
	Roy's Largest Root	.131	3.725[b]	2.000	57.000	.030	.116

a. Design: Intercept + Dyad role

Within Subjects Design: QCPR Time

b. Exact statistic

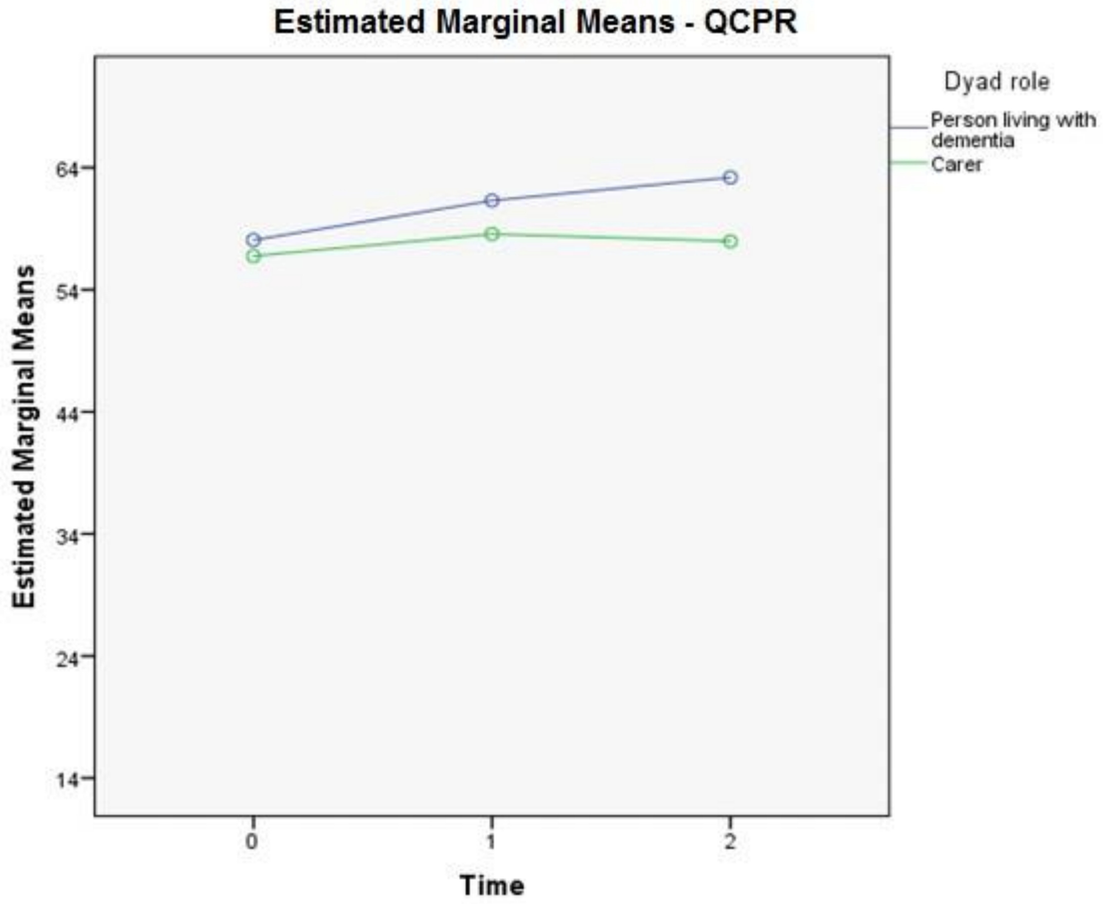


Figure 15: Quality of the Carer Patient Relationship scores across the three time points

The relationship between numbers of days that the iPad app was used by participants and outcome measurement scores

The relationship between the total number of days that participants interacted with the InspireD app and end point mutuality, WHO-5 and QCPR scores were measured using Pearson product-moment correlation coefficient. There was a positive correlation between number of days of interaction with the InspireD app and end point Mutuality scores, r = .207. The strength of the correlation was weak, and it failed to reach statistical significance (p = .125). It is possible that a larger sample may have resulted in a stronger relationship (Table 16).

Table 16: Correlation between app interaction days and end-point mutuality

		App Interaction days	T2 Mutuality
App Interaction days	Pearson Correlation	1	.207
	Sig. (2-tailed)		.125
	N	56	56
T2 Mutuality	Pearson Correlation	.207	1
	Sig. (2-tailed)	.125	
	N	56	60

Table 17 shows no relationship was found between the number of days of interaction with the InspireD app and end point WHO-5 scores (r = .048, p = .724).

Table 17: Correlation between app interaction days and end-point WHO-5

		App Interaction days	T2 WHO-5
App Interaction days	Pearson Correlation	1	.048
	Sig. (2-tailed)		.724
	N	56	56
T2 WHO-5	Pearson Correlation	.048	1
	Sig. (2-tailed)	.724	
	N	56	60

Table 18 shows a positive correlation between number of days of interaction with the InspireD app and end point QCPR scale, r = .145. The strength of the correlation was weak, and it failed to reach statistical significance (p = .287).

Table 18: Correlation between app interaction days and end-point QCPR

		App Interaction days	T2 QCGR
App Interaction days	Pearson Correlation	1	.145
	Sig. (2-tailed)		.287
	N	56	56
T2 QCPR	Pearson Correlation	.145	1
	Sig. (2-tailed)	.287	
	N	56	60

The correlation tests were then repeated separately for PLWD and their carers. Table 19 shows a positive relationship between number of interaction days for PLWD and endpoint Mutuality scores, r = .238 but the relationship was weak and did not reach significance (p = .22).

Table 19: Correlation between app interaction days and end-point mutuality (PLWD)

		App Interaction days	T2 Mutuality
App Interaction days	Pearson Correlation	1	.238
	Sig. (2-tailed)		.222
	N	28	28
T2 Mutuality	Pearson Correlation	.238	1
	Sig. (2-tailed)	.222	
	N	28	30

a. Dyad role = Person living with dementia

Table 20 shows that there was no relationship between number of interaction days for carers and endpoint Mutuality scores, r = .058, p = .77).

Table 20: Correlation between app interaction days and end-point mutuality (Carers)

		App Interaction days	T2 Mutuality
App Interaction days	Pearson Correlation	1	.058
	Sig. (2-tailed)		.769
	N	28	28
T2 Mutuality	Pearson Correlation	.058	1
	Sig. (2-tailed)	.769	
	N	28	30

a. Dyad role = Carer

In relation to WHO-5, Table 21 shows a positive relationship between the number of app interaction days for PLWD and their end-point WHO-5 scores, r = .15. However, the relationship was weak and failed to reach significance (p = .44).

Table 21: Correlation between app interaction days and end-point WHO-5 (PLWD)

		App Interaction days	T2 WHO5
App Interaction days	Pearson Correlation	1	.152
	Sig. (2-tailed)		.440
	N	28	28
T2 WHO5	Pearson Correlation	.152	1
	Sig. (2-tailed)	.440	
	N	28	30

a. Dyad role = Person living with dementia

Table 22 shows that no relationship was found between number of app interaction days of carers and their end-point WHO-5 scores, r = -.023, p = .91.

Table 22: Correlation between app interaction days and end-point WHO-5 (Carers)

		App Interaction days	T2 WHO5
App Interaction days	Pearson Correlation	1	-.023
	Sig. (2-tailed)		.909
	N	28	28
T2 WHO5	Pearson Correlation	-.023	1
	Sig. (2-tailed)	.909	
	N	28	30

a. Dyad role = Carer

In relation to the QCPR scale, no relationship was found between number of app interaction days for PLWD and their end-point scores, r = .07, p = .72 (Table 23). A similar picture emerged for the carers, r = .07, p = .67 (Table 24).

Table 23: Correlation between app interaction days and end-point QCPR (PLWD).

		App Interaction days	T2 QCPR
App Interaction days	Pearson Correlation	1	.070
	Sig. (2-tailed)		.723
	N	28	28
T2 QCPR	Pearson Correlation	.070	1
	Sig. (2-tailed)	.723	
	N	28	30

a. Dyad role = Person living with dementia

Table 24: Correlation between app interaction days and end-point QCPR (Carer).

		App Interaction days	T3 QCPR
App Interaction days	Pearson Correlation	1	.083
	Sig. (2-tailed)		.676
	N	28	28
T3 QCPR	Pearson Correlation	.083	1
	Sig. (2-tailed)	.676	
	N	28	30

a. Dyad role = Carer

Analysis of Covariance

Analysis of covariance was conducted separately for PLWD (Tables 25 and 26) and their carers (Tables 27 and 28) to compare the effectiveness of two different levels of app interaction for enhancing levels of mutuality. The independent variable was app interaction (12 or more days) vs 11 or less days) during the 12-week home use period. Fifteen PLWD had interacted with the app on twelve or more days and thirteen had interacted with the app on eleven or less days. The dependent variable consisted of Mutuality scores at endpoint. Mutuality scores at baseline were used as the covariate in this analysis. After adjusting for pre-intervention Mutuality scores, the two different levels of app interaction had no significant influence on endpoint Mutuality for PLWD, F (1, 25) = .88, p = .35, partial eta squared = .03. There was a moderate relationship between their pre-intervention and post-intervention Mutuality scores, as indicated by a partial eta squared value of .38. What this means is that the intervention is likely to account for only 3% of the effect on endpoint mutuality scores, whereas baseline mutuality scores are likely to account for 38% of the effect on endpoint mutuality scores.

Table 25: Levene's Test of Equality of Error Variances[a,b]

Dependent Variable: T2 Mutuality

F	df1	df2	Sig.
.007	1	26	.932

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Dyad role = Person living with dementia

b. Design: Intercept + T0Mutuality + AppUse

Table 26: Tests of Between-Subjects Effects

Dependent Variable: T2 Mutuality

Source	Type III Sum of Squares	Df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	.823^{b}	2	.411	7.834	.002	.385
Intercept	5.333	1	5.333	101.585	.000	.803
T0Mutuality	.814	1	.814	15.509	.001	.383
AppUse	.046	1	.046	.885	.356	.034
Error	1.313	25	.053			
Total	371.420	28				
Corrected Total	2.135	27				

a. Dyad role = Person living with dementia

b. R Squared = .385 (Adjusted R Squared = .336)

Eight carers had interacted with the app on 12 or more days, whereas twenty had interacted with the app on eleven or less days. After adjusting for pre-intervention Mutuality scores, there was no significant difference in effect between the two different levels of app interaction on the endpoint Mutuality scores of carers, F (1, 25) = .14, p = .71, partial eta squared = .01. There was a strong relationship between their pre-intervention and post-intervention Mutuality scores, as indicated by a partial eta squared value of .65, meaning that 65% of the effect on end point mutuality scores was likely to be accounted for by baseline mutuality scores (Tables 27 and 28).

Table 27: Levene's Test of Equality of Error Variances[a,b]

Dependent Variable: T2 Mutuality

F	df1	df2	Sig.
.053	1	26	.821

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Dyad role = Carer

b. Design: Intercept + T0Mutuality + AppUse

Table 28: Tests of Between-Subjects Effects

Dependent Variable: T2 Mutuality

Source	Type III Sum of Squares	Df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	6.705[b]	2	3.352	23.639	.000	.654
Intercept	2.722	1	2.722	19.192	.000	.434
T0Mutuality	6.690	1	6.690	47.171	.000	.654
AppUse	.020	1	.020	.143	.709	.006
Error	3.545	25	.142			
Total	272.727	28				
Corrected Total	10.250	27				

a. Dyad role = Carer

b. R Squared = .654 (Adjusted R Squared = .626)

DEMQOL

DEMQOL is a dementia-specific measure of health-related quality of life in dementia with robust psychometric properties (Smith et al. 2005). DEMQOL (Appendix 16) was used in combination with the DEMQOL Carer version (Appendix 17) primarily for the *health economic evaluation of this study* and will be reported in greater detail in Part 4 of this section of the report However, to maximise the use of all the data collected as part of this study and to contribute to the knowledge base around the suitability of scales and questionnaires for people living with dementia and their carers, we computed total scores for DEMQOL across the three time points, both for the PLWD and for the carer using the respective versions of the form.

DEMQOL consists of two interviewer-administered instruments, one completed with the PLWD and the other, a proxy report of the person living with dementia's quality of life, completed by the main carer. Smith et al. (2007) have highlighted that DEMQOL demonstrates high reliability through both internal consistency and test-retest, and moderate validity in people living with mild/moderate dementia.

The potential range of total score for the PLWD was 28 – 112, and the potential range of total score for the carer was 31 – 124. A one-way repeated measures analysis of variance was conducted to compare total DEMQOL scores at baseline (T_0), mid-point (T_1) and end-point (T_2) first for the PLWD. The means and standard deviations are presented in Table 29. At baseline, the mean total DEMQOL scores was 88.6, this increased to 92.3 at mid-point, and increased further to 94.5 at end point.

Table 29: DEMQOL scores over time (PLWD)

Person living with dementia	Mean	Std. Deviation	N
TotT0 DEMQOL	88.6071	16.89256	28
TotT1 DEMQOL	92.3571	12.36846	28
TotT2 DEMQOL	94.5714	10.24669	28

Table 30 shows that there was a significant effect for time for PLWD, Wilks' Lambda = .79, *F* (2,26) = 3.46, p = .04, multivariate partial eta squared = .21.

Table 30: Multivariate Tests[a,b] DEMQOL

Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
Time	Pillai's Trace	.210	3.462[c]	2.000	26.000	.046	.210
	Wilks' Lambda	.790	3.462[c]	2.000	26.000	.046	.210
	Hotelling's Trace	.266	3.462[c]	2.000	26.000	.046	.210
	Roy's Largest Root	.266	3.462[c]	2.000	26.000	.046	.210

a. Dyad role = Person living with dementia

b. Design: Intercept

Within Subjects Design: Time

c. Exact statistic

We next conducted a one-way repeated measures analysis of variance to compare total DEMQOL carer proxy scores at baseline (T_0), mid-point (T_1) and end-point (T_2). The means and standard deviations are presented in the table below. At baseline, the mean total DEMQOL carer proxy score was 90.5, this increased to 92.5 at mid-point, and decreased to 90.9 at end point (Table 31).

Table 31: DEMQOL scores over time (Carer)

Carer	Mean	Std. Deviation	N
TotT0 DEMQC	90.5714	17.88529	28
TotT1 DEMQC	92.5714	14.26581	28
TotT2 DEMQC	90.9643	16.33783	28

There was no significant effect for time using the DEMQOL carer proxy, Wilks' Lambda = .97, *F* (2,26) = .33, p = .72, multivariate partial eta squared = .025 (Table 32).

Table 32 Multivariate Tests[a,b] DEMQOL

Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
Time Carer	Pillai's Trace	.025	.330[c]	2.000	26.000	.722	.025
	Wilks' Lambda	.975	.330[c]	2.000	26.000	.722	.025
	Hotelling's Trace	.025	.330[c]	2.000	26.000	.722	.025
	Roy's Largest Root	.025	.330[c]	2.000	26.000	.722	.025

a. Dyad role = Carer

b. Design: Intercept

Within Subjects Design: Time Carer

c. Exact statistic

Calculation of Sample Size for a Follow-up RCT

A linear mixed model for a 2-way repeated measures ANOVA (fixed effects) was used to analyse the data. The between effect is dyad role, that is participants living with dementia versus carers. The statistical power for the between effect in the model, based on the results from the mutuality measure, was 36 individuals per group (total = 72). The power to detect the effects was set at 0.9 in all of the analyses.

For within effect (repeated measures for both carers and those living with dementia), to detect the main effect of time (within subject effect) a sample of 16 respondents would be required in each group (total = 32). For between-within subjects (interaction), to detect the interaction of condition (carer vs those living with dementia) and time would require a sample of 39 individuals in each condition (total = 78) to detect an effect similar to that present in the previous study, with a statistical power of 0.9.

These calculations were based on the results from the sample statistics from the current feasibility study. In future research these results will be combined with those obtained from related research to make a best approximation of the sample size for a possible randomised control trial.

Summary

Our study sought to investigate the feasibility of individual specific reminiscence, facilitated through the use of bespoke software on persons living with dementia and their carers. The foci of Phase 2, Part 2 was the implementation of an intervention to support individual specific, home-based reminiscence and testing the impact of this intervention on mutuality, wellbeing and quality of relationship for PLWD and their family carers. Our intervention differed in a number of ways to the approaches taken in recent reminiscence studies. The participating dyads engaged in individual specific reminiscence training and information technology training that was delivered in their homes. Following this, joint reminiscence was facilitated through the InspireD app hosted on an iPad. Carers in our study were predominately female (80%), while 66.7 % of PLWD were male. As might be expected, carers were younger and had more experience with information technology. Our findings indicated statistically significant increases in Mutuality, WHO-5 Index and QCPR scores from baseline to endpoint for participants living with dementia, with large effect sizes. In contrast, we observed no significant differences in Mutuality, QCPR and WHO-5 scores from baseline to endpoint for carers. We undertook ANCOVA on Mutuality only, as Mutuality was the primary outcome measure, and our sample size being small was unlikely to generate statistically significant results. An interesting finding was that a higher baseline Mutuality score was related with better outcomes. In a follow-up RCT, we plan to undertake ANCOVA and post hoc analysis using both primary and secondary outcome measures.

Chapter 7 - Phase 2:

Part 3

‘In the Moment’ Data

Analysis and Results

Introduction

This part of the report outlines a novel component of the analysis in which 'in the moment' questions, derived from the primary outcome measure (Mutuality Scale) were programmed to be delivered by the InspireD app during usage and responses were correlated to the mutuality data collected by researchers at baseline, midpoint and endpoint. Although this was *not* a specific study objective, the research team felt that it would have been a missed opportunity not to explore this type of data collection, particularly for people living with dementia, who may be best able to describe their feelings '*in the moment'* rather than through recollection of short term memories which are likely to be compromised as a result of their dementia diagnosis.

With the advent of model technology, and in particular the iPhone and related tablet devices, it is now possible to obtain effectively 'in the moment' information. Consequently, the procedures required to undertake such research are now receiving considerable attention. Kurt Lewin was one of the earliest proponents advocating investigating a 'topology' of daily activity (Lewin, 1935). The Experience Sampling Method (ESM) or the Ecological Momentary Assessment is the scientific method developed from these early perspectives. This method originally made use of diary techniques to enable people to record their observations or answers to specific questions and combined the ecological validity of diary approaches with the rigorous measurement techniques of psychometric research.

ESM therefore obtains, "*information about the private as well as the public parts of people's lives, it secures data about both behavioural and intrapsychic aspects of daily activity, and it obtains reports about people's experience as it occurs, thereby minimizing the effects of reliance on memory and reconstruction"* (Larson and Csikszentmihalyi, 2014, p. 25). Nowadays, smartphones enable the capture of implicit usage data from integrated sensors such as, for example, accelerometers, and these lifelogging and quantified-self techniques have gained increasing popularity as smartphones become ubiquitous in daily life (Wilmer et al. *2*017). Recent research has successfully shown how the use of these techniques combined with ESM can validate their integrated use (Intille et al. 2003), the SocioXensor system (Mulder et al. 2005) and the inHabit platform (Wiebe et al. *2*016).

The ESM is the original technique which informed the novel development of ‘in the moment’ questions in the InspireD system. The ‘in the moment’ questions comprised five items from the primary outcome measure for the study, the Mutuality Scale developed by Archbold et al. (1990). Recognising the limitations of conventional approaches to data collection, particularly for people living with dementia, these questions were designed to provide ‘in the moment’ data on the reminiscence experience.

The first area of investigation was the practical application of multiple items to measure a construct. This was important because most constructs in social and psychological research use multiple items to assess a construct, for example, depression is often evaluated through responses to a series of questions. A major advantage of ‘in the moment’ data is that the same questions can be repeated on a potentially large number of occasions. However, this presents its own difficulties, not least the possible burden that it could place on participants to respond to questions on a number of occasions. Additionally, since these occasions may not be very far apart, the potential effect of memory of previous response affecting the new response could be considerable.

The ‘in the moment’ phase was novel because it examined the feasibility of obtaining responses to the construct of mutuality by presenting a single item, rather than multiple items, when using the InspireD app. A key issue was to determine how these single items would represent the construct when combined. Another crucial factor in this approach is the issue of change, both within and between individual participants, with potentially different factors/variables having different effects at the different levels. A subsidiary issue is the type of response scale that might be used to obtain the information. This latter issue was examined in Phase 1 of the study when the User Development Group indicated their preference for a 5 category response scale as per the original Mutuality scale (Archbold et al. 1990)

Data Structure

Optimally, a response to one question could be obtained for each use of InspireD app. Five items (questions), relating to one construct (mutuality) were presented over a potential period of 12 weeks. A simple randomisation strategy was used to arrange the ordering of the presentation of the five items. This strategy has the advantage that it minimises recall bias, while still maintaining a high degree of ecological validity. Another advantage of this approach is the considerable amount of data that can be obtained: for example, if responses were received from 30 participants for five days per week over a period of 12 weeks, we would have 1,800 responses (60 x 30 = 1,800).

Method of analysis

Measurement models within a factor structure were used to examine the data. In the current context a latent variable (mutuality) was hypothesised to underlie the response to all of the manifest measures (5 questions). This is in keeping with theories of validity and reliability. Such models are invariably estimated using some version of maximum likelihood; however, in the current context due to the sample size, a Bayesian method of estimation was used. This was also likely to facilitate model convergence, which could have been a considerable problem given the distribution of the data. Formal testing of models has not been undertaken because of the limited sample size and the exploratory nature of the study.

Measures

When either the person with dementia or the carer logged onto the system, one of the five questions was presented in a random sequence. The perceived advantages of this strategy were (1) to minimise respondent burden, (2) to permit the dimensional structure of the concept (mutuality) to be represented, (3) to represent change across each individual and to see the extent of that change between study participants and (4) to establish the association between responses to these five items within two different formats: paper and pencil responses at three fixed points in time (beginning, middle and end of the study) and at numerous times within the momentary assessment when the software was in use.

The following items from the Mutuality scale were used to capture ‘in the moment’ data.

Item	Statement
3	How much do you enjoy sharing past experiences with him or her?
5	How attached are you to him or her?
7	How much do you like to sit and talk with him or her?
11	How much do the two of you laugh together?
12	How much do you confide in him or her?

App interaction and ‘in the moment‘ questions

To go some way to validate the algorithm that instantiates ‘in the moment’ (ITM) questions, we calculated the correlation between the number of interactions each subject had with the InspireD app and the number of ITM questions that were elicited to them via the app. There is a strong relationship between the number of ITM questions and the number of interactions ($r=0.86$, $p<0.001$, see Figure 16 which suggest that the proportion of ITM questions to the volume of interactions is consistent and proportionate. On average, 13% ± 6% of all app interactions are ITM questions. Thus, there are 13 ITM questions per 100 interactions (~1 ITM question per 10 interactions).

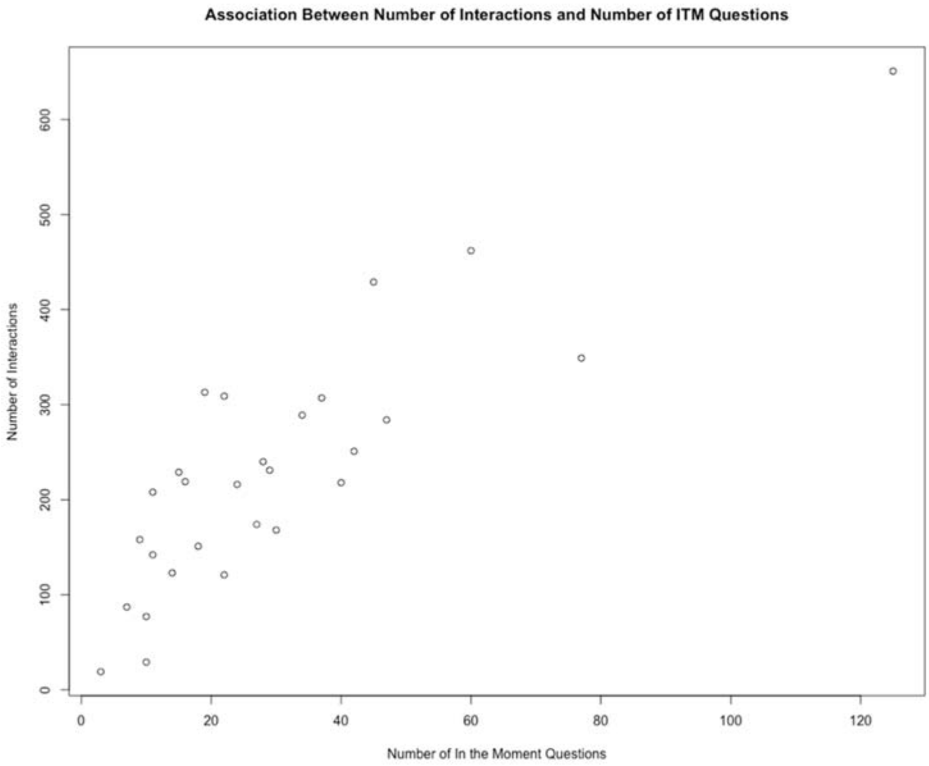
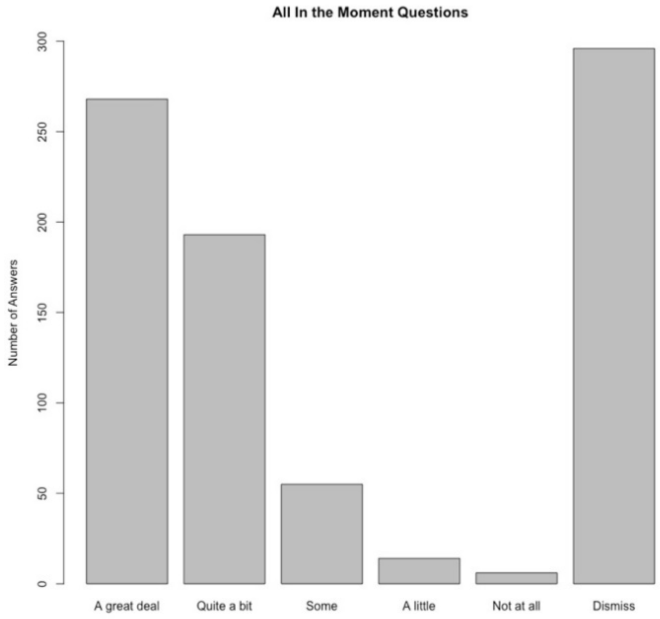


Figure 16: Scatter plot showing the number of subject interactions and ITM questions that are elicited to each participant.

Figure 17 shows all ITM answers during training and outside of training. The dismissal rate is 35.57% outside of training and 81.81% during training. Dismissal rate is 25.89% when excluding the entire training days (even though training only lasted 1 hour on those days). This could indicate that the number of ITM questions may need to be reduced by ~25% to avoid over prompting the user.



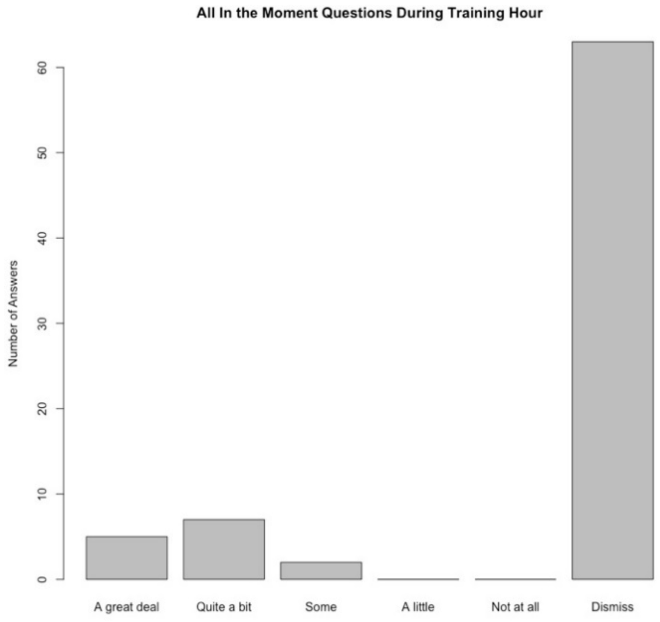


Figure 17: Upper image showing responses outside of training and the lower image shows responses during training.

In the bar charts below (Figure 18), the responses for each of the mutuality questions are shown, and below these figures are the number of question instances and their dismissal rates (Table 33).

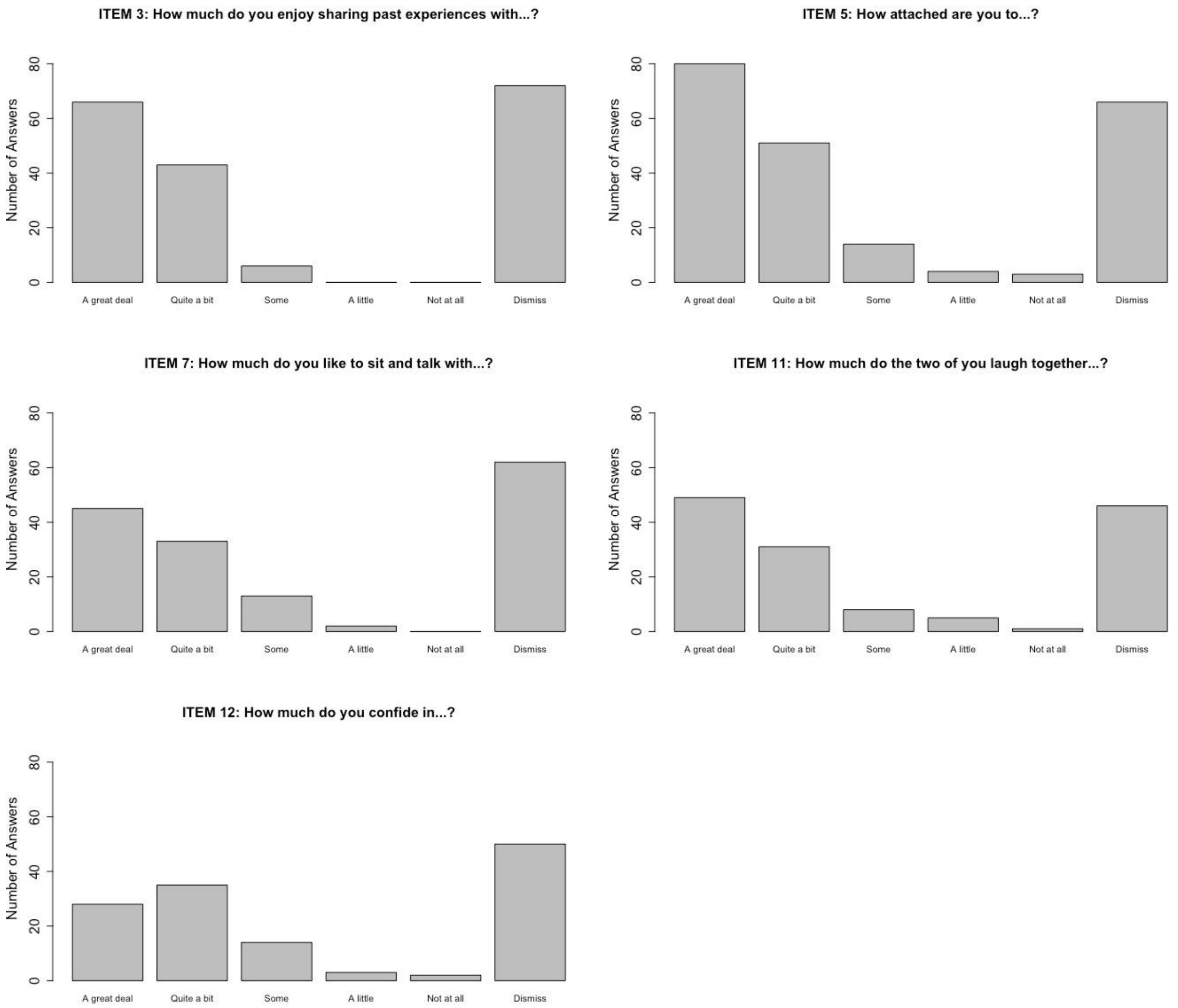


Figure 18: Responses to each of the mutuality questions.

Table 33: Number of question instances and dismissal rate for each item.

	ITEM 3	ITEM 5	ITEM 7	ITEM 11	ITEM 12
# of times question was asked in the moment	187	218	155	140	132
Dismissal rate	38.50%	30.27%	40%	32.85%	37.87%

Figure 19 shows the number of ‘in the moment’ questions asked per hour and Figure 20 shows the dismissal rate at each hour of the day. While there are a fair number of questions at 9pm, this time yields the smallest dismissal rate of 9%. This indicates that 9pm is the optimal time to execute’ in the moment’ questions. This is followed by 6pm and 2pm which are also the user’s preferred times in answering ITM questions.

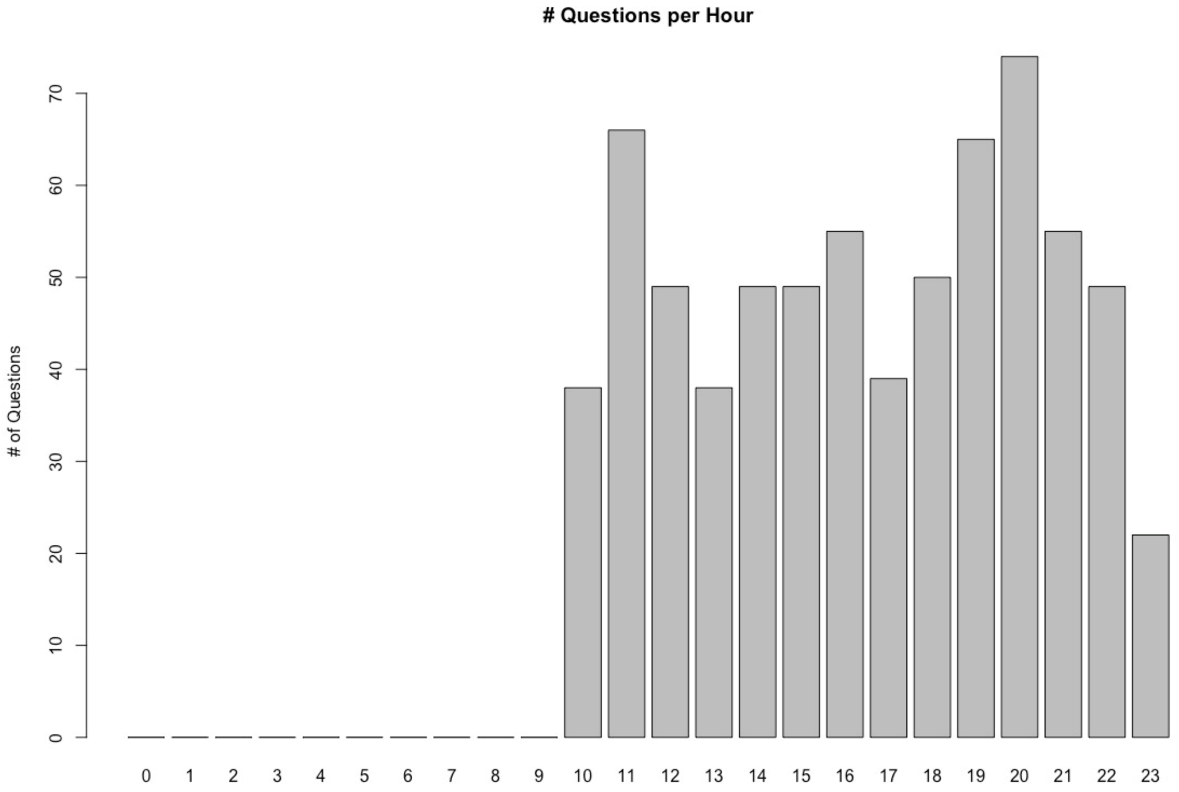


Figure 19: The number of questions asked per hour.

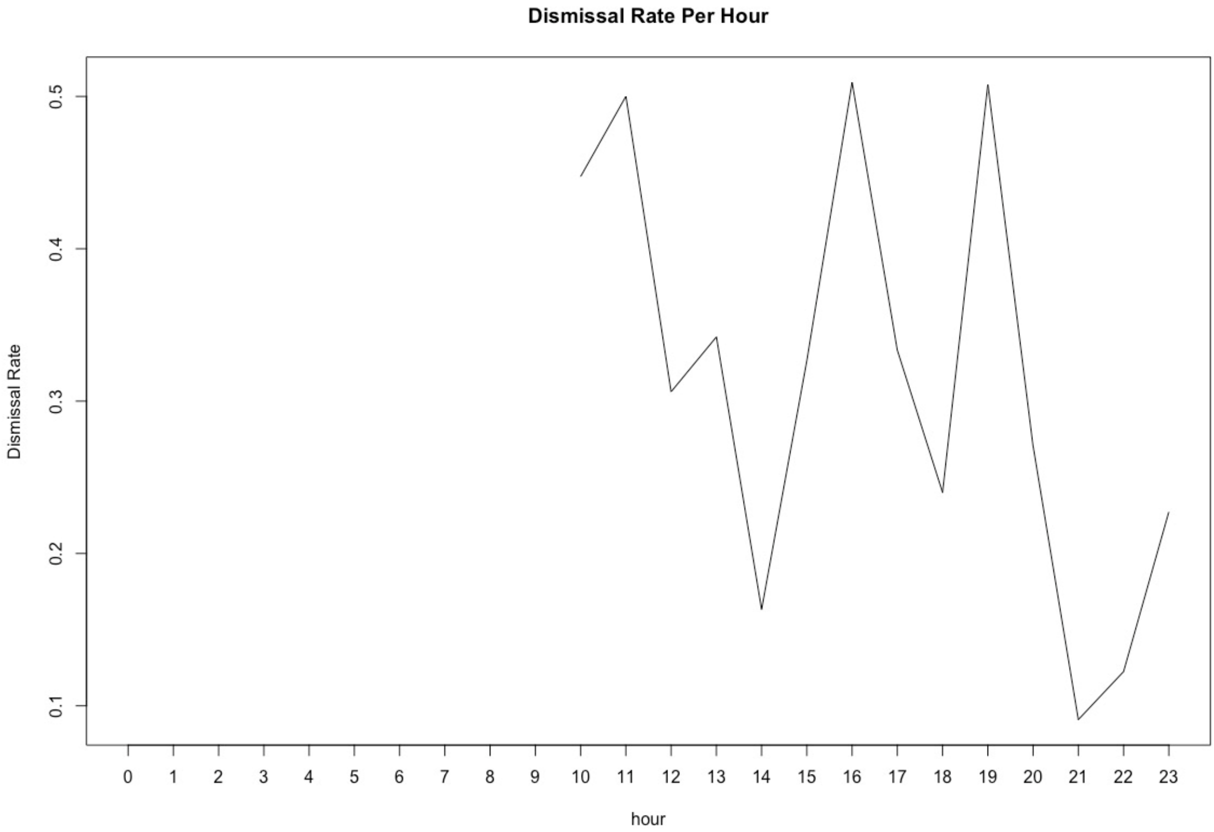


Figure 20: Dismissal rates at each hour of the day.

Figure 21 shows the dismissal rate over the trial days and weeks. The dismissal rate decreased as the trial progressed. Correlation between trial week and dismissal rate was r=-0.71 (p=0.008). Dismissal rate was on average 32% during the first six weeks but dropped to 9% in the last six weeks.

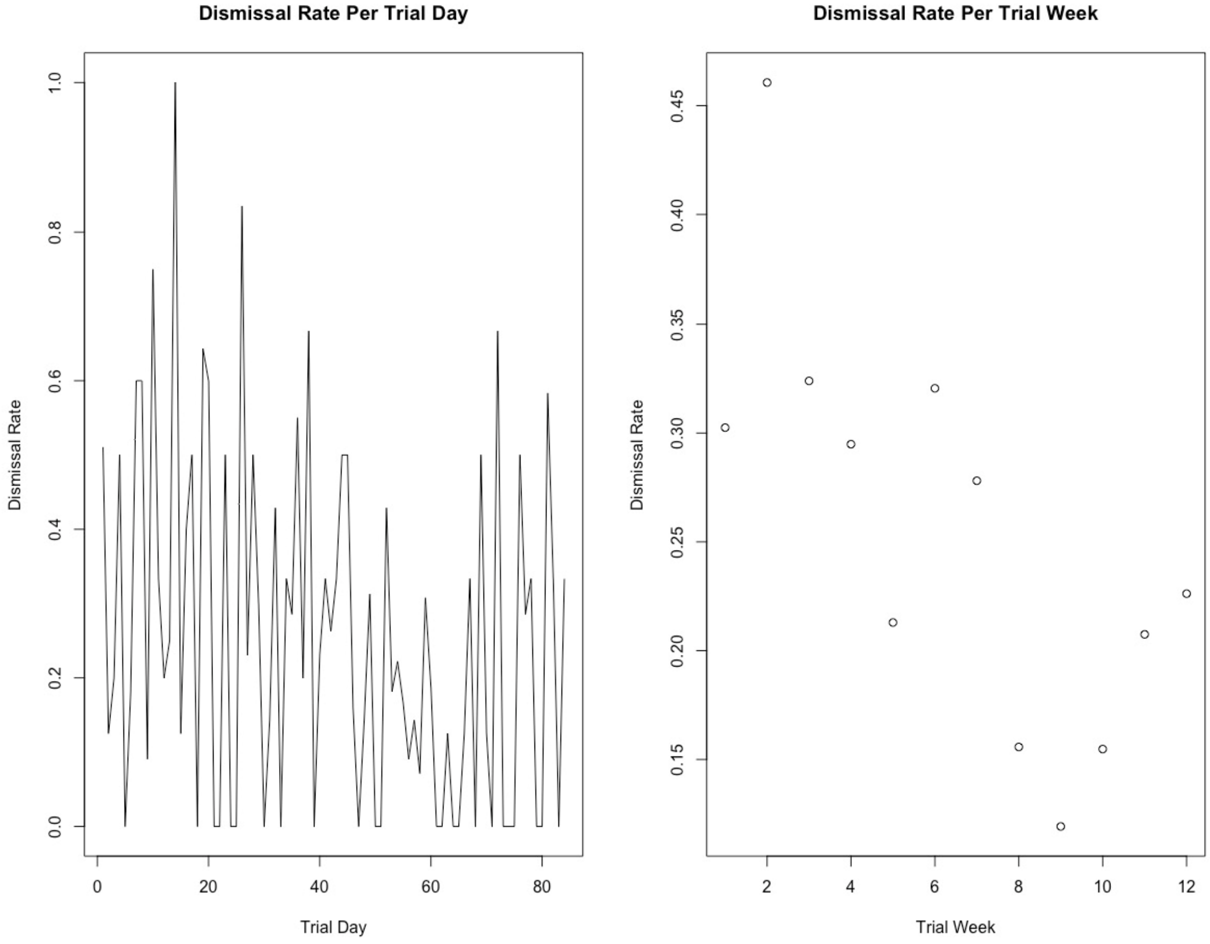


Figure 21. Association between trial timeline and dismissal rate of in the moment questions.

Figure 22 shows the correlation between the mean rating of mutuality from ITM questions for both PLWD and their carers. The correlation is moderate (r= 0.53, p= 0.01). This indicates that feelings of mutuality of the carer and PLWD are related. Figure 23 shows the association between the standard deviations of ratings from carers and PLWD. This is a weak correlation (r=0.15. p=0.521), possibly due to 6 outliers. Overall, PLWD had a higher mean rating in comparison to carers (PWD=4.26, carer=4.08, p=0.36). This finding was consistent with the results of the paper and pencil mutuality data collected by the researchers.

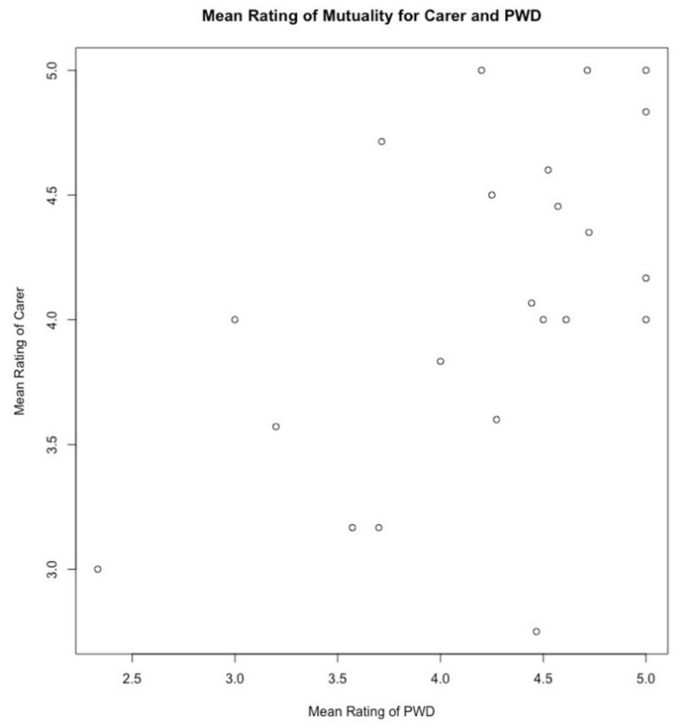


Figure 22: Association between mean rating from PLWD and carer.

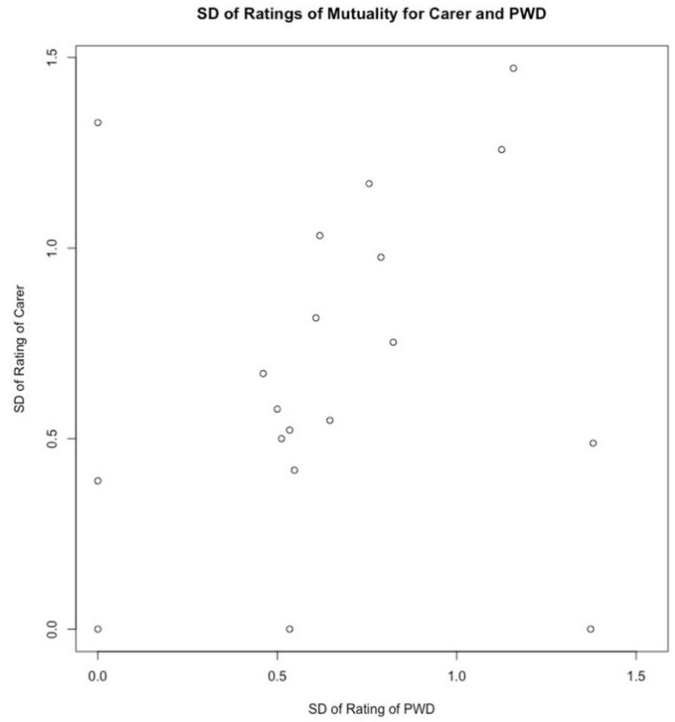


Figure 23: Association between standard deviations of ratings from PLWD and carer.

The ITM responses from each dyad are shown in Figure 24. The ITM data from 26 dyads informed this phase of the study. In the moment data from the remaining four dyads were not available due to corrupted files. Overall, there were 338 responses from PLWD and 198 responses from carers. This translates to ~1 response per week per PLWD and ~1 response per two weeks per carer.

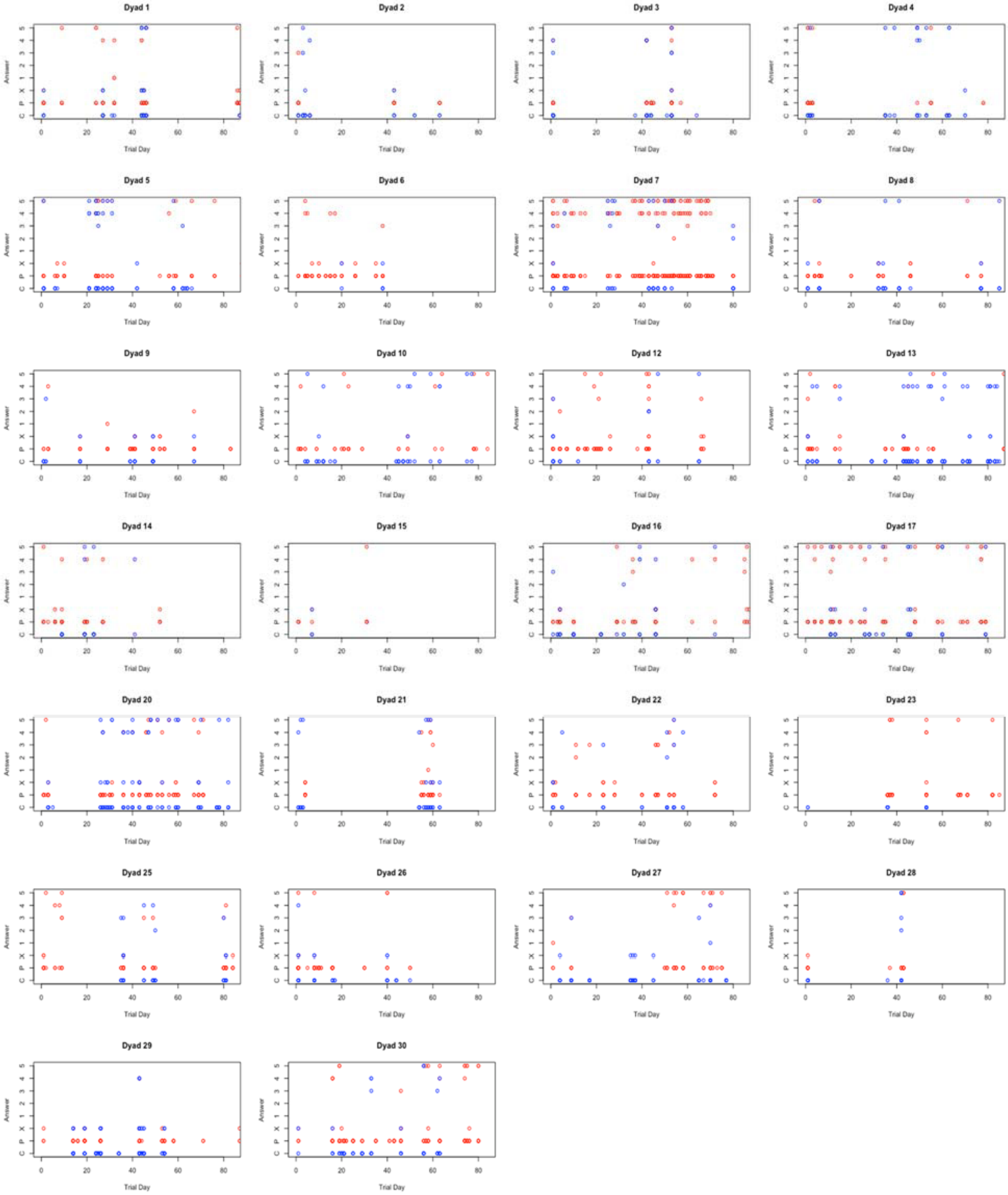


Figure 24: In the moment responses collected for each dyad (Red = PWD, Blue = Carers, X=dismissals, C=carer app usage, P=PLWD app usage). This includes responses from training sessions.

Consistency in responding to question over the 12-week period

The first part of this section of the report presents the results of the responses to the ITM questions both from PLWD and their carers. This will be followed by, and compared to, the responses to the same items on the Mutuality scale using the ‘pencil and paper’ approach carried out by the researchers at the three time points in the study.

Section 1: In the Moment Data Analysis and Results

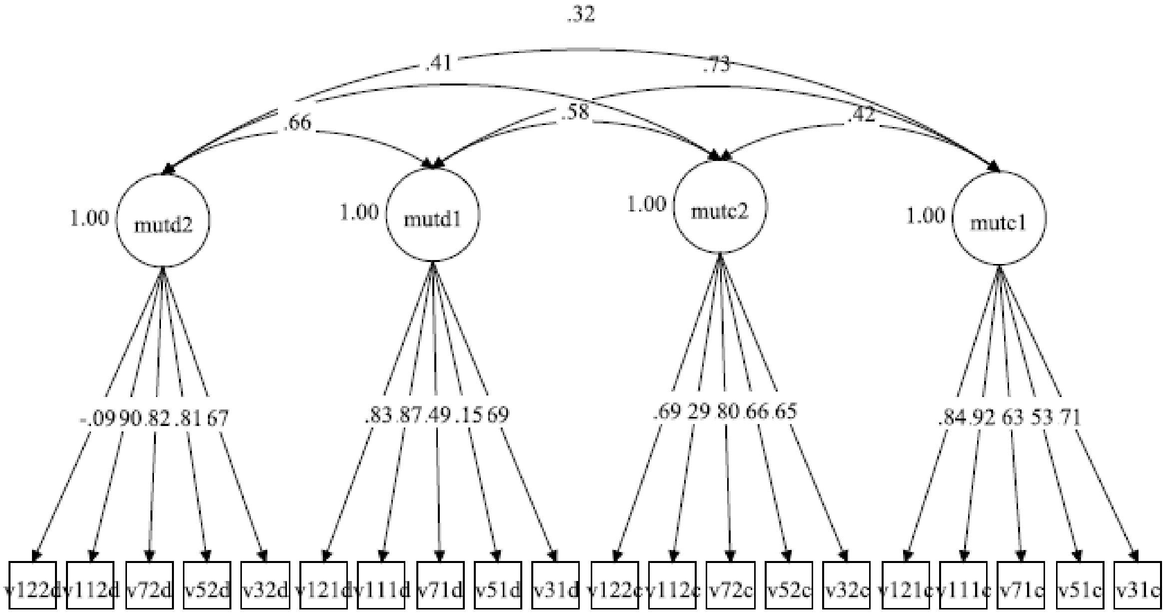
Table 34 shows the response frequencies (and proportions) among PLWD and their carers for data collected ‘in the moment’ via the InspireD app.

Table 34: Response frequencies (and proportions) among PLWD and their carers for data collected 'in the moment' (via computer)

Responses to each of 5 statements for those living with dementia (^{D}) and for those in a caring role(^{c})								
	First response occasion				Second response occasion			
	%	N	%	N	%	N	%	N
Response	Q3^{D}		Q3^{C}		V3^{D}		V3^{C}	
Not at all			5.6	1	6.2	1	11.1	1
A little	13.6	3	50.0	9	31.2	5	66.7	2
Some	22.7	5	44.4	8	56.2	9	22.2	3
Quite a bit	63.6	14			62.0	1		
A great deal								
	Q5^{D}		Q51^{C}		Q5^{D}		Q52^{C}	
Not at all	9.5	2	6.2		6.2	1	10.0	1
A little	4.8	1	6.2	1	6.2	1	10.0	1
Some	9.5	2	31.2	1	6.2	1	80.0	8
Quite a bit	28.6	6	56.2	5	31.2	5		
A great deal	47.6	10		9	50.0	8		
	V7^{D}		V71 ^{C}		V7^{D}		V72 ^{C}	
Not at all	25.0	4	12.5	2	10.0	1	8.3	1
A little	31.2	5	18.8	3	40.0	4	41.7	5
Some	43.8	7	31.2	5	50.0	5	50.0	6
Quite a bit			37.5	6				
A great deal								
	V11^{D}		V11^{C}		V11^{D}		V112^{C}	
Not at all	5.6	1	6.7	1	9.1	1	12.5	1
A little	11.1	2	20.0	3	9.1	1	12.5	1
Some	5.6	1	33.3	5	36.4	4	37.5	3
Quite a bit	44.4	8	40.0	6	45.5	5	37.5	3
A great deal	33.3	6						
	V12^{D}		V12^{C}		V12^{D}		V12^{C}	
Not at all	5.9	1	11.8	2	10.0	1	11.1	1
A little	5.9	1	35.3	6	40.0	4	22.2	2
Some	47.1	8	47.1	8	50.0	5	44.4	4
Quite a bit	41.2	7	5.9	1			22.2	2
A great deal								

The distribution of data is frequently skewed in a positive direction, implying that both the carer and the PLWD had strong feelings of mutuality towards one another. Because of the skewed nature of the data, it has been assumed that the data is ordinal in nature. A Bayesian estimator was used to estimate the respective factor models. In addition to providing more accurate model estimates, this approach allowed for missing data to be imputed at both the level of the observed and latent variables.

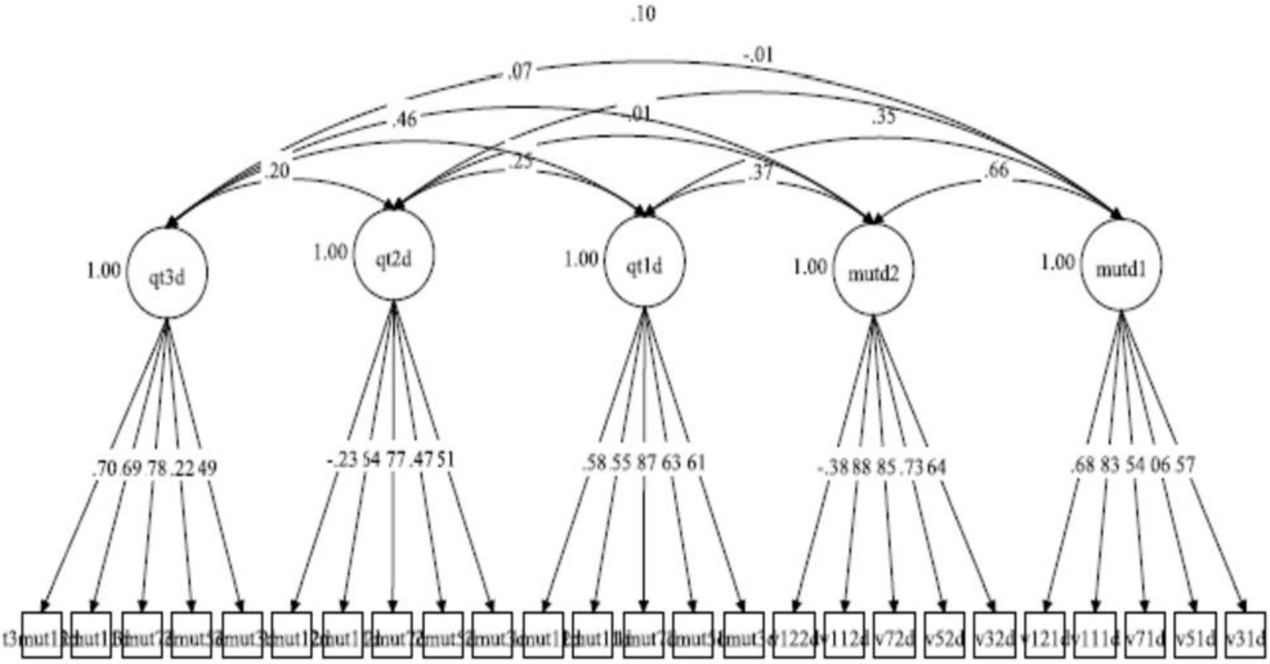
The relationship between the first and then the second presentation of the five Mutuality items as responded to separately by the carer and the PLWD is shown in Figure 25.



Note.
mutd2: factor representing mutuality at the second point in time (participant with dementia).
mutd1: factor representing mutuality at the first point in time (participant with dementia).
mutc2: factor representing mutuality at the second point in time (carers).
mutc1: factor representing mutuality at the first point in time (carers).

Figure 25: Factor loadings and the correlations between factors amongst PLWD and carers – 'in the moment data'

The five items of Mutuality presented on the first occasion are represented by the factor of mutd1 for PLWD and mutc1 for responses by the carer. With the exception of item five (How attached are you to him or her), where a low factor loading was obtained from the PLWD, all of the other items had reasonably good factor loadings. The correlation between these two factors was the highest in the current analysis (0.73). People living with dementia had the second highest correlation between response to the items on the first and second occasion (0.66). However, there was much more variability in terms of the factor loadings with only responses to questions 3 and 11 appearing to have been given a similar response. On the other hand, the correlation between carers to the same questions on two different occasions had greater similarity in terms of factor loadings. In measurement terms, this greater similarity is often referred to as metric invariance, and where formally applied is seen as indicating whether or not respondents on the different occasions have attributed the same meaning to the underlying latent construct (mutuality). The correlation between the mutuality factor for the responses to the questions on the first and second occasion was 0.43, indicating change in the rank ordering of responses in terms of the underlying factors (mutuality). When compared with the correlation between the two similar factors for PLWD where the correlation was 0.66, it would appear that PLWD kept a more consistent rank ordering in terms of the underlying factor.



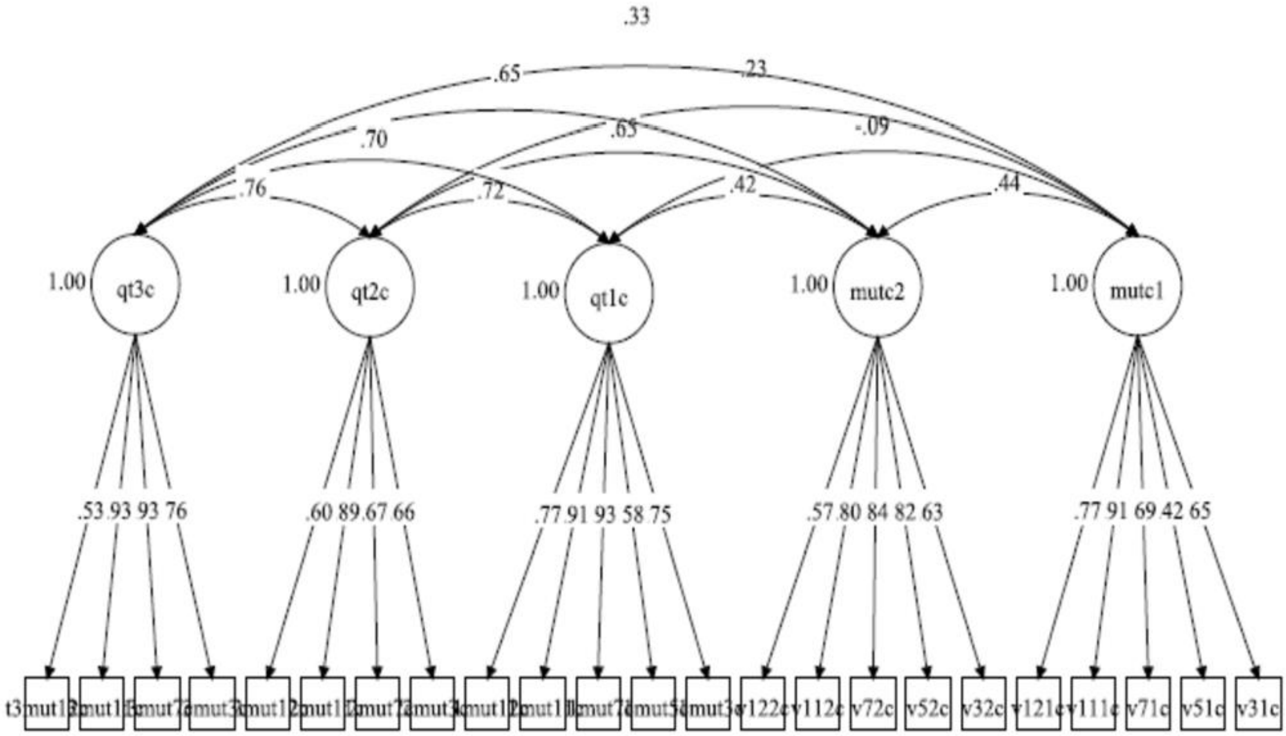
Note. q3td, qt2d and qt1d represent the factors of mutuality as measured on three occasions via pencil and paper.
mutd2 and mudt1 represent the factors of mutuality measured on two occasions via the computer (in the moment)

Figure 26: Factor loadings and the correlations between mutuality factors amongst PLWD

The five mutuality questions that were responded to in the Mutuality scale administered by the researchers at the three time points provided reasonably similar factor loadings (Figure

26). However, Question 12 on the second occasion had a factor loading that was in the reverse direction from what would have been expected. This also happened to the same question (12) when it was asked for the first time in the computerised presentation. An explanation for this may in part be down to the nature of the question (*How much do you confide in him or her?)* and its appropriateness in the context of relationships between people living with dementia and their carers. A general problem with both the questionnaire data and the computerised ITM questions is that the variability in responses to the various questions is small, as was also evident in the data shown in Table 34 (page 131).

More surprising are the relatively low correlations between the latent constructs of the five mutuality questions at the three points in time. The correlation between the first and second points in time was 0.2, while that between time points 2 and three was 0.25, and that between time one and three being 0.46. These seem rather low correlations for the association between measures of the same construct on three different occasions. One possible reason for this could be change between individuals in terms of how they are responding to the questions on the different occasions.



Note. q3td, qt2d and qt1d represent the factors of mutuality as measured on three occasions via pencil and paper.
mutd2 and mudt1 represent the factors of mutuality measured on two occasions via the computer (in the moment)

Figure 27: Factor loadings and the correlations between mutuality factors amongst the carers

In contrast to PLWD, it was evident that the correlations between the three measures of the ‘five’ item mutuality measure from the questionnaires (qtc1, qtc2, and qt3c) were high and the rank order of individual scores on the factors was reasonably stable (Figure 27). The correlation with the two factors representing mutuality in the ITM data (mutc2 and mutc1) are somewhat lower than that between the factors obtained from the pencil and paper presentation of the questions where they were reasonable high. The discrepancy is likely, in part, due to a potential method effect (questionnaire vs computer administered). However, one of the factor correlations is surprising (-0.09, qt2c and mutc1) and a ready explanation is not obvious, though we need to be mindful of the limited amount of data on which this analysis is based.

Another potential application with this momentary data is to examine change within individuals using various forms of autoregressive models (Table 35). These can be particularly useful for examining change over a substantial period of time, or where intensive information can be obtained over a shorter period of time. In the data shown below, the first column represents a particular response. The first three rows of this first column represent responses given by the same individual to the same questions on three different occasions. In the third column is the person's id and in the final column a number is used to designate whether the respondent was a PLWD or a carer. The expectation with such models is that data on any topic has been collected on many points in time, and in the present example the data has been restricted to only 3 occasions.

Table 35: Data structure for the analysis of change

4.00	1.00	7.00	1.00
3.00	1.00	7.00	1.00
4.00	1.00	7.00	1.00
4.00	2.00	17.00	1.00
4.00	2.00	17.00	1.00
4.00	2.00	17.00	1.00
………………………………..			
………………………………..			
………………………………..			
3.00	30.00	22.00	2.00
3.00	30.00	22.00	2.00
3.00	30.00	22.00	2.00

Nevertheless, for the purpose of exploration, a two-level time series analysis was undertaken with a univariate first-order autoregressive AR (1) model with both a random intercept and a random slope. In other words, the data were being described in terms of the previous response and where each individual could have a different level (intercept) roughly equivalent to a mean, though conditioned on the previous response. In addition, each person had the potential to change at a different rate across the period of time.

Table 36: Results for a fixed effects multilevel model for an analysis of both within and between groups

		Posterior	One-Tailed	95% C.I.		
	Estimate	S.D.	P-Value	Lower 2.5%	Upper 2.5%	Significance
Within Level						
F BY						
Y	1.000	0.000	0.000	1.000	1.000	
Residual Variances						
Y	0.130	0.087	0.000	0.009	0.344	*
F	0.089	0.083	0.000	0.002	0.302	*
Between Level						
S ON						
GROUP	0.538	0.814	0.237	-1.082	2.154	
Y ON						
GROUP	-0.118	0.388	0.368	-0.868	0.689	
Y WITH						
S	0.168	0.394	0.215	-0.454	1.086	
Intercepts						
Y	3.638	0.537	0.000	2.549	4.695	*
S	-0.722	1.152	0.253	-2.976	1.686	
Residual Variances						
Y	0.276	0.295	0.000	0.063	1.088	*
S	0.612	0.980	0.000	0.061	3.398	*

Given the limited amount of information available it is not surprising to learn that on average the mean (intercept) response was between the values 3 and 4 (3.64) on the five-point scale (Table 36). As previously pointed out, this lack of variability in the data is undesirable and other response scales should be considered. The slope (-0.72), if it were to be interpreted without the benefit of the p-value and confidence intervals, might possibly be seen as indicating a possible decrease in the level of mutuality. However, since this is likely to vary with each individual, a much more detailed analysis would be required to identify the varying profiles, but the principle underlying the information is evident. From the slope (0.54) it would appear that carers had a steeper slope over the periods in time, but of course, given the limited nature of the data, this can be little more than speculation. It might also be useful to qualify the slope in the light of the effect of the dyad (carer, PLWD) effect (-0.12), where it would appear that carers started out with an (on average) lower rating, so they had more room for change in a positive direction, given the limited range of scores (responses) being used.

Section 2: 'Pencil and Paper' Data Analysis and Results

Autoregressive models (simplex structures)

Direct effects

The model shown in Figure 28 provided a poor description of the data. An obvious modification would be to allow for a reciprocal relationship between the PLWD and the carer.

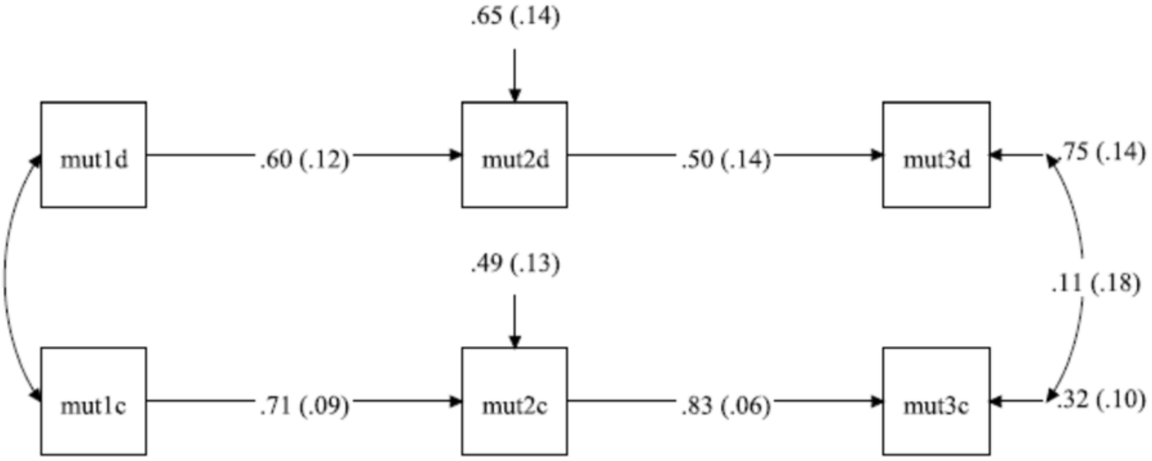


Figure 28: Causal effects model to represent the relationship between mutuality measures at 3 time points for PLWD and their carers

Cross-lagged relationships

The cross-lagged relationship was hypothesised to go in both directions, i.e., from the carer to the PLWD, and from the PLWD to the carer. This also did not provide an adequate description of the data. The measures were obtained some three months apart, so this is likely to have contributed to the poor model fit. This would be a perfectly plausible option if sufficient data had been available from the ITM data (Figure 29).

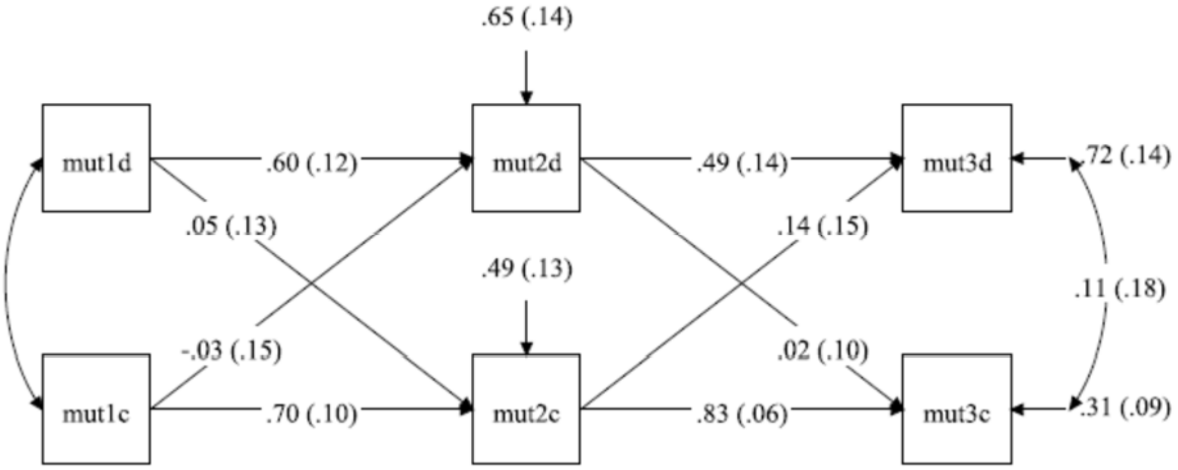
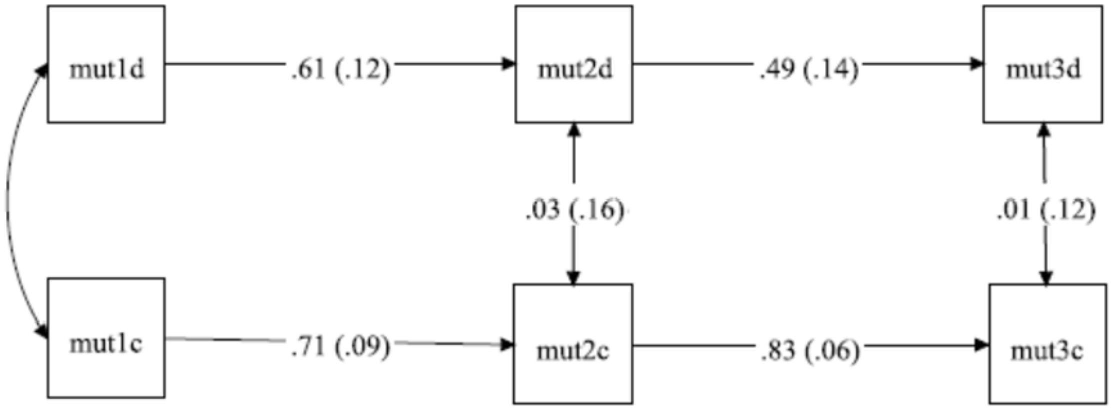


Figure 29: Cross-lagged model

The introduction of these reciprocal relationships did not help to describe the relationships any better (Figure30).



Note: the relationship between the carer and the PLWD at time two is shown as 0.03, and the reciprocal effect (not shown) is -0.08; neither of these were statistically significant. The respective effect sizes on the third occasion were 0.01 for the carer, and 0.17 for the PLWD. Again these results were not statistically significant at the 0.05 level. Residual effects have been removed for clarity.

Figure 30: Reciprocal relationships at time 2 and time 3

This model would imply that the data is to be explained by variables that have not been included in the model. However, this again failed to provide an adequate description for the data (Figure 31).

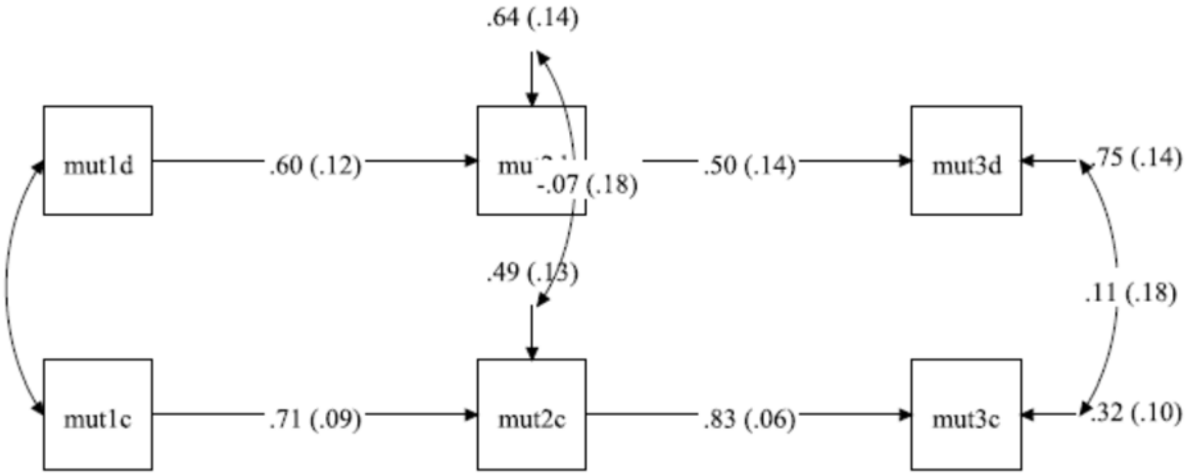


Figure 31: Correlated residuals

Empirically based modifications

At this stage a second look was taken at the first model, which was the model with the most degrees of freedom (simplest model), and an examination was made of empirically derived model modifications. In this analysis modifications above 3 were requested.

Table 37 Empirically based modifications for the first model (Direct effects, Figure 28)

```
Minimum M.I. value for printing the modification index     3.000
                                               M.I.     E.P.C.  Std E.P.C.  StdYX E.P.C.


ON Statements


(1)MUT2D    ON MUT3D                          5.133    -0.471      -0.471        -0.637
(2)MUT3D    ON MUT1D                          6.035     0.242       0.242         0.481
(3)MUT2C    ON MUT3C                          8.706    -1.061      -1.061        -0.938
(4)MUT3C    ON MUT1C                          9.023     0.326       0.326         0.437

WITH Statements


(5)MUT3D    WITH MUT2D                        6.035    -0.028      -0.028        -0.748
(6)MUT3C    WITH MUT2C                        9.023    -0.117      -0.117        -0.766
(7)MUT1D    WITH MUT3D                        4.723     0.058       0.058         0.461
(8)MUT1C    WITH MUT3C                       11.682     0.211       0.211         0.814
```

The results from the modification indices suggested 8 different options (Table 37). The first option (1) shown on the above table suggested that data from PLWD on the third occasion could have influenced scores at time two. Given the causal direction, this was not seen as a plausible option. By the same logic, option (3) would be rejected for the carers. Options (2) and (4) indicated that scores on the first occasion could have had an influence on scores on the third occasion. This relationship between scores on the first and third occasion are also represented in the seventh and eighth option in the above table, where the variance on the first occasion is related to the residual variance on the third occasion. This is an attractive option, given our current state of knowledge and the rather restricted sample, as it does not imply causation, but does imply that a source of variance is present on the first occasion and that this is related to the residual variance on the third occasion. This could be due to a source of variance from a common variable that had not been included within the analysis, or more likely that a subgroup of individuals had a greater correlation on these two occasions over and above that which can be explained by other parameters in the model. All previous models have allowed the residual variance on the final occasion for those in both groups to be correlated, implying that the sources of variance that could not be explained on these final occasions may be due to a common source. However, while this relationship has been kept, it should be noted that the correlation between these residual variances has not been statistically significant at the 0.05 level. This would indicate that there is little common variance shared between the final measure of mutuality in the two groups once the model has been conditioned on the previous occasions. In addition, the correlation between scores on the first measurement has been maintained. Figure 32 shows the final model used to describe the data with a series of correlated residual variances and a number of direct effects (standardised).

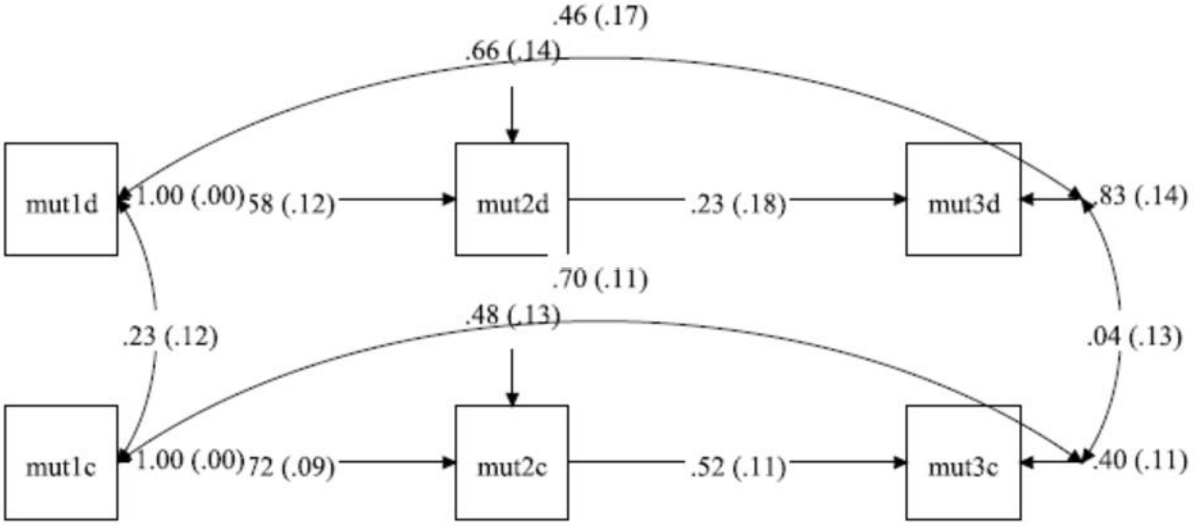


Figure 32: The final model used to describe the data with a series of correlated residual variances and a number of direct effects (standardised)

This model provided an adequate description of the data. An increase of 1 standard deviation in mutuality at time one had a 0.58 impact on mutuality on the second occasion amongst PLWD and a slightly stronger relationship amongst the carers (0.72). Both of these results are statistically significant at the 0.05 level. A value greater than 1.96 for the estimate divided by the standard error (shown in brackets) is statistically significant at the 0.05 level. The relationship between mutuality on the second and third occasion was not statistically significant (0.05 level) for PLWD. Amongst the carers, a reasonably strong direct association was present from the time two measure of mutuality to the third measure of mutuality.

The correlated residual of scores on the first occasion with scores on mutuality at the third occasion for PLWD indicated a statistically significant relationship (0.46), and this relationship was stronger amongst the carer group. As with all of the previous models, the correlation between the residual variances on the final occasion was not statistically significant, indicating that there was no common source of variance that was not explained by the model. The correlation between mutuality on the first occasion was relatively weak across all of the models, and again failed at the 0.05 level.

Table 38: Model fit information for five different representations of mutuality at three points in time, using the pencil and paper data

First-order non-stationary autoregressive models	Chi-square	RMSEA	CFI	TLI	SRMR
(1) Direct effects (Figure 28)	22.43 Df=9 pr=0.01	0.22 CI: 0.11 0.34	0.85	0.76	0.09
(2) Cross-lagged (Figure 29)	21.395 Df = 5 Pr = 0.00	0.331 CI: 0.20 0.48	0.81	0.47	0.07
(3) Reciprocal relationships (Figure 30)	21.411 df = 6 Pr = 0.00	0.293 CI: 0.17 0.43	0.82	0.59	0.07
(4) Correlated residual T2 (Figure 31)	22.306 df = 8 Pr = 0.01	0.244 CI: 0.13 0.37	0.84	0.71	0.09
(5) Correlated residuals T1 –T3 (Figure 32)	3.40 df = 7 Pr = 0.85	0.000 CI: 0.00 0.13	1.00	1.08	0.09

The fit-statistics indicate that models which predicted a statistical relationship between PLWD and their carers generally provided a poor description of the data. This was true of the first 4 models, where different types of cross group relationships were introduced, thus indicating that responses from the carers and the PLWD were relatively independent. This lack of statistical relationship between responses from PLWD and their respective carers may in part be down to the inconsistent pattern of responding amongst PLWD. In our analysis, where ITM data was used to examine the factor structure of a five item measure of mutuality, it was apparent that individuals living with dementia had a greater pattern of inconsistency in responses on the two occasions that were used. In Table 38, it is evident that the correlations between the three measures of the pencil and paper test were much lower amongst PLWD when compared with the results for the carers.

Given the limited sample of respondents used in this feasibility study, no measurement constraints were placed across the measurement properties of the factor model on each of the three occasions for the responses to the pencil and paper data, nor was this done to the 'in the moment' data collected on two occasions. However, it is evident that a number of the factor loadings from factors using both data collection strategies do not appear to be invariant across the different data collection points for PLWD. This has also been replicated in the first- order autoregressive models, where the relationship between responses on the second and third occasion, for PLWD was not statistically related at the 0.05 level.

Summary

Data were collected 'in the moment' via the InspireD app on a subset (5 items) of the primary outcome measure, the Mutuality scale. The complete 15-item Mutuality scale was administered to participants at three different time points (baseline, mid-point, and at the end of the study) was used as comparison data. Only one ITM question was presented during each log-in period. The underlying factor structures of the 5-item Mutuality construct were examined for both the 'in the moment' (via the InspireD app) and via pencil and paper method. The data from the pencil and paper tests produced better quality information in terms of the factor structures. The 'in the moment' data did produce the same underlying construct, but there was greater variability in the factor loadings and the correlations between the data from different occasions were much lower. The effective use of time series statistical analysis for the ‘in the moment’ data was limited, due to technical problems that arose during the recording of the data.

With the pencil and paper data, on 3 occasions, it was apparent that PLWD were less consistent in their pattern of responding to the five questions, hence reducing the association between measures on different occasions. Reciprocal effects that might have been expected to indicate a statistically significant association between the PLWD and the carer were not evident in the autoregressive models (simplex models), thus indicating the relative independence in terms of responses to this set of mutuality measures. It is to be expected that this will not be the case where emotionally loaded items are being responded to by individual participants in a dyad relationship. In other words, no relationship was shown between the responses to the items of mutuality, in terms of this model. This may in part be due to a lack of a similar pattern of responding to the items, but it may also be due to the lack of consistency in responses from those in the PLWD group.

It is also apparent, as evidenced by the ITM data, that certain items were not performing as expected; for example, a number of poor factor loadings were recorded using different methods of data collection. This issue of the reliability and validity of measures for PLWD requires further exploration.

Chapter 8 - Phase 2:

Part 4

Health Economics

Analysis and Results

Introduction

One of the key aims of the study was to incorporate a health economic component to inform the design of a potential future cost-effectiveness analysis to be carried out alongside a randomised controlled trial (RCT). This chapter provides details of data collection, analysis and results for the final part of Phase 2 of our study. A number of objectives for the health economic component were identified as follows:

- To measure and cost the resource use associated with the delivery of the intervention.
- To measure and cost health service use and unpaid carer support prior to and during the intervention.
- To measure the health–related quality of life (HRQoL) of people with dementia and their carers.
- To pilot the proposed intervention-related resource use, health service use and HRQoL instruments and assess the feasibility of incorporating them into a future RCT.

Basic overview of costing and quality of life methodology

The health economic aspect of the study involved three key components: measurement of the costs associated with the delivery of the intervention; measurement of the costs associated with health and social care service use and unpaid carer support; and measurement of health-related quality of life.

In a full health economic evaluation, a cost-effectiveness analysis or cost-utility analysis is carried out, often alongside a RCT. Costs (associated with the intervention) and health-related quality of life are assessed among the control group and intervention group. The key outcome measure, the incremental cost-effectiveness ratio (ICER) is calculated, which indicates the incremental costs associated with the intervention per incremental health effects gained:

$$\boxed{\frac{(\mathrm{Cost}_{new} - \mathrm{Cost}_{old})}{(\mathrm{Effectiveness}_{new} - \mathrm{Effectiveness}_{old})} = \mathbf{ICER}}$$

$$\mathbf{ICER = \Delta C \ / \ \Delta E}$$

So for example, if a full economic evaluation was carried out alongside an RCT based on the current reminiscence intervention, the ICER would indicate the additional costs (both direct and indirect) associated with the intervention, per additional quality adjusted life years (QALYs) gained. A full description of QALYs will be given in subsequent sections.

In terms of the costing element of health economic evaluations, there are three main steps to cost estimation: firstly, the key resources associated with the intervention must be identified. These may be resources directly associated with the delivery of the intervention or other indirect resources that are likely to be affected (e.g. health service use); secondly, the units of these resources are measured. For example, the number of GPs visits made within a certain period are measured. The third step is valuation of resources used or assignment of unit costs. Again, taking the example of GP visits, the unit cost of a GP visit is identified and multiplied with the number of GP visits to obtain an estimate of the full economic cost.

Health-related quality of life is the most commonly used indicator of health effects in economic evaluations. The QALY is a generic measure of health-related quality of life or disease burden, which incorporates both the quality and the quantity of life lived. The National Institute for Health and Care Excellence (NICE) recommends that outcomes or health benefits associated with new technologies or interventions are measured in QALYs in health economic evaluations (NICE, 2013). The current study piloted the use of two instruments that can be used to derive preference based weightings/indices used to calculate QALYs gained from an intervention, the Euroqol EQ-5D (Group EQ: EuroQol, 1990; Dolan, 1997) and the DemQoL (Rowen et al. 2012).

Instruments

Client Socio-demographic and Service Receipt Inventory

An adapted version of the Client Service Receipt Inventory (CSRI) (Beecham and Knapp, 1992; Chisholm et al. 2000) was developed for use in dementia studies. This was pilot tested by a carer with suggested changes incorporated into the final version and approved by the Northern Ireland Clinical Trails Unit. This was used to identify and measure the units of health and social care resources used in relation to the reminiscence intervention pertaining to this study (Appendix 18). The CSRI, which has been widely used in studies of mental health and dementia, collects service use data in a standardised way that best facilitates the estimation of component and total costs for each individual. The instrument includes detailed questions across a number of broad categories, including socio-demographic information, accommodation, community health and social care services, hospital services, medication and carer support. The researchers administered the CSRI to both PLWD and their carers at two time points, T0 and T2 and questions relating to service use covered a three-month recall period. For example, the question relating to the use of community health and social care services was posed as follows: *'In the last 3 months, has the study participant used any of the services below?'* The researcher then asked participants about their use of a range of services in the last 3 months including number of visits and average duration of visit.

The hospital services section asked about inpatient, outpatient, accident and emergency and day hospital attendances over the previous three months and elicited information on reason for attendance/inpatient procedure and duration of stay, where appropriate. The medication section elicited detailed information on prescription medications including specific medication preparation name, dosage, presentation and frequency of dosage. In the unpaid carer support section of the CSRI, the carer was asked about the nature of their caregiving duties and the number of hours of caregiving support provided on a daily/weekly basis.

Euro-qol EQ-5D

The Euro-qol EQ-5D (Group EQ: EuroQol, 1990) was administered to both PLWD and their carers at T0, T1 and T2. The EQ-5D is a standardised instrument for measuring generic health status (Appendix 19). It comprises 5 domains: mobility, self-care, usual activities, pain and discomfort, and anxiety and depression. Participants are asked to self-rate their level of difficulty for each dimension on a three-point scale with 1 indicating no problems and 3 indicating severe problems. The health status of each individual can then be described by a 5-digit profile, ranging from 11111 (no problems in any of the health dimensions) to 33333 (severe problems in all health dimensions). A total of 243 health states are possible based on response profiles. These profiles can subsequently be used to estimate a preference weight/utility score for that health status (with indices ranging from 0-1), which can further be used in the computation of QALYs to facilitate cost-effectiveness analysis.

DEMQOL and DEMQOL Proxy

Quality of life of PLWD was also measured at T0, T1 and T2 using the DEMQOL, which is a dementia-specific measure of health-related quality of life with robust psychometric properties (Smith et al. 2005). DEMQOL consists of two interviewer-administered instruments, one completed with the person living with dementia and a proxy report of the person living with dementia's quality of life completed by the main carer (Appendix 16 and 17). The instruments consist of 29 and 32 questions respectively across the following broad themes: feelings, memory, everyday life and overall quality of life. Participants were asked to provide responses to questions on a four-point scale ranging from a lot to not at all (and very good to poor for the final quality of life question). Smith et al. (2007) highlight that DEMQOL demonstrates high reliability through both internal consistency and test-retest, and moderate validity in people living with mild/moderate dementia.

Data Sources for Costing Information

Personal Social Services Research Unit

Estimates of the unit costs of the services described were extracted from the Unit Costs of Health and Social Care 2016 (Curtis and Burns, 2016). This is an annual publication produced by the Personal Social Services Research Unit (PSSRU), which provides the most up to date information on the costs of services in the health and social care sector in the UK. This publication was used to extract information on the unit costs of all the community health and social care services assessed using the CSRI, except for a number of services which were costed based on national minimum wage rates and NHS salary scales. Unit cost information provided by the PSSRU includes full economic costs. For example, the unit cost of GP services includes net remuneration, direct staff, administrative and clerical staff, office and general business, qualifications and capital costs, and is based on average GP working time. Full details of unit costs and cost components can be found at: http://www.pssru.ac.uk/project-pages/unit-costs/2016/ and a table of unit costs applied in the current study is presented in Appendix 20

Prescription Cost Analysis Data: Northern Ireland

Estimates of the unit costs of prescribed medications reported in the study were obtained from Prescription Cost Analysis (PCA) Northern Ireland 2015 (Health and Social Care Business Services Organisation, 2015). The PCA provides detailed information on every single individual medication preparation administered in Northern Ireland as well as the cost of these individual preparations/prescriptions based on the average pack size. PCA differentiates between costs of medication types based on different dosages and presentations. For example, for Omeprazole there are nine potential unit costs, depending on the dosage (10, 20 or 40mg) and presentation (tablet, capsule or dispersible tablet). Detailed PCA spreadsheets can be obtained from: http://www.hscbusiness.hscni.net/services/1806.htm. A full list of medication types reported in the current study and their associated unit costs is presented in Appendix 21.

National Reference Costs

Unit costs of hospital services were obtained from National Reference Costs 2015/16. National Reference costs have been collected annually by the Department of Health since 1997 and present the average unit cost to the NHS of providing defined services to NHS patients in England. In relation to the current study, National Reference Costs were used to determine the average cost of an inpatient procedure, an outpatient stay, an A&E visit and a Day Hospital case. In addition, more detailed unit cost spreadsheets are available indicating the cost of specific treatment/procedures, taking into account the length of stay among other key variables. These very specific costs were applied in the current study, where sufficient detail on the service received was provided. In other cases, average unit costs were applied. More information on National Reference Costs and access to unit cost spreadsheets can be found at: https://www.gov.uk/government/publications/nhs-reference-costs-2015-to-2016. A full list of unit costs applied to hospital services in the current study is presented in Appendix 22.

Methods of Analysis

Costs Associated with the Intervention

Training costs associated with the intervention, including the costs of staff who facilitated workshops, IT training and Reminiscence training were estimated based on hours of training and associated salary information. In addition, carer time in training sessions was also estimated using the 'replacement cost' methodology, which is described in further detail in subsequent paragraphs. Costs of equipment associated with the intervention, specifically, the cost of tablet devices was based on the purchase cost of 30 tablet devices, while software development costs were based on salary information and hours of time devoted by the software developer. The costs of travel by facilitators and carers to workshops and training sessions was estimated at 40p per mile.

Estimating Economic Costs of Service Use

In the current study, the costs of community health and social care services, hospital services, medication use and unpaid carer support was estimated in the three months prior to T0 and T2. At a very basic level, estimation of these costs involved multiplying the units of resources/services used by the relevant unit cost.

In relation to community health and social care costs, participants indicated the number of visits by the PLWD to each service provider in the previous 3 months, and where relevant, the average duration of these visits. This allowed the estimation of the total number of visits to/by each service provider and, where possible, the total number of minutes. For each participant at each time point, the costs of each service was calculated by multiplying the number of visits/minutes by the relevant unit cost. Total community health and social care costs at T0 and T2 were obtained by adding the costs of all services.

The costs of hospital services for each PLWD were also estimated by multiplying the number of visits/attendances by the relevant unit cost (average unit costs or more specific unit costs where possible). The total costs of hospital services at T0 and T2 were estimated by adding the costs of inpatient, outpatient, A&E and day hospital visits.

The estimation of medication costs was slightly more complicated. The unit costs of medication types provided in PCA data are based on the 'average prescription/pack size' for each individual preparation. It was, therefore, necessary to calculate the number of 'average pack sizes' used by each individual for each preparation within the three-month period prior to T0 and T2. As indicated previously, the CSRI elicited information on medication, which included the name of the individual preparation, presentation, dosage and dosage frequency. Based on this information, it was therefore possible to calculate the total number of prescription items for each preparation taken in a three-month period, and in turn the number of 'average pack sizes' used. The number of average packs used for each preparation was then multiplied by the relevant unit costs. The total costs of medication for each individual was estimated as the sum of all medication used over a three-month period and total costs of all medications estimated as the sum of all individual medication costs.

The costs of unpaid carer support were estimated using the 'Replacement Cost Approach', which involves the calculation of the potential cost of replacing informal caregivers' contribution by professional services, for example, the costs of domiciliary services could be used to value informal care time (Busschbach et al. 1998). In the current study, the replacement costs were assumed to be equivalent to the unit costs of a 'home care worker' (£24 per hour, see Community Health and Social Care Costs in Appendix 1). Costs of unpaid carer support over a 3-month period were estimated by multiplying the total number of hours of support by this replacement unit cost.

Estimating Health Related Quality of Life Preference Indices

Health-related quality of life of PLWD and their caregivers was assessed at T0, T1 and T2 using the EQ-5D (participants and carers quality of life) and DEMQOL (participants' quality of life). Both these instruments were used to derive a single index value for health status.

For the EQ-5D, this single index was estimated by applying preference-based utility weightings to each response level for each individual across the five dimensions assessed in the instrument. This single index was then used to calculate QALYs for use in cost-effectiveness analysis of interventions. In the current study, preference based weightings for the EQ-5D were assigned based on the ‘UK Value Set’ previously published response weightings based on a representative study of the UK population (Dolan, 1997).

Estimation of preference-based indices from the DEMQOL and DEMQOL proxy was conducted by applying scoring algorithms developed by Rowen and colleagues (Rowen et al. 2012). For the PLWD, these algorithms derive five dimensions of quality of life from the 29 item scale (positive emotion, memory, relationships, negative emotion and loneliness). Four dimensions are derived from the 32 item DEMQOL Proxy (positive emotion, memory, appearance and negative emotions). Weightings associated with response levels were applied based on a published UK preference weights (Rowen et al. 2012).

Presentation of results

The results presented in relation to the health economic element of our study are largely descriptive. Frequencies are presented summarising the units of resources used and mean and total costs for each costing element. In relation to health related quality of life, frequency of response levels and mean health related quality of life index scores are presented. All data manipulation, recoding and analyses were conducted using SPSS version 23.

Results

Costs Associated with the Intervention

Table 39 summarises the costs directly associated with the implementation of the reminiscence intervention. The overall costs associated with the intervention were £77,112, with the largest proportion accounted for by training costs (£41,032), followed by software development (£26,160).

Table 39: Costs Associated with the Reminiscence Intervention

Activity/Cost Element	**Costs (£)**
Training: IT Trainer Costs Reminiscence Training Network Carer Training Time **Total Training Costs**	 £20,441 £14,975 £5,616 (total of 234 hours) **£41,032**
Equipment	£7,864
Software Development	£26,160
Travel	£2,055.60 (4,568 miles)
Total Intervention Costs	**£77,112**

Community Health and Social Care Service Usage and Costs

Table 40 summarises the use of community health and social care services over three months at T0 and T2. As previously described, information on service usage was elicited from the following question in the adapted CSRI:

'In the last 3 months, has the study participant used any of the services below?'

Participants were presented with a list of 24 community health and social care services. Individuals who reported service usage were also asked additional questions in relation to number of visits and visit duration (where relevant).

All 30 PLWD at T0 and all 29 PLWD at T2 reported some type of community health and social care service usage in the previous 3 months. As expected, the GP was the most frequently used service in terms of the number of participants using the service and the total number of visits. There was also a high level of occupational therapy (OT) service usage at T0. However, given that occupational therapists were used in the recruitment of participants to the study, this figure and the comparison with the T2 figure should be interpreted with caution. Other services that were used by a substantial proportion of participants were Practice Nurse, Psychiatrist, Optician and Chiropodist. In terms of total number of visits, Home Help services (although used by a small number of individuals) were most frequently used at both time points. These high figures reflect high frequency of visits that were short in duration. This was followed by GP services, which were used 75 and 51 times in total at T0 and T2 respectively.

Table 40: Community Health and Social Care Service Use in Previous 3 Months (T0 and T2)

Community Health and Social Care Service	**No. Participants who used service T0 (N=30)**	**Total number of visits T0**	**No. Participants who used service T2 (N=29)**	**Total number of visits T2**
General Practitioner	25	75	23	51
Practice Nurse	16	27	13	18
Community/District Nurse	4	7	0	0
Mental Health Nurse	8	19	4	6
Psychiatrist	10	11	6	6
Social Worker	6	9	5	9
Psychologist	0	0	0	0
Physiotherapist	4	16	1	12
Occupational Therapist	17	74	1	1
Dietician	2	2	3	3
Counsellor	0	0	0	0
Mental Health Team Worker	4	15	0	0
Specialist Nurse	1	1	4	4
Home Help	4	342	3	300
Cleaner	2	24	3	30
Meals on Wheels	0	0	0	0
Laundry	0	0	0	0
Sitting Service	0	0	0	0
Carer Support Worker	0	0	1	2
Optician	7	8	13	14
Chiropodist	12	16	8	10
Dentist	7	8	6	6
Other	1	13	3	19
Any Community Health and Social Care Service	***30***	***667***	***29***	***491***

Table 41 presents a summary of the full economic costs of community health and social care service usage during the previous 3-months at T0. Total costs of all service use was £9,155.51, while the average cost was £305.18 per participant. GP services represented the highest cost with total costs of £3491.57 for all participants and an average cost of £116.39 per participant. Home help services accounted for the next highest cost component followed by dentist and psychiatrist services. Given that Occupational Therapists were used in the recruitment of participants to the study, costs relating to OT service usage have been omitted at both T0 and T2.

Table 41: Community Health and Social Care Costs Over previous 3 months T0

Community Health and Social Care Service	**Minimum**	**Maximum**	**Total cost**	**Mean**	**Std. Deviation**
General Practitioner	.00	432.00	3491.57	116.38	110.08
Practice Nurse	.00	32.25	200.67	6.69	8.76
Community/District Nurse	.00	26.67	63.33	2.11	5.97
Mental Health Nurse	.00	220.00	535.33	17.84	44.95
Psychiatrist	.00	276.00	839.50	27.98	61.28
Social Worker	.00	79.00	269.92	9.00	21.49
Psychologist	.00	.00	.00	0.00	0.00
Physiotherapist	.00	64.00	173.33	5.78	16.12
Dietician	.00	22.00	33.00	1.10	4.43
Counsellor	.00	.00	.00	0.00	0.00
Mental Health Team Worker	.00	129.00	186.33	6.21	24.08
Specialist Nurse	.00	11.00	11.00	0.37	2.01
Home Help	.00	540.00	1380.00	46.00	143.24
Cleaner	.00	43.20	86.40	2.88	10.96
Meals on Wheels	.00	.00	.00	0.00	0.00
Laundry	.00	.00	.00	0.00	0.00
Sitting Service	.00	.00	.00	0.00	0.00
Carer Support Worker	.00	.00	.00	0.00	0.00
Optician	.00	34.70	138.80	4.63	9.04
Chiropodist	.00	96.00	512.00	17.07	24.83
Dentist	.00	242.00	968.00	32.27	63.02
Other	.00	277.33	277.33	9.24	50.63
Any Community Health and Social Care Service	***0.00***	***774.67***	***9155.51***	***305.18***	***210.76***

Table 42 presents a similar summary of the full economic costs of community health and social care service usage during the previous 3-months at T2. Total costs of all service use was £7,791.58, while the average cost was £268.68 per participant. GP services again represented the highest cost with total costs of £2,520.00 for all participants and an average cost of £86.90 per participant. Home help services accounted for the next highest cost component followed by dentist and psychiatrist services.

Table 42: Total Community Health and Social Care Costs Over previous 3 months T2

Community Health and Social Care Service	Minimum	Maximum	Sum	Mean	Std. Deviation
General Practitioner	.00	324.00	2520.00	86.90	77.88
Practice Nurse	.00	43.00	189.92	6.55	10.45
Community/District Nurse	.00	.00	.00	0.00	0.00
Mental Health Nurse	.00	88.00	220.00	7.59	21.42
Psychiatrist	.00	103.50	448.50	15.47	31.98
Social Worker	.00	118.50	342.33	11.80	29.72
Psychologist	.00	.00	.00	0.00	0.00
Physiotherapist	.00	96.00	96.00	3.31	17.83
Dietician	.00	22.00	55.00	1.90	5.93
Counsellor	.00	.00	.00	0.00	0.00
Mental Health Team Worker	.00	.00	.00	0.00	0.00
Specialist Nurse	.00	22.00	73.33	2.53	6.58
Home Help	.00	1008.00	1968.00	67.86	224.96
Cleaner	.00	172.80	237.60	8.19	32.87
Meals on Wheels	.00	.00	.00	0.00	0.00
Laundry	.00	.00	.00	0.00	0.00
Sitting Service	.00	.00	.00	0.00	0.00
Carer Support Worker	.00	104.00	104.00	3.59	19.31
Optician	.00	34.70	242.90	8.38	9.97
Chiropodist	.00	96.00	320.00	11.03	21.43
Dentist	.00	121.00	726.00	25.03	49.88
Other	.00	144.00	248.00	8.55	29.77
Any Community Health and Social Care Service	***.00***	***1268.50***	***7791.58***	***268.68***	***261.66***

Figures 33 is a comparison of the average costs of each community health and social care service at T0 and T2. Costs of GP services were notably lower at T2 compared to T0. Average costs of mental health nurse, psychiatrist, chiropodist and dentist services were also lower at T2. IN contrast, the costs of home help services were notably higher at T2.

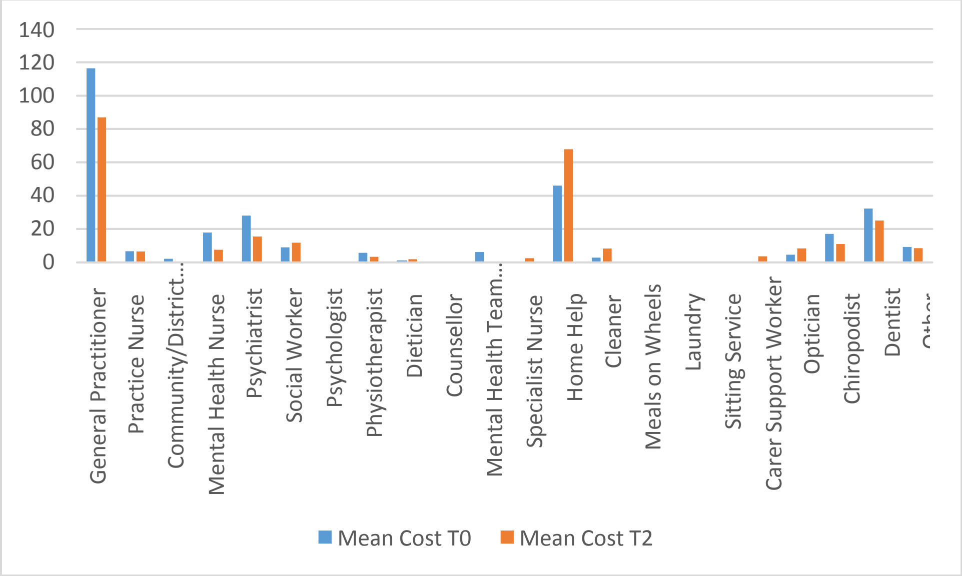


Figure 33: Comparison of Average Community Health and Social Care Costs T0 and T2

Hospital Service Usage and Costs

Table 43 provides details of hospital service usage during the previous 3 months at T0 and T2. Ten participants reported use of hospital services at T0 while nine participants reported hospital service at T2. Three participants reported using inpatient services at T0 while four reported usage at T2. The total number of inpatient days at T0 was 12 compared to 42 at T2. Similar outpatient service use was reported at T0 and T2. Six participants visited A&E in the three months before T0, while no participants reported A& E visits at T2. Six participants reported day hospital service usage at T0 and three at T2.

Table 43: Hospital Service Use over the Previous 3 Months T0 and T2

Hospital service	No. Participants who used service T0 (N=30)	Total number of days/visits T0	No. Participants who used service T2 (N=29)	Total number of visits T2
Inpatient	3	12*	4	42*
Outpatient	4	6	4	6
Accident and Emergency	6	7	0	0
Day Hospital	6	1	3	4
Any Hospital Service	10		9	

*represents days

A summary of the costs of hospital services used by participants in the three months before T0 is presented in Table 44. The total cost of hospital services use was £20,107.55, while the average cost per participant was £670.25. Inpatient services accounted for the highest proportion of the overall cost with overall costs of £17,674.00.

Table 44: Hospital Service Costs Over Previous 3 months T0

Hospital Service	Minimum	Maximum	Total Costs (£)	Mean (£)	Std. Deviation
Inpatient	.00	10,176.00	17,674.00	589.1333	2,044.74630
Outpatient	.00	308.49	727.55	24.2517	65.40462
Accident and Emergency	.00	278.00	973.00	32.4333	70.05696
Day Hospital	.00	733.00	733.00	24.4333	133.82688
Total Hospital Costs	.00	10,176.00	20,107.55	670.2517	2,053.92586

A similar summary of the 3-month costs of hospital services used by participants in the three months before T2 is presented in Table 45. The total costs of all hospital services used was

£28,096.36, while the average cost per participant was £968.84. Inpatient services again accounted for the highest proportion of the overall cost with total costs of £23,607.00.

Table 45: Hospital Service Costs Over Previous 3 months T2

Hospital Service	Minimum	Maximum	Total Costs	Mean	Std. Deviation
Inpatient	.00	10,616.00	23,607.00	814.0345	2,370.13475
Outpatient	.00	266.02	824.36	28.4262	75.49171
Accident and Emergency	.00	.00	.00	.00	.00
Day Hospital	.00	1,466.00	3,665.00	126.3793	395.16818
Total Hospital Costs	.00	10,616.00	28,096.36	968.8400	2,360.12201

Figures 34 compares average hospital costs at T0 and T2. Average inpatient costs were greater in the three months before T2, while A&E costs were higher at T0. Interpretation should however reflect the small numbers reporting each of the hospital related services.

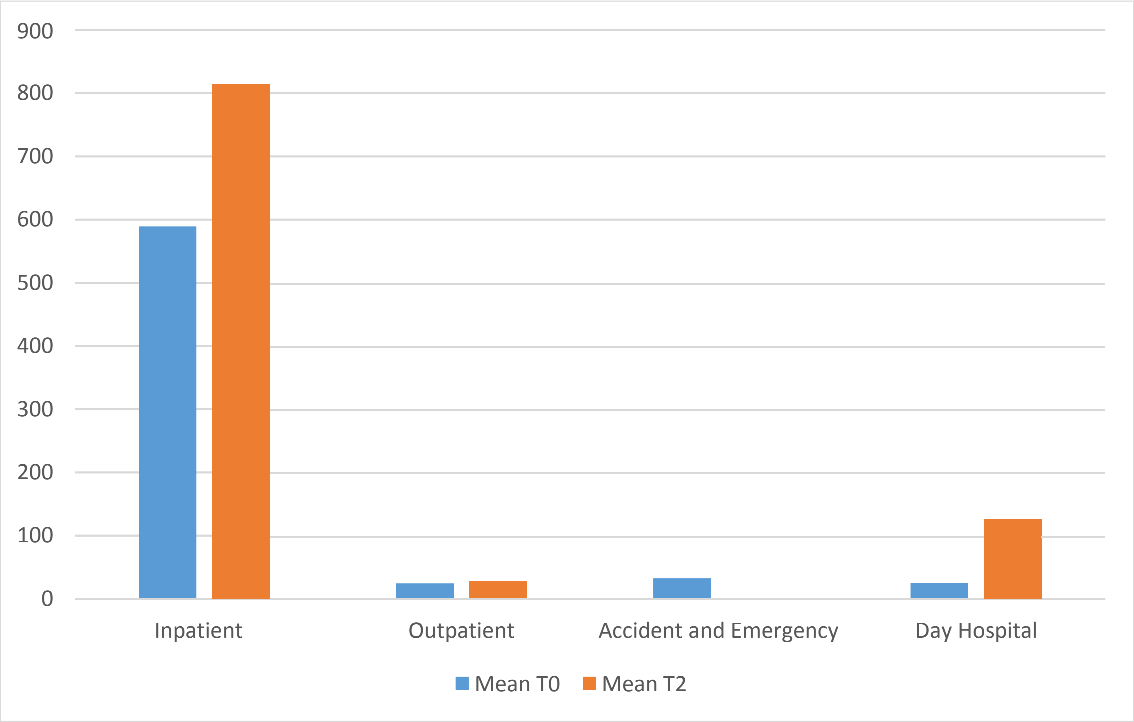


Figure 34: Comparison of Average Hospital Costs T0 and T2

Prescribed Medication Use and Costs

Tables 46 and 47 summarise the number of different prescription medication types/preparations used by participants in the three months before T0 (Table 46) and T2 (Table 47). All participants reported use of prescription medication at both T0 and T2 and the majority of participants used multiple medication types. For example, 11 and 9 participants reported use of seven different medication types in the three months prior to T0 and T2 respectively.

Table 46: Number of Prescription Medication Types used in the 3 months prior to T0.

No. Medication Types	**No. Participants (N=30)**	**%**
1	3	10.0
2	1	3.3
4	4	13.3
6	1	3.3
7	11	36.7
8	1	3.3
9	4	13.3
10	1	3.3
11	2	6.7
12	1	3.3
15	1	3.3
Any Prescription Medication	***30***	***100***

Table 47: Number of Prescription Medication Types used in the 3 months prior to T2.

No. Medication Types	**No. Participants (N=29)**	**%**
1	3	10.3
2	1	3.4
3	1	3.4
4	1	3.4
5	2	6.9
6	2	6.9
7	9	31.0
8	1	3.4
9	3	10.3
10	1	3.4
11	1	3.4
12	3	10.3
15	1	3.4
Any Prescription Medication	***29***	***100***

The 3-month costs of prescription medication at T0 and T2 are summarised in Table 48. The cost profile appears similar at both time points. Total costs were £6,817.41 at T0 and £6,770.59 at T3, while mean costs per participant were £227.25 and £233.47 respectively.

Table 48: Medication Costs Over previous 3 months T0 and T2

	N	Minimum	Maximum	Total Costs	Mean	Std. Deviation
Medication Costs T0	30	3.90	1494.53	6817.41	227.2469	302.38664
Medication Costs T2	29	3.90	1494.53	6770.59	233.4686	308.88315

Unpaid Carer Support

At T0 and T2, both 'co-habiting' and 'non co-habiting' carers were asked about the number of hours they devoted to supporting the PLWD on a daily/weekly basis. At T0, 22 carers lived with the PLWD while 8 lived elsewhere. The corresponding figures for T2 were 23 and 6 respectively. Table 49 summarises the hours of unpaid carer support and associated economic costs of unpaid support based on the 'replacement method' described earlier. At T0 the average number of unpaid carer hours of support was 1,188.53 over the previous 3 months, with a total of 35,656 hours of support from all 30 carers over this time period. The corresponding average and total costs of this support was estimated to be £28,524.80 and £855,744.00 respectively.

At T2 the average number of carer support hours was higher at 1,331.90, with a total of 38,625 hours from all 29 carers over the previous 3-month period. Associated economic costs of carer support at T2 were therefore higher, with an average cost of £31,965.52 and total costs of £927,000.00. Differences in carer support hours and costs at T0 and T2 and potential contributing factors will be considered in the discussion section.

Table 49: Unpaid Carer Support and Associated 'Replacement Costs' at T0 and T2

	N	Minimum	Maximum	Sum	Mean	Std. Deviation
TotalCarer_hrs_3mths_T0	30	26.00	1890.00	35656.00	1188.5333	758.98093
TotalCarer_hrs_3mths_T2	29	39.00	2160.00	38625.00	1331.8966	734.62465
TotalCarer_costs_3mths_T0	30	624.00	45360.00	855744.00	28524.8000	18215.54230
TotalCarer_costs_3mths_T2	29	936.00	51840.00	927000.00	31965.5172	17630.99169

Health Related Quality of Life

Findings from the EQ5D for participants with dementia

As previously outlined, health-related quality of life was assessed using the Euro-qol EQ-5D instrument for both carers and PLWD at T0, T1 and T2. To recap, the EQ-5D has five dimensions with three response levels for each dimension. Response profiles can be used to estimate preference based utility weights for the indicated health status. These weights may then be combined with time (e.g. resulting from an intervention) to produce quality adjusted life years (QALYs), which are recognised as the standard measure in full economic evaluations of interventions.

Table 50 below summarises response levels for each of the 5 dimensions assessed using the EQ-5D at T0, T1 and T2 for the PLWD. For the mobility dimension, no participants reported being confined to bed at any time point, while other respondents were relatively evenly divided between those reporting no problems and some problems. No participants reported severe problems with self-care, with the majority reporting no problems at all. The profile of responses in relation to usual activities shows a more varied response that changed over time. At all three time points, 19 respondents had no pain or discomfort. The numbers reporting extreme pain/discomfort at T0 and T2 were low, but six participants reported extreme pain at T1. Finally, a substantial number of participants reported being moderately anxious or depressed at all three time points with a small number extremely anxious or depressed.

Table 50: Summary of EQ-5D Response Levels for Participants with Dementia

Dimension/response level	**No. Participants T0 (N=30)**	**No. Participants T1(N=30)**	**No. Participants T2 (N=28)**
Mobility			
No problems	17	15	17
Some problems	13	15	11
Confined to bed	0	0	0
Self-care			
No problems	23	24	25
Some problems	7	6	3
Unable to wash or dress	0	0	0
Usual Activities			
No problems	13	9	12
Some problems	16	19	10
Unable to perform usual activities	1	2	6
Pain/Discomfort			
No pain/discomfort	19	19	19
Moderate pain/discomfort	8	5	8
Extreme pain/discomfort	3	6	1
Anxiety/Depression			
Not anxious/depressed	11	16	16
Moderately anxious/depressed	15	13	12
Extremely anxious/depressed	4	1	1

Participant EQ-5D response levels were used to estimate a preference based utility index for each participant, (based on weights attached to each response level from previous population studies). The resulting single index is measured on a scale from 0 to 1 where 0 represents death and 1 represents perfect health. The EQ-5D also permits index scores that are less than 0, indicating that some health states may be worse than death. Average EQ-5D indices at all three time points are shown in Table 51 below. At all three time points, at least one participant indicated that they had perfect health-related quality of life while the minimum utilities at T0 and T1 were less than 0 (interpreted as worse than death) and close to 0 at T3. Average utility scores were similar at T0 (0.64947) and T1 (0.65173) but the mean score was notably higher at T2 (0.71850).

Table 51: Summary of preference based health–related quality of life indices for participants with dementia

	N	Minimum	Maximum	Mean	Std. Deviation
Participant EQ5D index T0	30	-.181	1.000	.64947	.301430
Participant EQ5D index T1	30	-.077	1.000	.65173	.340671
Participant EQ5D index T2	28	.088	1.000	.71850	.250028

Findings from the EQ5D for Carers

Health-related quality of life of carers was similarly assessed at all three time points using the EQ5D. Table 52 summarises the response levels for the five dimensions assessed. No carers reported having extreme mobility problems, with the largest number reporting no mobility problems, but a substantial number reporting some problems. The vast majority of carers had no problems with self-care at all three time points. Most carers had no problems with usual activities, but again a substantial number reported some problems at all three time points. In relation to pain, 14, 15 and 14 carers reported moderate pain or discomfort at T0, T1 and T2 respectively, with two participants reporting extreme pain or discomfort at all three time points. Fourteen carers reported they were moderately anxious or depressed at T0, thirteen at T1 and eight at T2, indicating a decreasing trend over the course of the study.

Table 52: Summary of EQ-5D response levels for carers

Dimension/response level	No. Participants T0 (N=30)	No. Participants T1(N=30)	No. Participants T2 (N=28)
Mobility			
No problems	17	18	20
Some problems	13	11	9
Confined to bed	0	0	0
Self-care			
No problems	28	28	27
Some problems	2	1	2
Unable to wash or dress	0	0	0
Usual Activities			
No problems	22	20	18
Some problems	8	9	11
Unable to perform usual activities	0	0	0
Pain/Discomfort			
No pain/discomfort	14	12	13
Moderate pain/discomfort	14	15	14
Extreme pain/discomfort	2	2	2
Anxiety/Depression			
Not anxious/depressed	16	14	19
Moderately anxious/depressed	14	13	8
Extremely anxious/depressed	0	2	2

Table 53 summarises the resulting EQ-5D indices for carers at T0, T1 and T2. Similar to the sample of PLWD, at all three time points at least one carer indicated that they had perfect health-related quality of life while the minimum utilities were close to 0, indicating very poor health-related quality of life. Average utility scores varied slightly across three time points (T0=0.7654, T1=0.7250, T2=0.7485), although interpretation of these changes is limited given the small numbers involved.

Table 53: Summary of preference based health –related quality of life indices for carers

	N	Minimum	Maximum	Mean		Std. Deviation
	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic
EQ5D index_carersT1	30	.09	1.00	.7654	.04358	.23869
EQ5D index_carersT2	29	.09	1.00	.7250	.04834	.26032
EQ5D index_carersT3	29	.06	1.00	.7485	.05314	.28616

A comparison of EQ-5D indices between PLWD and carers at all three time points is displayed in Figure 35. Carers had higher scores than PLWD at all three time points, although the differential is smaller at T2 than at the previous time points.

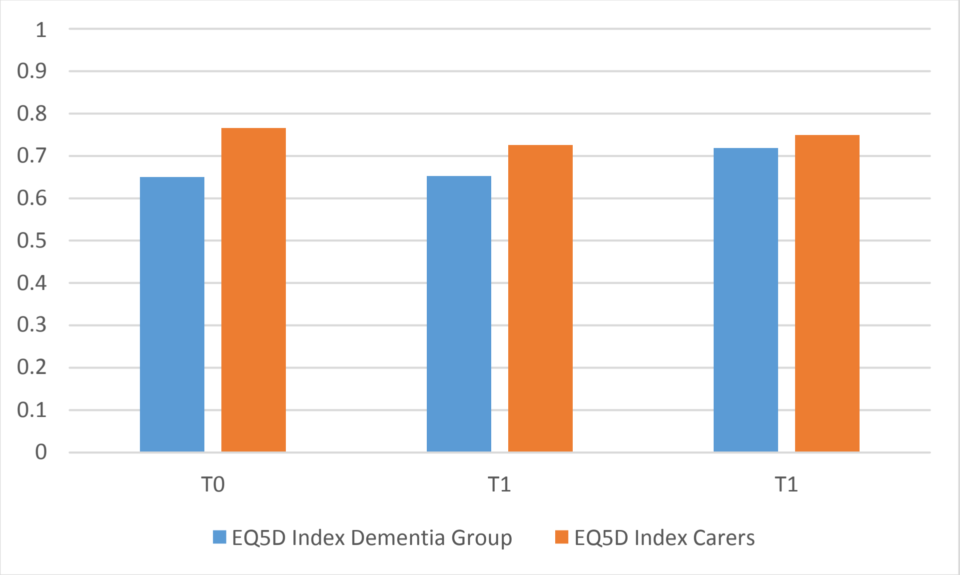


Figure 35: Comparison of Mean EQ5D Index Scores among Participants with Dementia and Carers

Findings from the DEMQOL for people living with dementia

Health-related quality of life for PLWD was also assessed at three time points using the DEMQOL. The DEMQOL consists of two questionnaires, the first is a 28-item questionnaire administered to participants living with dementia and the second a proxy questionnaire consisting of 30 items, which was administered to the carer. A comprehensive overview of the DEMQOL questionnaires has already been provided at the beginning of this chapter.

To recap, in both questionnaires participants were asked to provide responses to questions on a 4-point scale. A total score was calculated with a maximum possible score of 112 (and 118 for the proxy measure) and higher scores indicated better health-related quality of life.

Table 54 summarises total DEMQOL scores at all three time points for PLWD. Mean scores were 86.73, 90.43 and 91.50 at T0, T1 and T2 respectively showing an increase in average scores over the duration of the intervention.

Table 54: Summary of total DEMQOL Scores for Participants with Dementia

	N	Minimum	Maximum	Mean		Std. Deviation
	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic
TotalDEMQOL_T0	30	58.00	99.00	86.7333	2.11450	11.58159
TotalDEMQOL_T1	30	68.00	104.00	90.4333	1.66277	9.10734
TotalDEMQOL_T2	28	73.00	102.00	91.5000	1.36906	7.24441

As outlined in the methodology section, algorithms have been developed by Mulhern et al. (2013) to generate a preference-based single index for the DEMQOL system (DEMQOL and DEMQOL-Proxy) for use in economic evaluation using general population values. Similar to indices generated from the EQ-5D, indices from the DEMQOL range from 0 to 1, with 1 indicating perfect health and 0 indicating death. These algorithms were applied to the study data at all three time points and summary data is presented in Table 55. Average DEMQOL indices were notably high in comparison to those indices generated by the EQ-5D. The average indices at T0, T1 and T2 were 0.8445, 0.8679 and 0.9013 respectively. At all three time points the maximum index was 0.99, while the minimum indices were 0.46, 0.30 and 0.75 respectively.

Table 55: Summary of Preference Based Health–related Quality of Life Indices for Participants with Dementia, based on DEMQOL

	N	Minimum	Maximum	Mean	Std. Deviation
DEMQOL Index T0	30	.46	.99	.8445	.14146
DEMQOL Index T1	30	.30	.99	.8679	.14517
DEMQOL Index T2	28	.75	.99	.9013	.06559

A summary of total DEMQOL-Proxy scores reported by the carers are presented in Table 56. The average total scores at T0, T1 and T2 were 87.53, 85.97 and 89.13 respectively, which, contrary to DEMQOL figures reported by the PLWD, suggests a slight decrease in health-related quality of life from T0 to T1. Average figures however, once again, show a slight increase in health related quality of life over the duration of the intervention (i.e. from T0 to T2).

Table 56: Summary of total DEMQOL-PROXY Scores for PLWD (reported by Carer)

	N	Minimum	Maximum	Mean		Std. Deviation
	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic
TotalDEMQOLC_T0	30	46.00	115.00	87.5308	3.25536	17.83034
TotalDEMQOLC_T1	29	57.00	109.00	85.9707	2.52449	13.59481
TotalDEMQOLC_T2	29	59.00	109.63	89.1278	2.93525	15.80682

Applying the associated DEMQOL-Proxy algorithms developed by Mulhern et al. (2013), a preference-based single index was again generated for each PLWD, indicating their health related quality of life on a scale from 0 to 1 based on responses provided by their carer.

The average indices generated by the DEMQOL proxy, are more in line with those generated from the EQ-5D for the PLWD (Table 57). Average indices were 0.6740, 0.6990 and 0.6669 at T0, T1 and T2 respectively, although these figures do not suggest a similar increase in health-related quality of life over the duration of the intervention.

Table 57: Summary of Preference Based Health–related Quality of Life Indices for Participants with Dementia, based on DEMQOL.

	N	Minimum	Maximum	Mean		Std. Deviation
	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic
DEMQOL-PROXY Index T0	30	.38	.90	.6740	.02668	.14614
DEMQOL-PROXY Index T1	29	.41	.91	.6990	.02887	.15546
DEMQOL-PROXY Index T2	29	.41	.87	.6669	.02609	.14049

Key Findings from Health Economic Analysis

The health economic element of the current study sought to estimate the costs directly associated with the reminiscence intervention and also to estimate health and social care costs potentially affected by the intervention at baseline and follow-up, including, community health and social care costs, costs of hospital attendances, medication costs and costs of unpaid carer support. Health related quality of life of both PLWD and their carers was also assessed at baseline, mid-point and end-point.

Costs Directly Associated with the Intervention

The cost elements associated with the delivery of the intervention included IT trainer costs, Reminiscence Facilitator training costs, carer training time, equipment, software development and travel. The overall costs associated with the intervention were £77,112 (£2,570 per dyad), with the largest proportion accounted for by training costs (£41,032), followed by software development (£26,160).

Community Health and Social Care (CHSC) Costs

All participants at T0 and T2 reported some type of community health and social care service usage in the previous 3 months. At T0, total costs of all community health and social care service use was £9,155.51, while the average cost was £305.18 per participant. GP services represented the highest cost with total costs of £3491.57 and an average cost of £116.39 per participant. Total and average costs were lower at T2 although costs were based on a lower number of respondents (n=29) at this time-point. The total cost of all community health and social care services was £7,791.58 and the average cost was £268.68 per participant.

The GP was the most frequently used service in terms of the number of participants using the service. However, there was a notable reduction in the number of GP visits, with 75 visits and 51 visits in total at T0 and T2 respectively. Average and total costs of mental health nurse, psychiatrist, chiropodist and dentist services were also lower at T2 while the cost of home help services was higher at T2. There was also a much higher level of occupational therapy service usage at T0. However, given that OTs were used in the recruitment of participants to the study, this figure and the comparison with the T2 figure should be interpreted with caution.

Cost of Hospital Services

Estimates of hospital services costs reveal some differences across the two time points, but a clear overall trend is not apparent. Ten participants reported use of hospital services at T0 while nine participants reported using hospital services at T2. Three participants reported using inpatient services at T0 while four reported usage at T2. The total number of inpatient days was much lower at T0 (12 compared to 42 at T2). Similar outpatient service use was reported at T0 and T2. Six participants visited A&E in the three months before T0, while no participants reported A&E visits at T2. Six participants reported day hospital service usage at T0 and three at T2.

The overall cost of all hospital services used at T0 was £20,107.55 while the average cost per participant was £670.25. Inpatient services accounted for the highest proportion of these costs amounting to £17,674.00. In contrast to findings in relation to community health and social care costs, total costs of all hospital services used was higher at T2 £28,096.36 while the average cost per participant was £968.84. Inpatient services again accounted for the highest proportion of the overall cost amounting to £23,607.00.

Prescription Medication Costs

All participants reported use of prescription medication at both T0 and T2 and the majority of participants used multiple medication types. For example, 21 and 19 participants reported use of seven or more different medication types at T0 and T2 respectively. The cost profile appears similar at both time points. Total costs were £6,817.41 at T0 (N=30) and £6,770.59 at T2 (N=29), while mean costs per participant were £227.25 and £233.47 respectively.

Unpaid Carer Support

At T0, twenty-two carers lived with the PLWD while eight lived elsewhere. The corresponding figures for T2 were twenty-three and six. At T0, the average number of unpaid carer hours of support was 1,188.53 over the previous 3 months, with a total of 35,656 hours of support from carers (n=30) over this time period (these figures include overnight hours). Based on the ‘replacement costing methodology’, the total costs of this carer support was estimated to be £855,744.00, while the average cost was £28,524.80

At T2 the average number of carer support hours was higher at 1,331.90, with a total of 38,625 hours from carers (n=29) over the previous 3-month period. Associated economic costs of carer support at T2 were therefore higher, with an average cost of £31,965.52 and total costs of £927,000.00.

Breakdown of Health and Social Care Costs

Table 58 and Figure 36 show the proportion of costs accounted for by each of the health and social care cost categories at T0 and T2. At both time points, the economic equivalent of unpaid carer support dominated the overall cost profile, accounting for 96%and 95% of overall costs at T0 and T2 respectively.

Table 58: Summary of Total and Average Costs of Care for participants living with dementia at T0 and T2

	T0		**T2**	
	Total	**Average**	**Total**	**Average**
CHSC Costs	9,156	305	7,792	269
Hospital Costs	20,108	670	28,096	969
Medication Costs	6,817	227	6,771	233
Unpaid Carer Support Costs	855,744	28,524	927,000	31,966
All costs	**891,825**	**29,728**	**969,659**	**33,436**

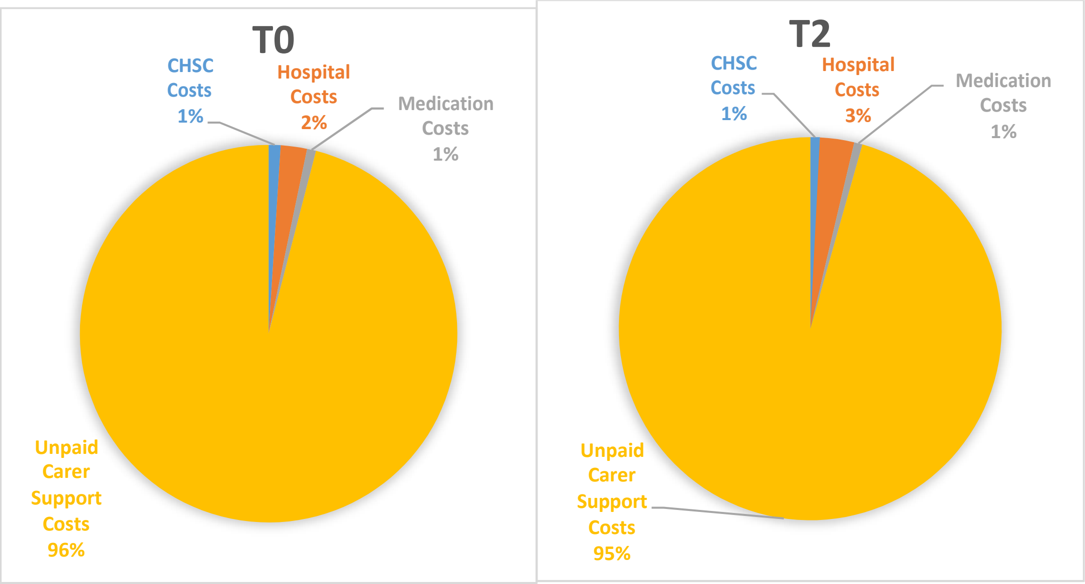


Figure 36: Percentage Breakdown of Average Costs at T0 and T2

Health-related Quality of Life of Participants with Dementia

Health-related quality of life of PLWD was measured at T0, T1 and T2 using three instruments: EQ-5D, DEMQOL and DEMQOL Proxy. Each of these instruments was used to estimate a preference based utility index for each participant (ranging from 0 to 1 where 0 represents death and 1 represents perfect health), which may be used in future cost-effectiveness studies to estimate QALYs.

The DEMQOL and DEMQOL Proxy Instruments were firstly used to calculate total scores for each participant, with a maximum possible score of 112 and 118 respectively, and higher scores indicated better health-related quality of life. Based on DEMQOL responses, mean scores were 86.73, 90.43 and 91.50 at T0, T1 and T2 respectively, showing an increase in average scores over the course of the intervention. Average total scores at T0, T1 and T2 based on DEMQOL Proxy responses were 87.53, 85.97 and 89.13 respectively, which, contrary to DEMQOL figures reported by the PLWD, suggests a slight decrease in health-related quality of life from T0 to T1. Average figures however, once again, show a slight increase in health related quality of life over the duration of the intervention (i.e. from T0 to T2). Applying algorithms to DEMQOL and DEMQOL Proxy responses to derive a preference based index for health–related quality of life, returned the following average indices at T0, T1 and T2: 0.8445, 0.8679 and 0.9013 based on DEMQOL responses and 0.6740, 0.6990 and 0.6669 based on DEMQOL Proxy responses.

Examining findings based on EQ-5D responses, at each of the three time points at least one participant indicated that they had perfect health-related quality of life while the minimum utilities at T0 and T1 were less than 0 (interpreted as worse than death) and close to 0 at T3. Average utility scores were similar at T0 (0.64947) and T1 (0.65173) but notably higher at T2 (0.71850).

While indices based on DEMQOL Proxy and EQ-5D responses are comparable, indices calculated using DEMQOL responses are much higher. A possible explanation for this is that

PLWD rate their quality of life higher than that rated by their carers using the DEMQOL Proxy (Figure 37).

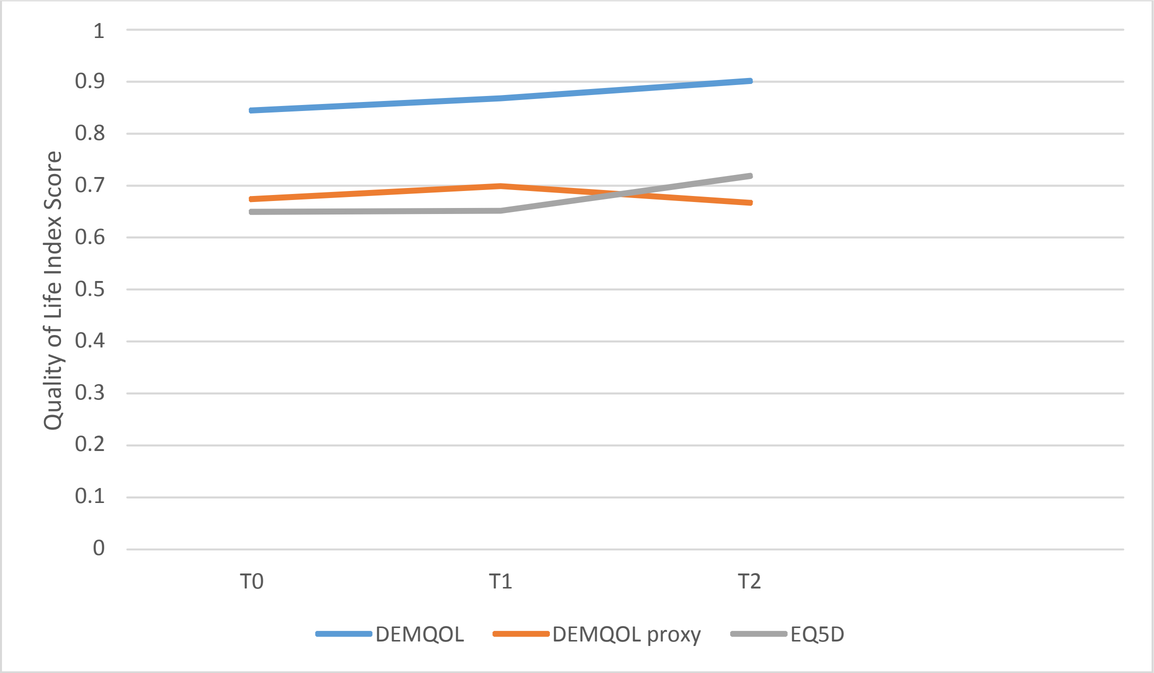


Figure 37: Summary of Health Related Quality Indices based on DEMQOL, DEMQOL Proxy and EQ-5D

Health-related Quality of Life for Carers

Similar to the sample of PLWD, at all three time points at least one carer indicated that they had perfect health-related quality of life while the minimum utilities were close to 0, indicating very poor health-related quality of life. Average utility scores varied slightly across three time points with the highest quality of life at baseline (T0=0.7654, T1=0.7250, T2=0.7485), although interpretation of these changes is limited given the small numbers involved. Carers had higher scores than PLWD at all three time points, although the differential is smaller at T3 than the previous time points.

Summary

The health economic component of this study aimed to estimate both the costs and quality of life effects that may have been affected by the reminiscence intervention with the overall aim of informing a future RCT and related cost-effectiveness analysis. The study found a decrease in community health and social care costs, and increase in hospital costs and informal care costs and no change in medication costs. The results suggest a moderate improvement in health related quality of life for PLWD. These findings from this study will inform the development of a subsequent full cost-effectiveness study, designed in accordance with the NICE 'Reference Case' (NICE, 2013).

A full cost–effectiveness analysis could include a similar range of cost-categories and methods in terms of collection of information on resource use and assignment of unit costs. However, minor amendments to data collection are recommended for a future study to improve accuracy of cost estimation. Specifically, in relation to use of hospital services, a refined CSRI instrument should distinguish between elective and non-elective hospital procedures, given their differential costing. As indicated in the results relating to health and social care costs, occupational therapy costs were much higher at T0. This however relates to the role of occupational therapists in delivering a cognitive rehabilitation programme to some participants prior to the InspireD intervention, rather than the effects of the intervention itself. It is recommended that a future cost-effectiveness study would distinguish between occupational therapy costs associated with the *delivery of the intervention* and those potentially associated with the *effects of the intervention.*

Furthermore, a full cost-effectiveness analysis alongside an RCT would require a larger sample size and longer follow-up period to allow potential effects of the intervention to be realised and differences between intervention and control groups to be accurately detected.

Chapter 9 - Phase 3: Qualitative Interviews

Introduction

This chapter presents the findings from Phase 3 of our feasibility study. This phase involved 31 semi-structured interviews with participants living with dementia and/or their family carer. The interview schedule used for this phase was informed by the findings from Phase 1, Workshop 4 and from learning gained through the dynamic and evolving nature of this study. This chapter outlines the rationale for using semi-structured interviews, the access to, and recruitment of participants, data collection methods, analysis and finally the key themes that emerged from the qualitative interviews with study participants. The chapter concludes with a summary of the key findings.

Aim

The aim of Phase 3 was to meet objective 6 of the overall feasibility study.

> ***Objective 6:*** *Explore users' views on the intervention*

Study Design

A qualitative approach is an appropriate methodological choice when an understanding of how an individual has both personally and socially experienced a phenomenon is necessary (Creswell, 2013). The qualitative phase of this study was therefore designed to provide an understanding of the experience of participants as they progressed through the various phases of our study. O' Cathain et al. (2015) argued that a strength of qualitative research is that it can be responsive and flexible to emerging issues encountered in fieldwork and can therefore make a significant contribution to knowledge within a feasibility study.

The qualitative design chosen for a study requires consideration to be given to the evidence generated and its relevance to the research question. However, a qualitative semi-structured interview approach can encounter methodological problems, through the inappropriate application of a philosophical underpinning which is inconsistent with the nature of the exploration (Kvale, 1996). The use of an approach such as grounded theory facilitates the generation of evolving theory requiring the researcher to remove any pre-determined assumptions or understandings (Glaser and Straus, 1967). This would not be appropriate when a specific and focused understanding of an intervention and its structure and processes is required. Equally, an ethnographical approach would require the interpretation of findings within their cultural context which may disregard the intricacies of the feasibility of an intervention (Denzin and Lincoln, 2013). Both the use of narrative inquiry or case studies provide invaluable personal insights but lack the consensus of experience required within the specifics of a feasibility study (Creswell 2013).

As this phase aimed to explore participants' lived experience of all aspects of the intervention, it could be argued that a phenomenological approach may have been appropriate. However, the bespoke design of the semi-structured interview schedule was not aligned to a phenomenological stance. Ultimately, the analysis of data relevant to various aspects of this feasibility study required an accessible and flexible approach. For this reason, data gathered from the interviews with participants were primarily analysed using Braun and Clarke's (2006) method of thematic analysis. Miles and Huberman's (2014) checklist matrix was also used as it was considered more appropriate for the analysis of responses to questions of a more structured type.

Method

The interview

DiCicco-Bloom and Crabtree (2006) have differentiated qualitative interviews into unstructured, semi-structured and structured, depending on the type of question asked and the overall aim of the interview process. Structured interviews involve questions which have been pre-determined and have limited response options whereas a semi-structured approach involves the development of a loose interview guide rather than a strict interview structure (Parahoo 2006). Within this phase of the research study, the choice of a semi-structured interview schedule (Appendix 23) was guided by the clear focus of Objective 6, which was to explore the user's views on the intervention.

While the interview schedule used in this study may appear quite structured, relative to more free-flowing schedules typically used in qualitative work, it is important to note that interview centred around three key issues. These were to 1) to ascertain feedback on the extent to which the modified InspireD app addressed the issues identified in Phase 1, Workshop 4 by the User Development Group 2) to address significant feasibility considerations within the study such as acceptability, usability and practicality (Bowen et al. 2009) and 3) to incorporate iterative flexibility in order to capture the impact of the intervention on the lives of people living with dementia and in particular on their relationship with their carers (O' Cathain et al. 2015). In this context, a more extensive, bespoke, semi-structured interview schedule facilitated a methodological '*triangulation'* which enabled the exploration of issues arising from the multiple strands of data that comprised this feasibility study (Parahoo, 2006).

O' Cathain et al. (2015, p. 6*)* have identified four key areas that qualitative research can explore in a feasibility study. These include '*Intervention, Processes, Outcomes and Measures'*. These four areas were adapted for this study and subsequently guided the development of the interview schedule used in this study (Figure 38).

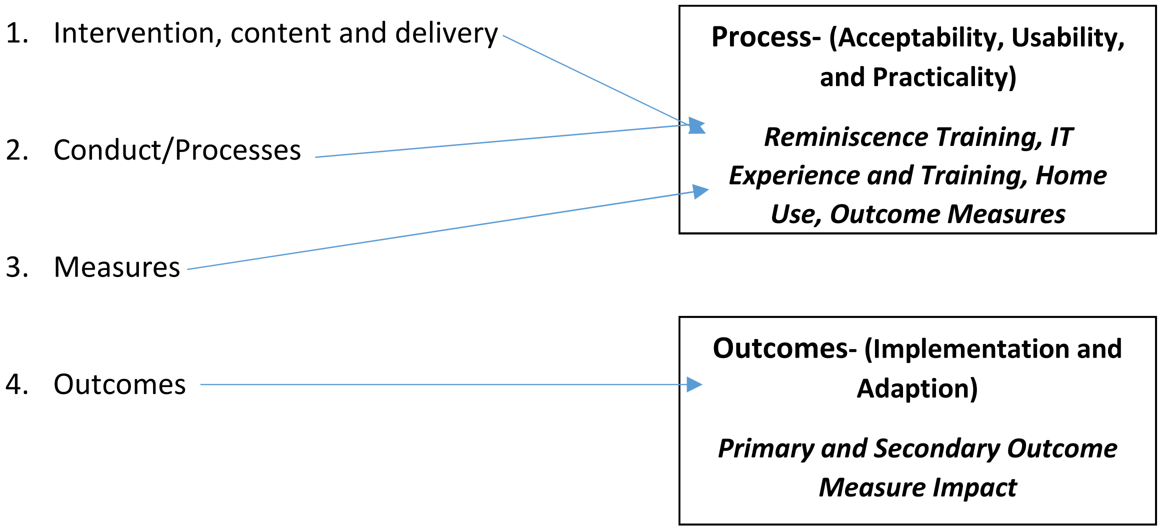


Figure 38: Four areas of qualitative exploration in the current feasibility study (Adapted from O' Cathain et al. *2015*)

Recruitment

Midway through the 3-month period of home use, the researcher provided all participants living with dementia and their carers with a 'Letter of Invitation' to consider involvement in Phase 3 of the study (Appendix 24). Home visits were arranged with potentially interested participants to outline what was involved in the qualitative phase of the study and to provide them with the Participant Information Sheet (Appendix 25 and 26). During this visit, the researcher answered any questions arising from the Participant Information Sheet and provided information on the conduct and recording of the interview.

At completion of the intervention, an appointment was then made to conduct the interviews at a time and date most suitable for participants. The interviews did not commence until the consent form (Appendix 27 and 28) had been verbally read to all participants to ensure fully informed consent. Recruitment continued until saturation (where no new themes had been identified) was reached at 31 interviews. In order to maximise the quality of data collected, the research team made every effort to conduct these interviews no later than two weeks after the intervention.

Sample

While participants in Phase 2 were purposively sampled to meet the study's inclusion and exclusion criteria, a volunteer sampling strategy was employed in Phase 3. As with the quantitative data collection, the qualitative interviews were conducted separately for PLWD and their carers. This strategy was employed as it recognised the individuality of participants while also enabling all interviewees to be frank and honest in their responses without having to worry about upsetting the other dyad member. Recruitment to Phase 3 was not contingent on both dyad member's willingness to be involved and as a result, a slightly higher number of carers completed interviews. One dyad requested a joint interview due to personal reasons and this was accommodated by the research team.

As stated earlier, data saturation was reached at 31 interviews. Table 59 provides a detailed breakdown of recruitment for Phase 3. There was a higher number of women interviewed than men, 19 to 13 respectively. The age range was representative of the Phase 2 sample with the youngest interviewee aged 31 years and oldest, 94 years. Six of the 17 dyads lived in rural areas and the remaining 11 lived in urban areas. In total, the final sample comprised 15 participants living with dementia and 17 carers.

Table 59: Dyad Number and Interviews Details

Dyad No.	Interview Conducted	PWD	Carer	Gender	Rural	Interview Total
Dyad 1	No	Declined	Declined	-	-	0
Dyad 2	No	Deceased	Declined	-	-	0
Dyad 3	Yes	X	X	F/F	No	2
Dyad 4	Yes	X	X	M/F	No	2
Dyad 5	Yes	X	X	F/F	No	2
Dyad 6	Yes	-	X	F	Yes	1
Dyad 7	Yes	X	X	M/F	Yes	2
Dyad 8	Yes	X	X	F/M	No	2
Dyad 9	Yes	X	X	M/F	Yes	2
Dyad 10	No	Co-morbidity	Co-morbidity	-	-	0
Dyad 11	Yes (Joint)	X	X	M/F	Yes	1
Dyad 12	Yes	X	X	F/M	No	2
Dyad 13	Yes	X	X	F/M	No	2
Dyad 14	Yes	X	X	M/F	No	2
Dyad 15	Yes	X	X	M/F	No	2
Dyad 16	Yes	X	X	F/M	Yes	2
Dyad 17	Yes	X	X	M/F	No	2
Dyad 18	Yes	X	X	M/F	No	2
Dyad 19	No	Memory concerns	Declined			0
Dyad 20	No	Memory concerns	Declined			0
Dyad 21	No	Declined	Declined			0
Dyad 22	No	Co-morbidity	Co-morbidity			0
Dyad 23	No	Declined	Declined			0
Dyad 24	No	Memory concerns	Declined			-

Dyad 25	Yes	Declined	X	F	Yes	1
Dyad 26	No	Memory concerns	Declined			0
Dyad 27	No	Memory concerns	Declined			0
Dyad 28	No	Co-morbidity	Co-morbidity			0
Dyad 29	Yes	X	X	M/F	No	2
Dyad 30	No	Co-morbidity	Co-morbidity			0
Total	17 Dyads Involved	15	17	19 Women 13 Males		31 interviews

Data Collection

Face to face interviews were used to collect qualitative data at the close of the intervention period. These interviews facilitated an in-depth exploration of participants' perspectives about their involvement in the study and the usability of the InspireD iPad app. The three members of the research team who conducted the interviews (Drs McCauley and Laird and Prof Ryan) sought participants' consent to digitally record the interviews. The prepared questions and prompts in the interview schedule (Appendix 23) assisted the researchers to stimulate discussion on participants' experiences of their involvement in the study. This included their views on the reminiscence training, IT support, use of the app and reminiscence activity to ensure that the qualitative phase addressed key aspects of a feasibility study (acceptability, implementation and practicality) as outlined by O' Cathain et al. *(*2015).

The interviews also enabled the research team to explore the impact of the intervention on the relationships between PLWD and their family carers. It was anticipated that the interviews would last no longer than 45 minutes but in practice, the length of each interview was determined by the participant. The research team were alert to signs of participant fatigue and problems with concentration or memory so regular breaks were offered and the duration of the interviews was adjusted accordingly. In general, the interviews with carers lasted longer that those involving PLWD.

Ethics

The full study received a favourable review by Ulster University's Filer Committee and received full ethical approval from ORECNI in February 2016. However, given the focus of this research study and involvement of PLWD, a number of ethical issues did arise and merit considerations.

The research team acknowledged that it is possible for a person who has received a diagnosis of dementia, to be unable to recall that diagnosis at a later time. The team was also cognisant of the potential distress which may be caused by use of the term 'dementia' in the context of a home environment. The three members of the research team who conducted the interviews have extensive clinical experience of working with vulnerable groups. The Chief Investigator (Prof Ryan) and Co-investigator (Dr Laird) are registered nurses with expertise in dementia and the care of older people, and the Research Associate (Dr McCauley) is a registered pharmacist with ten years' experience working with people with a range of health conditions, including dementia and co-morbid conditions. In addition, Dr McCauley undertook specialist training in February 2016, on one-to-one communication with PLWD and their families, provided by a Dementia Champion working within the WHSCT Cognitive Rehabilitation Team. This experience and learning ensured that Dr McCauley's engagement with PLWD and their carers was sensitive and appropriate during all stages of the research process.

Potential participants were made aware of what was involved in their participation in Phase 3 and of support available to them. This is clearly outlined in the Participant Information Sheets (Appendices 25 and 26) and was explained further during the mid and end-point home visits. Research ethics include principles of respect for persons and their autonomy and this was achieved by obtaining separate informed consent from the PLWD and their carer (Appendices 27 and 28). A Lone Worker Protocol was also developed to minimise risk to members of the research team while visiting participants in their own homes.

The team recognised that some memories may be upsetting for PLWD and their carers. A Distress Protocol and a Support Pack were developed to assist the research team in dealing with any difficulties that arose during the study. Such a difficulty was encountered which involved a participant living with dementia disclosing that he had been a victim of a historical crime. To minimise any further distress, the interview was brought to a sensitive close. The three members of the research team involved in the Phase 3 interviews, subsequently listened to the recording in its entirety and agreed a suitable course of action. The individual was contacted and a visit arranged with the Chief Investigator and Co-Investigator. The allegation was discussed and the individual was informed that the information provided would have to be referred to the appropriate authorities, in this case the Safeguarding Team, within the Western Health and Social Care Trust. The participant agreed and welcomed the intervention.

Acknowledging the sensitivity of the subject matter and the need to maintain confidentiality, this interview was transcribed in full by the Research Associate. However, all other interviews were professionally transcribed by a professional transcription services. With due regard to the importance of confidentiality, these anonymised recordings were sent as electronic files. Storage of the data was in accordance with Ulster University's Code of Practice for Professional Integrity in the Conduct of Research.

Data constitutes both written documentation and electronic information and included consent forms, records of visits, outcome measurements, digital recordings from interviews and data analysis files. Electronic files were stored on password protected computers in the offices of Ulster University staff working on the study. For the purpose of analysis, all other electronic data were retrieved from Ulster University's servers and stored on the researcher's password protected computer. The offices of Ulster University researchers are locked when vacated and all paper documents and recording devices were stored in locked filing cabinets in these offices. Paper data was destroyed in confidential waste and electronic data will be deleted ten years following completion of the study by the Chief Investigator in line with research governance protocols at Ulster University.

Data analysis

Data analysis was conducted in two stages. Miles and Huberman's (2014) checklist matrix was used to analyse responses to questions of a more structured type, for example, pertaining to previous experience of computers and reminiscence. However, Braun and Clarke's (2006) method of thematic analysis was primarily used to guide the analysis of the qualitative data generated in this phase of the study. Both approaches are now described in detail.

Stage 1 Data Analysis

The data was first read a number of times by the Research Associate and following a debriefing session with two other members of the research team, it was agreed that some interview schedule questions relating to previous experience of reminiscence or technology produced a nominal response. Such responses were informative, and while they did not provide an in-depth understanding of participants' experience, they were nonetheless important in providing background and contextual information that may have influenced participants' overall experience of the intervention. Miles and Huberman's (2014, p. 144) method of exploring variables through a checklist matrix was therefore employed as it makes the analysis,

> *"…more systematic, enables verification, encourages comparability, and even permits sample quantification when appropriate."*

The use of Miles and Huberman's (2014) checklist matrix not only enabled the exploration of all participants' responses to one key variable but it also enabled the display of a specific participant's responses to a range of variables (Table 60).

Stage 2- Thematic Analysis

The second stage of analysis was conducted using a "*dynamic approach"* in which issues which emerged throughout the feasibility study were explored and analysed by the research team (O' Cathain et al. 2015, p.9). The analytical approach was therefore determined by the need to find key themes and core consistencies amidst a large amount of qualitative data. According to Green and Thorogood (2014, p. 210), thematic analysis.

> *"…provides a 'map' of the content and topics across your data set, and a way of summarizing the variation and regularities within the data".*

Braun and Clarke's (2006, p. 78) six phased method of analysis was used as it provided the flexibility and responsiveness needed for a rich and dynamic approach to analysis, while also giving the researchers *"theoretical freedom"* to provide thematic clarity on complex data. Braun and Clarke (2006, p.87) 6 phased method of analysis comprises the following steps:

1. Familiarizing yourself with your data
2. Generating initial codes: Coding interesting features of data
3. Searching for themes: Collating codes into potential themes
4. Reviewing themes: Generating a thematic 'map' of analysis
5. Defining and naming themes: Ongoing analysis to refine
6. Producing the report

Trustworthiness/Reliability/Rigour

All interviews were read several times and all non-verbal observations and researcher comments were noted to inform the analysis. The trustworthiness of qualitative research can be assured by using Lincoln and Guba's (1985) four criteria of credibility, dependability, transferability and confirmability. The credibility of analysis was enhanced by frequent peer debriefing sessions and the random selection of interview transcripts which were read by other research team member to independently identify emerging themes. These were then re-read by the researcher who conducted the interview to cross compare their own field notes with the transcription. The rigour of analysis was also enhanced by the three members of the research team who conducted the interviews, discussing and agreeing a consensus on the emergent themes. This process of peer validation was enhanced by the fact that all three team members were already familiar with many participants having been involved in recruitment and data collection in Phase 2 of the study.

The dependability of the analysis was demonstrated by the Research Associate maintaining a diary throughout the entire study. This enabled the analysis to be conducted from a position of reflexivity (Polit and Beck, 2012). The transferability of the qualitative phase of our study has been demonstrated by the transparent presentation of the process of recruitment, data collection methods and ethical considerations. The confirmability of the analysis has further been demonstrated by the comprehensive presentation of data displays outlining sample characteristics and initial data analysis methods providing a visual audit of the analytical processes. The rigour of analysis was further enhanced through the use of methodological triangulation in which the results of the Phase 3 qualitative interviews can be mapped against the key priorities identified in the final User Development Group Workshop in Phase 1.

Stage 1: Findings

Table 60 summarise participants' responses to a small number of questions on the interview schedule which were mainly answered using Yes/No responses or which lent themselves to a quantifiable presentation. The summary at the bottom of Table X shows that only 3 participants, all carers, has completed any type of reminiscence activity before the present study. The majority of PLWD (n=12) had no previous experience with technology but carers responded more positively with the same number (n=12) indicating that they had previous experience in this field. Looking at photographs and listening to music were the most preferred type of reminiscence activity. There was unanimous support for the home base nature of the intervention and all interviewees also stated that they would recommend involvement in future research to other PLWD and their carers. In general, participants preferred to use the InspireD app in the late afternoon or evening. When asked, the majority of participants indicated that they would continue to use the app after the study.

Table 60. Qualitative Questions Quantitatively Expressed –Checklist Matrix (Miles and Huberman 2014)

Dyad No.	**Completed any type of reminiscence activity before?**	**Any previous experience with technology?**	**Preferred functionality**	**Home Based Intervention Preferable**	**Time of day**	**Continued Usage after study**	**Recommend Research Involvement to Others**	**Biggest Achievement**
Dyad 3 PWD	No	Yes	Photos	Yes	Pm	Yes	Yes	Being open
Dyad 3 Carer	No	Yes	Music/ Video	Yes/ Suggested one external session	PM	Yes	Yes	Being closer to her mum
Dyad 4 PWD	No	No	Photos/ videos	Yes	PM	Yes	Yes	Learning to use the app
Dyad 4 Carer	No	No	Photos/ Videos	Yes	PM	Yes	Yes	Able to talk to people better

Dyad 5 PWD	No	No	Photos/ Music	Yes	PM	Yes	Yes	Learning to use the iPad/getting involved in other group
Dyad 5 Carer	No	Yes	Photos	Yes	PM	Yes	Yes	Coping better/ more understanding
Dyad 6 Carer	No	Yes	Photos/ music/ video	Yes	PM	Yes	Yes	Learned a lot about the disease and PWD
Dyad 7 PWD	No	No	Music/photos	Yes	PM	Yes	Yes	Put everything in his life and that he loves into a little piece of machinery.

Dyad 7 Carer	Yes	Yes	Photos/ Music	Yes	PM	Yes	Yes	Seeing PLWD enjoying it and happier.
Dyad 8 PWD	No	No	Photos/ Music	Yes	Afternoon/ PM	Yes	Yes	More conscious of memory and to remember things
Dyad 8 Carer	No	No	Photos/Music	Yes	Afternoon/ PM/ Sunday	Yes	Yes	Broader knowledge of family/ helping PWD
Dyad 9 PWD	No	No	Photos	Yes	Sporadic use mainly PM	Yes	Yes	Feeling a bit better
Dyad 9 Carer	No	No	Photos	Yes	Sporadic use mainly PM or	Yes	Yes	Recording all the memories and going back over them

					special occasions			
Dyad 11 Interview (Together)	No	Basic	Photos	Yes	Sporadic use	Yes	Yes	Not asked
Dyad 12 PWD	No	No	Photos	Yes	Regular use	Yes	Yes	Enjoying all the research process
Dyad 12 Carer	No	Yes	Music/ photos	Yes	Regular use	Yes	Yes	Brought dyad closer since diagnosis
Dyad 13 PWD	No	No	-	-	Little memory of usage	-	Yes	-
Dyad 13 Carer	Yes	Basic	Photos	Yes	Regular use PM	Yes	Yes	Learnt to us the iPad

Dyad 14 PWD	No	No	Music	Yes	PM	Yes	Yes	“keeping the head thinking”
Dyad 14 Carer	No	Yes	Photos	Yes	Regular	Yes	Yes	Everything about it
Dyad 15 PWD	No	No	Music	Yes	Sometimes	-	Yes	-
Dyad 15 Carer	No	Yes	Music/Photos	Yes	Quiet times	Yes	Yes	Enjoying the company/just felt so at home
Dyad 16 PWD	No	No	Photos	Yes	Regular use	Yes	Yes	Probably just talking
Dyad 16 Carer	No	Yes	Photos/Bit of music	Yes	Early afternoon	Yes	Yes	The whole thing
Dyad 17 PWD	No	No	Music	Yes	Infrequent	Yes	Yes	I was able to answer satisfactorily and clearly

Dyad 17 Carer	No	Yes	Music/Photos	Yes	AM	Yes	Yes	Putting photos in app/being involved in research
Dyad 18 PWD	No	Yes	Photos/Music	Yes	Frequent/ Evenings	Yes	Yes	Enjoying doing it
Dyad 18 Carer	No	No	Photos	Yes	Regular use	Yes	Yes	Learning to use the iPad and meeting lovely people.
Dyad 25 Carer	No	Yes	Photos/Music	Yes	PM	Not asked	Yes	How well PLWD is holding his own.
Dyad 29 PWD	No	No	Photos	Yes	Afternoon	Yes	Yes	The relationships I had with people

Dyad 29 Carer	Yes	Yes	Photos	Yes	PM	Yes	Yes	Learning to put everything on the App.
Total 17 Dyads Involved, 30 (+1 dyad interview)= **32**	14 PWD-No 13 Carers-No 3 Carers- Yes	12 PWD-No 2 PWD- Yes 4 Carers-No 12 Carers- Yes	3 Dyads enjoyed Photos/ Music/Video 14 Dyads enjoyed Photos/ Music	All preferred home based intervention	2 Dyads Am/Early afternoon 15 Dyads Late afternoon/ PM	16/17 Dyads will continued usage	All dyads would advise research involvement	Qualitatively explored.

Stage 2 Findings

Process Themes

Stage 2 data is presented under themes related to process and outcomes as recommended by O Cathain et al. (2015). According to O'Cathain et al. (2015), process themes pertain to acceptability, usability and practicality and in the context of our feasibility study this related to the reminiscence training, IT experience and training, home use and views on the outcome measures. Outcome themes are primarily focused on implementation and adaptation and in the context of our study, pertained to the overall impact of the project. Five process related themes emerged through analysis:

1. **Reminiscence - "It brought back what there would be a risk of forgetting."**
   Supporting Memory - "*It makes you remember"*
   Learned Communication- *"What skills do I need to pick up?"*

2. **IT Training- "Step by Step…A Great Help"**
   Carer Support- *"Able to keep me right"*
   Carer Unengaged- *"I'm not accepting of it"*

3. **Usability- "It's Part of My Life Now"**
   Convenience and Mobility- "*We took the iPad out for Dinner"*
   Functionality- *"To keep the memories going"*
   Home Use- *"It was homely"*

4. **Outcome Measures- "Sometimes you have to ask personal questions"**

5. **Impact of Usage- "A wee bit of self-worth or comfort"**
   "You've nothing to lose, and something to gain"

Reminiscence - "It brought back what there would be a risk of forgetting."

The reminiscence training received by the participating dyads as part of this study was viewed by all interviewees as an enjoyable and interesting process. For the PLWD, it created the space to focus on their memories and in doing so enabled them to focus their attention on significant aspects of their life:

> *"I think it was lovely for me to be looking back and see the photographs and remembering exactly, as near as I can to when it was, what year it was and who was there and you know, I was able to look back at things and think a lot and then there's times that, if I hadn't have had that I wouldn't have been thinking." (*PLWD 29)

> *"it brought me back a good bit, like, you understand life, you know. I was a go, go guy, like, you know, always on the go. I wouldn't have had time for anything like that in my life, but when I see this, this, sort of, made me sit up and take notice" (*PLWD 4*)*

> *"A pleasant experience. "No, it was, it was good in the sense that it brought back what there would be a risk of forgetting."* (PLWD 17)

For the carers, the process of reminiscence training also offered them the time to share memories which were defining moments in their relationship and their history. By using their own photographs and memorabilia, the reminiscence process enabled participants to use their shared memories as a focal point in the training.

> *"I really enjoyed it… Because it was a time whenever you were really, if you could say, made to sit down and think about things that had happened. It's lovely to go over all those things that happened"* (C 15)

> *"Oh, it's lovely to have them and nice to look back…I would have photographs and every year or so you might look through them, but apart from that, no, you never would have bothered."* (C 14)
>
> *"I found that really nice. It was nice to talk to somebody. It was nice to think back and think, 'I remember that. We went on holiday" (*C 7)

However, for one carer, sharing memories was somewhat of a challenge as the PLWD was able to recall vivid memories of his childhood and early life which his carer was not able to relate to.

> *"It was pleasant and it worked well but you've got to bear in mind we've only been together 12 years, Y's Alzheimer's taken him back to prior to that…."* (C 25)

Supporting Memory - *"It makes you remember"*

All the PLWD described how the reminiscence training, not only supported their ability to remember memories which were incredibly important to them, but it also reminded them how much they could still remember. This had a considerable impact on the PLWD by bringing joy, insight and feeling good about, and within, themselves.

> *"I could remember was the main thing… I can go way, way back, remember everything…. very vivid, you know, memories." (*PLWD 3)

> *"Interesting! Interesting…because I did…know a lot about the past if you like to put it that way…my early childhood…"* (PLWD 11)

> *"Well, it makes you remember what you had forgotten sort of thing, you know, if that makes sense? it made me feel good."* (PLWD 16)

> *"I felt, the good times I felt more calm with myself than anything and sort of serene with the good ones and there was plenty of them, plenty of memories going back. From the photograph, I could look at this and see the type of day I had, you know near enough, you know like, it gave me a lot of insight and…how I reacted to different things… It brought it back."* (PLWD 29)

The carers described how impactful the PLWDs' ability to remember was for them, making them feel happy and helping them see their loved one from a completely different perspective. Not only did the carers learn things about their lives that they had not previously known, but they also began to realise the true depth of the life their loved one had lived.

> *"There was some things I hadn't heard before so, so that was interesting…in fact she remembered some things in the past in amazing detail and she was taking about her nursing days in Belfast, she could speak about the train she got and what time it arrived in Belfast for her nursing training from Dublin…you know things like that I didn't know, so she could remember that much detail in the past at the same time while losing the detail of the present."* (C 3)

> *"I suppose I've got an insight into, you don't tend to ask your parents when they were younger, you know, but bringing up photographs my mum was a lot younger and dad obviously, then you start to hear things that you've never heard, you know"* (C 16)

> *"There was actually, I learned lots, and lots of things about her in the few sessions with X facilitator, you know, that I didn't, that none of the family would have known, and we probably never would have known, if that hadn't have happened… the beauty about it, the fact that her long-term memory is still very good, you know…. Yeah, and, I mean, I have learnt stuff about my mum that I didn't know" (*C 13)

Learned Communication - *"What skills do I need to pick up?"*

For the carers, watching the facilitator interact with their loved one demonstrated a new way of communication. The facilitator's manner, their use of memory triggers and the attention paid to early memories had a significant impact on the carers and how they viewed their own communication with their loved one.

> *"I think maybe having the reminiscence person in was a good way in and you can actually, because he had a particularly good manner, I think of engaging with her that, that was really good just there, to see how he, he developed topics or maybe he came in with an object, like a stick or something or maybe a stone and like we always collect white stones from a particular beach in Mayo, you know so, just little tools really…just makes you think well, what skills do I need to pick up because there's no skills unless someone decides to go along themselves, there's no training or there's no skills"* (C 3)

> *"I thoroughly enjoyed her visits. You know, we both enjoyed them. My mum would have been laughing her head off, you know, talking about this, that, and the other things that happened*

> *in the past, you know. And X was very good at, sort of, thinking of, you know, mentioning topics and things that might have happened in the days gone by which my mum then talked very, talked in great detail about, you know, and had some very vivid memories of doing various things, you know."* (C 13)

> *"I thought it was very good, it was very good for mum because it kind of, it got through to mum probably better than I would get, you know. His use of things was very good… everything he done, you know, he could get through to, I think he knew the right questions to ask mum, you know, whereas I wouldn't have been, it's all new to us." (*C 16)

Participating dyads described how the role of a designated reminiscence facilitator was extremely beneficial, however, both the carers and the PLWD experienced the benefit in different ways. For the PLWD, the facilitator made them feel good, understood and that someone was interested in them:

> *"Very, very good. X (the facilitator) was very good to understand, and done different photographs, and we talked through different things. She was really good. Oh, a good effect on me. I felt a lot better with, you know, reminiscing with her." (*PLWD 5)

> *"They were interested in me and they were interested in me being interested in the photographs and the joy that I was getting out of these photographs"* (PLWD 7)

IT Training "Step by Step…A Great Help"

Of the 14 PLWD interviewed, only 2 had previous experience with technology, however, 12 of the carers had used technology both privately and professionally. The participating dyads all received three IT training sessions following their reminiscence training. In general, participants found this training very helpful and supportive.

> *"No. It was great. Not only, if you were scared that you were going to be missing something that she was saying, you know, you were trying to take it all in, there was a wee booklet, and it gave you step by step as well, which was a great help" (*C 5)

> *"I found A (IT Trainer) brilliant, you know, the way she could explain to me and help me, do you know what I mean, I found it great like that, you know, she was, and then she also left me a A4s, you know, directions of what to do and all, but she was very helpful, you know." (C* 6)

> *"Well, the training in using the iPad and the app part of it was sufficient. I was able to do that, no bother, even though I had never used an iPad, or an iPhone, or, any of those types of things in my life, you know." (*C 13)

Some of the dyads felt that the constant practice and usage of the device was the only way to ensure they did not forget what they had learned. They found that time working through the app was crucial but a minority believed that more training would have benefitted them.

> *"if I wasn't using it for a few weeks I would just forget again, like anyone it's the practice keeping doing it"* (C 3)

> *""if I had have had a wee bit more time it might have been more helpful." (*C 13)

> *"Well, it depends on how much time the person has that's doing it, I mean you can't expect somebody to be with you every week if they're doing other things." (*C 18*)*

Carer Support - "*Able to keep me right"*

Some PLWD felt quite nervous about using the InspireD app and consequently, depended on their carers to set it up and to support them when using it.

> *"At the start I was a bit wary of it, you know, because I never had used nothing like that, but then with her coming out always, and with X(Carer's) help, and my other daughter, I only had the two daughters, you know, her showing me, I feel that it's great that I can look back over my photographs. And there's some music on it." (*PLWD 5)

> *"I forgot quite a bit but X (Carer) has a good memory and she was able to keep me right. Just the basic things now. I'm starting to get really good. I'm faster as well.* "(PLWD 7)

> *"Aye, it was grand. I would be very, very slow in picking a thing up, but I'm getting on to it now. The wife knows a bit about it so she can help me." (*PLWD 14)

> *"…at first Y (PLWD) was scared with the working of it but now she's beginning to, if she gets mixed up or anything she'll say to me I'm lost here, I just straighten it out if I can" (*C 12)

Most carers felt that a bit of extra training would have beneficial throughout the study to improve their confidence and ability to use the app. Some stated that such training may have been more appropriate in shorter and more regular sessions rather than the three one-hour they had received.

> *"I think what, why we haven't pushed and gone a bit further yet is because we did have the hiccup, we were absolutely terrified of it happening again so we thought if we get it all done, get it on a memory stick that if it did happen again, and I think it had just made us a bit nervous."* (C 8)

> *"I think I'm one of those people that needs to be shown things a couple or three times, I don't, I'm not one, I'm not a person to pick up straight away so it would be practice with me. So, probably, maybe not so much a bit longer but more often if you know what I mean, it's not going to, if you try and teach me a whole pile of stuff in 2 hours you'd be as well doing it in 4 half hour sessions. That would suit me better that way, you know."* (C 16)

> *"Because of the way you had to like, events and working and family and history and all of that you probably could have went into that a bit more you know. Aye, probably, could have had more training on that aye." (*C 29)

Carer Unengaged - *"I'm not accepting of it"*

In the case of dyads who struggled to use the app or admitted to infrequent usage, carers acknowledged they had not adapted well to this type of technology or felt this type of medium was not appropriate for their loved one. Without carer support, usage of the app to facilitate reminiscence was not as impactful for the dyad.

> *"I would put the whole thing down to me. I'm not accepting of it. I wasn't maybe doing as much as I should have been doing."* (C 9)

> *"Well definitely for some people who are not au fait with computers or…it was a very difficult mountain to climb…I am neither a TV fan or a radio fan or any…I have no interest in any of them things at all…not at all."* (C 11)

> *"I'm not too bad, I work with computers day in and out, I've phones and all this. Y(PWD), very, very little, very, very little technology. At the moment, even the telly stumps him, phone confuses him, so I don't think really the iPad gave him the experience you were all looking for. Training was brilliant, the girls were brilliant, gave everything, answered all the questions and again, I just think, wrong medium, I think the iPad, the apple, it's awkward to load." (*C 25)

Usability- "It's Part of My Life Now"

The carers interviewed attributed the ease of use of the app to the reason they remained engaged with the project throughout the duration of the study. They also considered the app an immediate tool which could be used to support their loved one. As a result, it became integrated into their lives life despite a lack of confidence at the outset.

> *"It was simple. It was nice and easy, wasn't it daddy, the wee app and the photographs, it was easy to do. You know, I think that, because the programme was so simple, do you know what I mean, if it had've been something more complicated I think we would've lost interest."* (C8*)*

> *"You know so it's handy just as an immediate term of reference."* (C 3)

> "*It's just a, yeah, it's a tool for helping to orientate her"* (C 13)

> *"It's a part of my life now. It was something that I never thought that I could use. I didn't think that I could use that…" (*C 4)

Convenience and Mobility - *"We took the iPad out for dinner"*

The ease of use was very much influenced by the compact nature of the iPad which participants felt they could carry with them throughout their day and use at their own convenience. The memories captured were very precious to the dyads and it followed that a secure and protected virtual storage space which could be kept clean and protected was particularly important to them:

> *"Well, the thing about it, you have it on your knee, and you can sit and just go through it, you know… Whereas, if it's an album, usually they're stuck in a drawer or something, and you wouldn't be bothered going to look for them." (*PLWD 5)

> *"I think it's wonderful because it's so small and so compact. It's something that you can give a little wipe and clean and it looks good and everything is stored in there, all that information that you want about your family history from when you were growing up, right through to now. Everything is in there and you just find what to click on. Everything is in there for you. It's so small and neat and compact. They're not like photo albums. They get all dusty and dirty. You can keep them in a little plastic sleeve and give them a wipe and look after them." (*PLWD 7)

> *"because the photographs are so precious… mum's able to share it with the grandchildren who are what, 9 and younger and you don't want them, hands all over these photos and things like that. So, you know, having it on an apt where you can wipe the screen it's just, I think it's just fantastic." (*C 8)

A significant factor which impacted the convenient use of the iPad app was its mobility. The InspireD app offered a different way of capturing their day to day life and that of their families. It became a travel companion and even a dinner guest on family occasions that were special and significant to the dyad.

> *"And when we go away for a drive in the car…that there goes with us… It goes everywhere with us…. "So, it brings the trips alive." (*PLWD 4)

> *"Like, because sometimes you're away in the car, it's something, like, you, sort of, like, taking binoculars with you." (*C 4)

> *"I hope to be able to, bring it, say go down to Mayo and bring it with me" (*PLWD 3)

> *"When she gets visitors, aye, she just loves it, or when something happens, like, when my brother was back, we took the iPad out for dinner... usually mobile phones are banned at the table, and all this, but we were allowed the iPad out for photos and all, and she was trying to take some herself."* (C 5)

Functionality - *To keep the memories going”*

Participating dyads enjoyed the use of all functionalities such as photographs, music and videos. However, interview participants indicated that using the app to look at photographs which were particularly special for them helped to trigger memories for the dyad to discuss.

> *“Photographs, photographs definitely… Because it’s visual, it’s visual, you know… And I think you need that, you know, visual side of it to keep the memories going too” (*C 8)

> *“You can write; you can have your own captions. I know you can write on the back of photographs too, but… We, sort of, we write time and date, well, I do it with all my photographs anyway, but a lot of photos is just like a bit too suffocating… She can almost pick her favourites.”* (C 5)

> *“Why I’ll use it most of all, if I’m doing something which is interesting I keep it and I if I go back to the photograph, if I’m having problems, it would sort of make it easier for me to think.”* (PLWD 29)

For some participants, music was the preferred function as it allowed them to access music that was particularly special to them. They could also listen to it at times throughout the day and night which they found particularly beneficial.

> ***“****My main interest overall is listening to music… And I have a much better access to achieving that with this equipment.” (*PLWD 17)

> *“I love it for the music…I use it at least every other day, but some days two or three days in a row. There are nights when I don’t turn it off until 12 midnight or after it. I go to bed and take it with me.”* (PLWD 14)

Some participants commented that they found the video functions particularly exciting and innovative as it allowed them to capture memories currently being made. It also appeared to trigger special shared memories of TV programmes significant to the dyads. In this way, the video function of the app enabled the present to be preserved for the future and the past to be relieved in the present.

> *"Y was having a great time with the children playing and, what was it, Junior Monopoly or something like that, Snakes and Ladders, you name it. And like they were a pantomime and my son actually videoed them, you know, them with y, it's great, it's on the iPad and it's great craic, so it shows this here." (*C 18)

> *"And she also put on, when we were, you know, used to go out years ago we'd come home on a Sunday night really early to see Glenroe (Irish television Soap Opera) and she put that on for us and we just, I'm just, it was as good for me because I loved it."* (C 6)

For some carers the usage was enhanced by further extending the existing functionalities to accommodate extra functions such as YouTube, Skype/FaceTime and a Flicker photo account. This extended usage provided an even bigger source of connection for the PLWD as they could seek out music which held specific memories for them or as a means of visual communication with family who lived away. Some carers expressed a desire to link the app to a Facebook or Flicker account although this was beyond the remit of this particular study.

> *"She was on YouTube and she listens to music on it." (*C 12)

> *"Well, I like the idea that I have Facetime on it now… but I mean that's good for him too, do you know what I mean.* (C 6)

> *"I would have liked more, maybe working along with Facebook or something that, you know the way they've added photographs to Facebook and I wanted to put them on to that, I didn't know how to do that, that you could link up. The flicker account gets added on it, it's an account for all the photographs, you can't transfer them onto granny's memory page. They have to be direct from, you have to take an actual photo off a photograph, or in person…. So, you can't download it onto the memory book... So, you can't download directly from flicker."* (C 5)

Home Use - *"It was Homely"*

A key aspect of this intervention, which included reminiscence training, IT training and independent use of the app, was the home based nature of its delivery. All of the interviewees found the home based nature of this intervention especially appealing, as it enabled them to feel safe and secure which was integral to their involvement in the study.

> *"So there's that safety that you're in your own space for starters and just talk about the pictures on the wall and it's more relaxing and then also, if they're using that technology in the home it's not as if it's outside and it's separate"* (C 3)

> *"I never would have gone anywhere. I just wouldn't have gone out of the door. I wouldn't have gone anywhere…I'm in my own atmosphere. You don't feel as if it is…it's just like somebody you're chatting to… probably more confident. That's probably what you feel more…more secure…in your own house".* (PLWD 14)
>
> *"Oh, it was brilliant. You didn't have to go out. The people come to you, and it was great. You were in your own home, that you didn't have to, oh, my god, I don't feel like going out today…It was brilliant. I think it's really brilliant in your own home."* (C 4)

> *"the fact that you're just being where you normally are… In surroundings which was totally familiar to you" (PLWD 17)*

Participating dyads further articulated that the home-based nature of this intervention enabled the PLWD to feel more relaxed. This in turn facilitated the sharing of more personal and intimate memories in private rather than having to navigate the challenges of a more group based activity. This was considered key to their continued participation in the study for the 3 –month period of home use.

> "*You would be withdrawn if it was any other place, if that would be the right word to use? "I probably wouldn't have been as open…I feel more relaxed, would be the main thing I think, your home environment."* (PLWD 3)

> *"I think it was more personal and easier. You're in your own space and you feel calmer and, I suppose, more truthful. If you were in a group in a centre, you'd probably be saying things to*

> *please people. When you're in your own home, you think, 'This is the truth'. I think in the centre, where you would be with other people, you'd be very wary of what you said. I certainly wouldn't say that I get a bit of peace at night. They'd probably think, 'Oh my goodness, listen to her!'."* (C 7)

> *"Well, I think you can express yourself better in your own home…Not so much, I just think it's just nicer to talk face to face with somebody rather than in another room with other people… Because everybody's thoughts are different." (*PLWD 16)

> *"Well, I suppose it's the intimacy of it, I don't think I would've enjoyed it as much, you know, open space if you understand what I mean. No, no I think this is a much better idea…an added bonus that it was at home, definitely."* (C17)
>
> *"It was good… It was homely, the people I was working with were very good, very kind, very understanding and brought a lot, brought a lot to my mind and depth you know" (*PLWD 29*)*

> *"I think that's a good thing. I think it would've been more intimate as in it's just you or it's just mum rather than there being 10 people out or whatever it would be." (*C 16)

Outcome Measures- "Sometimes you have to ask personal questions"

As this was a feasibility study, participating dyads were questioned about their thoughts on the primary and secondary outcome measures used during Phase 2 of the data collection process which explored mutuality, quality of relationships, wellbeing and community health and social care service use. As some of these instruments included questions of a personal nature, interviewees were asked their opinion about these. Most participants did not identify any major problems with the questions:

> "*Oh, I didn't have any problem with them at all."* (*C 18)*

The majority of participants viewed the outcome measures questions positively, stating that they enabled them to talk about aspects of their lives and their relationship that they didn't often get an opportunity to think about or discuss with others.

> *"I think it's just because, not everybody comes in and ask you about your relationship and even our children like, one or two of them think we're quite soppy because we just, that's us, we love each other and that's it." (*C 12)

> *"One simple reason… you're asked questions which you wouldn't normally expect to receive, on subjects which you take for granted."* (PLWD 17)

> *"They brought a sense of normality now, not normality but a sense of, what way will I explain it? I've been more aware, more aware of my feelings more than anything and trying to understand them, it helped me there."* (PLWD 29)

However, a minority of carers expressed negative views about the questions, citing them as unnecessary and unrelated to their understanding of the project, irrelevant to their current situation and not focusing on the aspects of the relationship most challenged by the diagnosis of dementia.

> *"Some of them unnecessary… the degree that I didn't fill some of them in and I did say to (X , the researcher), like seriously this is just totally unnecessarily, doesn't even need to be asked…"Well, I thought they were quite unrelated to the project and it's not that they were too personal because I think sometimes you have to ask personal questions to, you know, when you're doing things like this but some of them just weren't related to a degree that I said, is that necessary even to fill that or."* (C 8)

> *"Terrible. Yeah, I thought they were awful. Some of them were… It was the same thing but putting a different language into it…but they weren't actually, there were some, you could ask other questions which would bring out more of the difficulties and that, that you would be going over, if they were worded properly."* (C 15)

Impact of Usage- "A wee bit of self-worth or comfort"

For the PLWD interviewed in this phase of the study, learning to use the app to connect to memories, and the feelings that underpinned these memories, had a significant impact on how they felt within themselves. They commented that the experience of using the app to facilitate reminiscence had enabled them to feel capable and in control of their memories and their feelings.

> *"It makes me feel that I have everything on it that I really need, and it makes me feel better in myself that I can lift it, and use…But since taking part in that there now, it has, kind of, levelled everything out, you know" (*PLWD 5)

> *"Well, it made you feel as if you were more in tune with everything, if you know what I mean, if that makes sense? Well, it gets your feelings out and you can talk about them." (*PLWD 16)

> *"I think it's good and it's a sharing, caring opportunity in your life to do something that's really wonderful; the iPad and being able to store it and all the technology and the films and the music and all the entertainment. I think it's great. And then the comfort of your own home" (*PLWD 7)

From the perspective of participating carers, usage of the Inspired app was also impactful. However, the degree of impact experienced by carers appeared to be directly related to the positivity demonstrated by their relative living with dementia and the way in which the use of the app triggered memories and connection for them. Usage of the app also highlighted to carers that they were not alone in their journey and the intervention, by its very design, made them feel they were enabling their loved one to find comfort and self-esteem.

> *"I could see him lighten up, do you know what I mean, when he'd see pictures or music or something that he knew, do you know what I mean. I could see him interested in it which I felt was, he doesn't have much interest in anything really" (*C 6)

> *"I feel happy because I can look at X's (PLWD) face and see X (PLWD) lighting up." (*C 4)

> *"It makes you kind of aware as well how many people out there, the same way and you know something like this programme here would help, might give him a wee bit of self-worth or comfort, do you know?"* (C 29)

"You've nothing to lose, and something to gain"

Participants were asked about their experience of being involved in our study and about their interest in future dementia research studies. Carers felt that their experience had been beneficial but recommended more IT support and the application of the InspireD app to mobile phones.

> *"I would really recommend it to anyone with memory problems or, I really would honestly, I think people be very foolish to not avail of it because I feel that it has helped us, you know" (*C 6)

> *"I think the, being able to use the iPad and, you know, maybe just having, meeting such lovely people so it's a good thing, it was really great, you know, because you felt, I felt quite happy about the whole thing when, you know, when they were coming to see me and things like that. I wasn't sort of stressed or anything like that, I thought it was, you know, quite enjoyable so. It helped, definitely helped, very helpful, you know." (*C 18)

> *"I do think that if this application was on the phone as well, that if you're in, you know, if you're in certain places, you know, just for an instance if we were going to the hospital with dad, I can't leave the hospital with mum because she'll fret. If you had the likes of that on the phone… she is reminiscing about older times if you're in certain places, you know" (*C 16)

> *"I've no criticisms really. I would just say, you need to be ultra-careful and making sure that the person participating with, you know, the relative, or carer, or whoever it's going to be, is going to be able to make use of the iPad, you know…I think it was very worthwhile, you know… and I'm glad now, that I did, you know." (*C 13)

Participants living with dementia described how much they enjoyed their involvement in the study and the way in which they looked forward to the home based reminiscence and IT training sessions. They further described how they found the process and the design of the study to be sensitive to their needs and their experience and they expressed sentiments of gratitude rather than putting forward any specific recommendations.

> "Well I thought it was brilliant from start to finish and I really enjoyed it and looked forward to you coming." (PLWD 3)

> "Just that, my experience of working here was excellent, really enjoyable, understanding and caring and I would advise anybody else that if they could do that their programme there it would help a lot." (PLWD 29)

> "It's just wonderful to have people like you who care about people like me and want to do something wonderful for me, like giving me the iPad, which I really appreciate. It's certainly changed my life and I love it to bits. Thank you very much." (PLWD 7)

Outcome Themes

Five outcome related themes emerged through the analysis of the data generated in the qualitative phase of our study.

1. **Impact of Diagnosis- "A real shock to the system"**
2. **Service Use- "I feel we are really isolated"**
3. **Ability to Remember- "There is still so much inside"**
   "It's become very close"
   "Memories that are important to me"
4. **Impact on Self and Relationship- "An Enjoyable way to Care"**
   "They are amazed at her"
5. **Greatest Achievement- "Keeping the Head Thinking"**

Impact of Diagnosis "A Real Shock to the System"

A number of participants discussed the impact of the initial diagnosis on themselves and their loved one and how this impacted their relationship. Participants described being numb with shock, feeling frightened about the future and what would happen to the life and the relationship they had known.

> *"it's a real shock, it's a real shock to the system."* (C 29)

> *"When there was a label put on it, you just go numb, you know, and you go numb for a few days... You just, how do I handle this? how am I going do it? I didn't know how to handle, to*

> *look after, you know, it's a big thing that you have no idea until it hits you what is expected off you."* (C 4)

> *"At the start, everything seemed to be happening too quick, you know. There was this, there was that, the other. There were people coming in, and get this, and you're getting that, and, now, I think it's more normal. She knows now she's just as normal as what she was."* (C 5)

> *"You understand it more yourself, because whenever they come and talk through, you know, what…at the start I was very worried, at the start" (*PLWD 5)

> *"She's coming to terms with it and now or as before she would have said like, I have dementia and I don't want to go into a home and all this. Now, she'll say, whatever happens we'll be together, it doesn't matter. She's accepted it and that's it now. Oh, it's made a big improvement in her mind." (*C 12).

Service Use "I feel we are really isolated"

Participants described how, since their diagnosis, they felt they had received minimal support from external services citing involvement in the study as one of the only contact they had made. As a result, carers, particularly in rural areas, felt isolated and unsupported.

> *"But there's nothing out there…because we live in the country it has affected a lot of – well, the services as well, but it can't be helped. We picked to live here, but we didn't know what was going to happen to X (name of PLWD)"* (C 7)

> *"Nobody had come to us and even after that there's, nobody from the, what do you call the dementia group, we haven't had any contact with them… So that's, our only contact really has been with yourselves"* (PLWD 18)

> *"Well, I haven't really been to talk to anybody… Or seen anybody or anything, no."* (C 18)
> *"So, no, I feel we are really isolated and I don't feel we get the support that we should be entitled to."* (C 25)

However, since their participation in our study, some interviewees felt they had regained the confidence to attend services provided by local community and voluntary groups. These groups were not specifically targeted at PLWD but included activities that PLWD and their carers could enjoy.

> *"I do go to a…I never went to nothing like that. Never, so I didn't. I just, I'm a, kind of, a family person and, you know, and they come to see me, or some of them would took me to see, but now I go to a wee group on a Tuesday morning" (*PLWD 5)

> *"so I think you know that would be good for us now and I think that it's something around yoga or meditation would be good for us or Thai chi so for balance or relaxation for the carers as well."*
> (C 3)

Ability to Remember "There is still so much inside"

Participants described how the process they embarked on in this intervention represented a different way of caring for each other and for exploring shared memories together. By engaging in a process of joint reminiscence, they were able to focus on what still remained and what they could still gain rather than a continued focus on the losses associated with a dementia diagnosis.

> "The study has been a way to engage with my mother in a, probably a more mutually enjoyable way, sometimes it can be very frustrating" *(*C 3)

> *"That has been good. That has been good because that's given us more closeness and something to do together. When I'm doing the photographs, we're doing it together." (*C 7)

> ***"****It's great, you know because you're kind of exploring things together you know in it." (*PLWD 12).

> *"I really love my mother, and I do, but that stress and caring can take you out of that and really realise oh this is an enjoyable way of part of the caring process…thinking about, it's a different way of thinking about caring because we tend to have, there's a lot of sort of negative really in the way, even though there might be love there, you know it's sort of presented in terms of*

> *what you would lose as a carer in your life rather than… that it could actually develop your relationship" (*C 3)

> *"You feel you're losing her completely and then during the project thinking my God, you know, there's still so much inside that head still, so and we need to get it out before, you know" (*C 8)

> *"you feel that you're getting through to them, that's the thing, it's getting through to them and hopefully they're enjoying it. Whereas, I mean for instance, a play or a film on television, they don't seem to be able to concentrate to that length of time and I don't think it goes in."* (C 17)

It's become very close

As a result of sharing memories that were individual, specific and special to the dyad, participants reflected that they felt closer to their loved one. Carers highlighted that having an aid for communication, a stimulus to share memories was a significant factor in this.

> *"I would say I would be closer to my mother, not to be so anxious in some ways that you can actually stop and do a different type of thing instead of thinking of all the things like medication, what's going to happen and whatever, that it's more an in the moment type of experience" (*C 3)

> *"it's become very, very close because you don't have to try and bring a subject up on your own, you just open the iPad and things happen and I find that great." (**C12)***

> *"We're still very close. We always will be, as far as things go. But having that there now it's completely different" (*C 4)

This increased sense of closeness was experienced and articulated differently dependent on participants' roles with the dyad. Some of the PLWD highlighted an increased level of openness and understanding in their relationship with their carer whereas other felt that their carer had become more protective of them.

> *"We were always comfortable but no barriers at all, no hidden barriers, if there's such a thing…. Really is more open I think now, I use the word open." (*PLWD 3)

> *"X (carer) is more protective now and all that, now, so she is, and she's always asking me am I all right, or getting up in the morning she's always shouting to me, are you all right granny, and, you know, and things like that. You know, she's more protective of me now." (*PLWD 5)

> *"I think he's more understanding… Well, I think it's talking about it and accepting the way that I am, you know, but trying not to think about it. I don't let it be the main thing in my mind that my memories not good." (*PLWD 16)

Carers talked about the way in which they had developed a richer perspective of their loved one as an individual with memories and a story of a life lived. As a result, they felt that they had more patience, respect and understanding for their loved one.

> *"I'm a bit more patient or maybe it's just the time I'm actually taking to do it is a big thing, especially in today's world. So, if you're sitting and you're actually looking and choosing and talking then that's something that mightn't otherwise have happened. You know, so closer in some ways and I suppose when your mammy's your mammy you don't look at your mammy as sneaking out the window to the dance or you know whatever, you know that type of thing" (*C 3)

> *"Doing the project is I think a lot of respect has to be given to my mummy for the memories she has about this which has helped me to realise that there's still a lot there, do you know what I mean?"* (C 8)

> *"It's stuff I wouldn't have known about, you know, you don't tend to think about, you know, mum will chat about things with dad and chat about things, I might catch bits of it but mostly now I'd spend a bit more time with mum chatting about all the times and the things she got up to when, you know" (*C 16)

"Memories that are important to me"

Participants described how important memories of their loved ones were to them. Photographs of family members, family holidays and of their early life together were particularly special to them.

> *"The most important memories to me is that my wife and myself is on it, and the grandchildren are on it." (*PLWD 4)

> *"I would say whenever we were younger, really. We used to go on holiday together. Whenever I first met her in Bangor…Memories like that, whenever we were young. We started to go out together and hang about together and she would go to her friends' and see her friends at the weekend and go out dancing with them to a dance. I didn't like dancing but I used to wait outside for her." (*PLWD 7)

> *"The most important, God, they're all important to me, aye…I remember things or, laughs and things, you know, me and her went to Scotland when she was young… Things like that there, you know. It's all important things is all about her."* (C8)

> *"Memories that are important to me. Oh, I think family, friends, what we've done, where we've been, where we've lived… Well, it's nice to think that he could remember them." (*C 17)

However, some carers acknowledged that not all memories were happy and spoke of the challenges they encountered revisiting such memories and understanding the significance they held for their loved ones. Although distressing at the time, this process appeared to be crucial to reconnecting with the PLWD and this, in turn, enabled the dyad to address the feelings behind painful memories while preserving them on the app.

> *"At the start, I was a bit emotional, because all the photos, like, my mum, and my granda, and Y (carer's son) when he was a baby, and my brothers, and all is on it. But, no, it's nice now. I think you get over that wee hurdle. Then something always comes back to her every time you use it." (*C 5)

> *"X picked out lots of photographs and he picked out a few of my daughter's funeral. I didn't like that. They were hard, but they were what he picked and there was nothing I could do about it. They were his memories; they were what he wanted for the iPad. I would flick through them but this is all about X, it's not about me."* (C7)

> *"Ones which, you know, happened during the Troubles, you get worked up a wee bit when you tell them. But the other ones, you know, which happened to me when I was younger they were*

> *different, you smiled, laugh at them but when you get to the serious ones that happened to you, your sort of memories come back."* (C 8)

> *"Even when the, well I say when the children were growing up and, you know, memories we've had of them and, you know, even the two wee boys that died, you know, things like that, you know, we can talk about it. I would say maybe even more now than we could at the time, you know, so I would say it's been good, you know, even."* (C 18)

Perhaps not surprisingly, some carers found the recollection of memories by the PLWD, that did not include them, to be difficult to handle. This indicated that shared memories, regardless of their nature, were particularly impactful for connection and closeness.

> *"…he's been married before and I was married before so, I don't really feel that we've probably benefitted as much as some couples may have, we haven't got that memory together"* (C 25)

> *"I would like to sit and share memories with X (PWD) all the time, but as I say, X (PWD) has a one-track mind as regards things to do. Those things to do are mainly to do with cars. That was part and parcel of his whole life and you can't weed that out. I would like to be able to share a whole lot of things with him, but I know I won't get a good response sometimes and then I don't bother."* (C 9)

Impact on Self and Relationship- "An Enjoyable way to Care"

For the participants living with dementia, involvement in the research study appeared to have had a significant impact on their sense of wellbeing. They discussed how they felt they were able to feel more content and were more conscious now of the importance of keeping their mind active.

> *"You feel more content. You're sitting quite content doing it." (*PLWD 14*)*

> *"I would be more conscious now to keep my mind more active, you know, too." (*PLWD 7)

> *"Yeah, it helped me find myself again, so it did." (*PLWD 29)

Carers described how this change in their loved one directly impacted the dynamic of their relationship. While the benefit may not have been immediate, they began to notice this change in mood and self-perception in their loved one over time. This created the opportunity to relieve and create new memories but ultimately to celebrate the life they had lived and continued to live. Carers also noticed a change in themselves as they had access to a new of caring for their loved one which was enjoyable for the dyad.

> *"You don't realise the benefit. You don't notice it right away, but, maybe, over three weeks, four weeks, you do notice it, you know, the change in the people." (*C 5)

> *"On Saturday night we have a couple of cans of beer in the kitchen and we bring the iPad in and we put our music on. I'll choose things like 'Puppy Love', because that was our song when we were children. We grew up together and everything. It brings back lots of nice memories; you know? We have the odd wee dance" (*C 7)

> *"And just capturing huge enthusiasm about the life she led"* (C 13)

> *"it's a different way of caring than we think, see it as more person centred caring, a holistic way of caring and looking at them as the person, as I say it's all new to me and I would have thought I'm a very patient person but I would have found myself snapping at the seventh time and then feeling really terrible and feeling oh god that's terrible, it's terrible doing this but then like you're not taught…this project actually works very well… I think presenting it maybe as an, as an enjoyable way to care"* (C 3)

"*They are amazed at her"*

Participants also discussed how an increased sense of closeness and connection was not just confined to their relationship but that it also impacted the wider family circle and in particular, younger family members. This trans-generational impact was attributed to the use of modern technology as it made their loved one, and the memories significant to their life story, have contemporary relevance.

> *"Well, the children would come up and show X(PLWD) how to work it and it was one of the children who showed her how to go on the YouTube first and then she asked me how to do it, so she's learning from them as well … They're amazed at her." (*C 12)

> *"My daughter and my sons…. Oh aye. They like me to use my mind, to keep tinkling on it. They do. They think it's a great idea…. I suppose they're happy that I'm doing something. They love the music.* (PLWD 14)

> *"The memories are protected but on the other side of it too, I know for a fact like knowing my dad's two grandchildren that are both 9, would rather get handed an iPad than get handed a book. So they actually are taking more interest because it's on an iPad" (*C X)

> *"They would actually relate more to it through the technology in this way than if you said, oh, here's the photos, do you want to see some of the old photos, no say here, do you want to look through this and see do you like any of them, they'd engage much more" (*C3)

Greatest Achievement- "Keeping the Head Thinking"

Participants were asked at the end of each interview what they viewed to be their greatest achievement as a result of their involvement in the study. The responses to this question were varied but, interestingly, showed a different focus dependent in the dyad role. Carers described their achievements to be more relationship and 'outcome' focused.

> *"The biggest achievement is being more understanding… and learning to say nothing at times, you know, when they're just repeating themselves over, and you're, like, you told me that already." (*C 5)

> *"I learned a lot from them really, you know, from, really did learn a lot I felt, you know, about the disease and what he should, what interests him and things like that, you know. Which I wouldn't really have known, you know." (*C 6)

> *"I suppose just the whole thing, there wouldn't be one stand out thing, not that I can think of anyway, it would just be the, you know, being able to I suppose, take them 10 minutes or 20 minutes or half an hour and spend that sitting with mum going through this, I mightn't have done that before now."* (C 16*)*

For participants living with dementia, their biggest achievements appeared to be more 'process' focused in that that mastery of modern technology and learning a new skill was a significant personal achievement for them at this stage in their dementia journey.

> *"The training on the app was the turning point for me. That was the turning point for me" (*PLWD 4)
>
> ***"****The wee iPad definitely. The iPad and getting on to it. There's a lot to learn on it yet. I've plenty of time to do it. It's keeping the head thinking."* (PLWD 14)
>
> *"I put everything to do with my life and the people I love inside a little piece of machinery that is wonderful. At the touch of a button, it can reflect everything that has happened to me in my past and the lovely people I've met" (*PLWD 7)

Summary

The analysis of the semi-structured interviews explored two key aspects of the feasibility study related to process and outcome. Five core 'p*rocess'* themes emerged which highlighted how positively participants experienced reminiscence and IT training and the compatibility of the app with their daily life, while also identifying the necessity of support and engagement. The outcome measures used to explore mutuality, well-being and the quality of the caring relationship were deemed appropriate by most of the participants although a minority stated that the instruments used did not capture many of the challenges with caregiving relationships in the context of a dementia diagnosis. The positive impact of the intervention on relationships and as a confidence building measure, particularly for PLWD were also key themes.

The second aspect of this feasibility study explored *outcomes,* resulting in the emergence of*,* five core themes. The devastation of the diagnosis and perceptions of limited support from external services, provided an emotive thematic context for this exploration. The dominant theme of this aspect of the analysis focused on the impact of the intervention on relationships and on a new narrative that recognised abilities and gains rather than losses and disabilities. The significance of personal memories was a core theme although this was not without its challenges, particularly in situation where such memories were painful. The intervention had a significant impact of the dyadic relationship and was viewed as an enjoyable way to care for themselves and their loved one. Personal achievements through study involvement were revealed, differentiated by the dyad role. Carers' achievements tended to be more relationship and outcome focused, whereas the PLWD expressed these as 'processes' citing app usage and their ongoing skills development as particularly significant.

Chapter 10 -

Discussion

Introduction

This study comprised three distinct phases. Phase 1 focused on developing and testing the InspireD app which was subsequently introduced to 30 PLWD and their carers in Phase 2. Phase 3 constituted the qualitative arm of the study where the views and experiences of participating PLWD and their carers were elicited. This chapter highlights key findings and critically analyses these in the context of other literature on the use of technology facilitated reminiscence for PLWD and their carers.

Technology development and testing

It is widely accepted that user involvement in the design and testing of IT systems is necessary (Lazar, 2014; O Connor et al. 2016). Others have highlighted the important contribution that PLWD make to the development of user-friendly, supportive IT applications (Span et al. 2013). The InspireD app, created to facilitate an individualised approach to reminiscence, was developed with input from a Lead User Dyad and a User Development Group. This approach ensured that the views and opinions of seven PLWD and their carers informed the design of the app.

As more apps and medical technologies are being developed for use by PLWD, it is becoming necessary to adapt and refine traditional research methodologies to effectively evaluate the usability of these applications (McHugh et al. 2014; Kerssens et al. 2015). Perhaps, not surprisingly, the testing of the InspireD app by PLWD and their carers using standard usability metrics in Phase 1 yielded interesting findings which merit further discussion.

In Phase 1, we wanted to establish whether standard tests and matrices were adequate for evaluating the usability of an app for PLWD. Dementia is likely to adversely affect short-term memory, and the thinking and reasoning functions of the brain (Alzheimer's Society, 2017; Wayman, 2017). As a result, protocols which involved estimating values, for example levels of difficulty or describing processes (Sauro and Lewis, 2012) or thinking aloud as they completed a task (Lewis, 1982), were the most problematic for PLWD. People living with dementia also found it difficult to assign a value for the SEQ (Single Ease Question) pre- and post-task ratings devised by Sauro and Lewis (2012).   Asking them to assign a number to a perceived difficulty rating was problematic for PLWD and only the carers were able to give a reliable difficulty level to these questions. It was also found that completing post-test questionnaires, administered after an event, presented a problem for PLWD, perhaps exposing short-term memory loss. Two out of the six PLWD were unable to complete SUS (Systematic Usability Scale) devised by Sauro and Lewis (2012) as they could not understand the questions sufficiently or remember their experience of using the app. As a result, the reliability of the SUS scores could not be assured. The overall SUS rating given to the InspireD app by carers was 67.5% and the 4 PLWD who completed the SUS questionnaire awarded the app 78.75%. However, the task completion rates indicated that carers found it easier to use the app than PLWD. The disparity between these two results may be explained by an unwillingness on the part of the PLWD to admit to difficulties with the task or by a desire to please the researchers.

As reported elsewhere, most of the carers found it easier to use the application than the PLWD (Karlsson et al. 2014; Hamel et al. 2016). Carers completed 100% and 96% of tasks successfully in the two respective workshops. Of the PLWD, one person was unable to complete any of the tasks successfully and although the other five people completed some tasks without help or prompts, completion rates were much lower than those of the carers. It is important to acknowledge that post-test surveys such as the SUS instrument can be difficult since they require accurate retrospective reflection of their user experience. Additionally, the SUS survey itself has an intricate design where the Likert scale of each question alternates between the highest rating being positively or negatively worded.

The results of Phase 1 suggest that observation and recording of task completion rates and times (Bangor et al. 2008; Gibson et al. 2016) produced the most reliable results. The use of a post-test survey such as SUS may not be reliable when measuring the user experience of PLWD since these users suffer from a cognitive condition that usually affects short term memory. A camera based mobile usability testing unit (MOD 1000: Mobile Observation Device) (Lewis, 1982; Sauro and Lewis, 2012) was equally unsuitable for this client group as participants assumed that it was part of the mobile application. Audio recording (Lewis, 1982; Sauro and Lewis, 2012) did not work since little to no 'think-aloud' data were recorded given that PLWD found it difficult to verbalise their human-computer interactions. This led us to conclude that standard protocols used to test the usability of IT systems and apps may not be appropriate for PLWD.

Our contention is that it is not enough to test the usability of a system using protocols where the measurement tools themselves may cause distress or confusion to the system users. Just as it is important to consider the needs of the user when using the system, it is equally important to be aware of the suitability of the criteria we are employing to measure its usability. It is possible that the methodology selected to assess usability, the choice of venue to carry out the usability testing and the amount of time given to allow participants to feel comfortable may have influenced the results. It is suggested that in future studies of this kind, data collection should focus on understanding errors related to usability rather than time on task or user satisfaction. This suggests that there is a research opportunity to design new protocols or to optimise existing ones to improve the data collected from usability testing of devices and apps in a dementia context.

User engagement

Although some studies have reported difficulty in recruiting PLWD to research studies (Karlsson et al. 2014), the recruitment and retention rates for the three phases of our study indicates that this was not the case. All aspects of our study were influenced by a growing body of evidence to suggest that PLWD can be actively involved in research and development activity and can learn and benefit from user-friendly technology (Magnusson et al. 2006; Hanson et al. 2007). However, Hanson et al. (2007) argued that success in this field is contingent on the following: (1) prioritisation of the well-being of participating people with dementia by ensuring that the project is run by experienced staff and that participants are recruited as early as possible within their dementia in order to maximise their learning potential, (2) allowing sufficient time for the creation of a supportive environment and for repetition of information and clarification of tasks, (3) providing active and continuous support by exploring participants' expectations of the project and avoiding overload by proper pacing and structuring of sessions and (4) ensuring the continued support and involvement of their closest family member. Our team was experienced in working with PLWD and their family carers and consequently made every effort to take these recommendations on board. This may have been a factor in the successful recruitment and retention of participants to our study.

The involvement of PLWD and their carers has been identified as vital to ensure that the most effective psychological and social interventions are trialled and made available, quickly and efficiently, to people living with the condition and their families (DHSSPS, 2011). The role of technology in facilitating social interaction for PLWD has received considerable attention in the literature (Kerkhof et al. 2017; Lorenz et al. 2017). The findings from Phase 1 reinforce the considerable impact such engagement has on informing the design and development of new supports, such as user friendly technology, to improve quality of life (Hanson et al. 2007). Our findings contribute to this evidence base and suggest that participating dyads viewed the InspireD app as having the potential to facilitate social interaction.

Our study has demonstrated the importance of working with PLWD and their carers in the co-creation of technology to positively impact quality of life and relationships. Consistent with the findings of other studies, IT training, ease of use, convenience and familiar memorabilia were key factors which enhanced user engagement with the InspireD app (Ancient et al. 2011; Savage, 2017). Participants acknowledged that, while personal memorabilia can be stored on other technological devices such as Laptops and personal computers, none of these provided the same user friendly interface as the iPad. Additionally, participants acknowledged the benefits of a mobile device in enabling the PLWD to have easy access to the InspireD app whether at home or out and about.

The focus group interview in Phase 1 also highlighted key issues relating to enhancing the usability of the system for PLWD. These have been reported elsewhere (Good et al. 2012; Lorenz et al. 2017) and included careful positioning of the icons and increasing font size. IT training was viewed by participants as essential. Consistent with Astell et al. (2010), the touch screen style device was well received. Additionally, participants highlighted the importance of personalised and familiar memorabilia relating to their locality or their own personal history. This finding concurs with Subramaniam and Wood's (2012) proposition that a more individual approach to reminiscence shows longer term psychosocial benefits.

Working with dyads

Subramaniam and Woods (2012) foresaw that the future would bring new opportunities for reminiscing and digital life story making, facilitated by touch-screen interfaces, and conjectured that this would have the potential to take forward person-centred care to a new and higher level. Our study sought to appraise outcomes from a feasibility study of individual specific reminiscence facilitated by a programme of training and an iPad app. Phase 2 of our study sought to quantitatively measure the outcomes of our home-based, individual specific reminiscence intervention for PLWD and their carers. A total of 60 participants, in thirty dyads, were recruited to the study. Thirty dyads is a significant increase from previous feasibility and pilot studies (Subramaniam and Woods, 2012) so a major strength in our study was the number recruited and the percentage of dyads that remained in the study at completion. Compared to other reminiscence studies (Charlesworth et al. 2016; Woods et al. 2016), we had a low percentage of missing data which lends support to the view that self-reported data from people living with mild-moderate cognitive impairment is reliable, valid and consistent (Logsdon et al. 2002; Whitlatch et al. 2005).

Only six (20%) of the PLWD had some or a lot of IT experience. In contrast and as reported elsewhere (Sarne-Fleischmann and Tractinsky, 2008; McHugh et al. 2012) the majority of carers (63%) had some or a lot of IT experience. Given the rurality of the geographical context of our study, it was encouraging to find that the majority of PLWD (83%) and carers (90%) had access to the internet at home. Our oldest PLWD was 94 years, and our oldest carer was 91 years. Fifty-eight participants (29 dyads) were retained in the study at completion. This is noteworthy as, over the course of our research intervention, many participants faced their own challenges which included illness, hospitalisation and bereavement. Despite this, they remained committed to our study supporting the view that neither age nor a diagnosis of dementia are barriers to engagement in research and technology (Smith and Mountain, 2012; Kerkhof et al. 2016).

Our reminiscence intervention differed in a number of ways to the approaches taken in recent studies (Charlesworth et al. 2016; Woods et al. 2016; Amieva et al. 2017) in that it was home-based with participating dyads receiving a programme of individual specific training in reminiscing and information technology. While the recruitment of dyads was essential to explore the impact of the intervention on relationships, the individuality of each dyad member (PLWD or carer) was upheld as evidenced by 1) the way in which the reminiscence and IT training attempted to addressed the needs of both the PLWD and carer, 2) the use of separate information leaflets and consent forms for PLWD and their carers and 3) providing each participant with his/her own unique access log-in details. While a person-centred approach to care has been advocated in the literature (Kitwood, 1997, McCormack and McCance, 2016), it was not without its challenges as there were occasions when the reminiscence materials selected by the PLWD were not consistent with what the carer would have chosen, either because they brought back painful memories or because the PLWD had memories of a life that the carer was not part of. These challenges have been identified by others (Dewar and Nolan, 2013) and suggest the need to find ways of delivering care that is both person-centred and relationship-centred.

Impact of the intervention

The three outcome measures utilised in our study were Mutuality (Archbold et al. 1990), Quality of the Carer-Patient Relationship (Spruytte et al. 2002) and WHO-5 Well-Being Index (Bech et al. 2003). All three tools have previously undergone extensive testing for validity and reliability and have been widely used in studies of this kind.

Across all the participants, the mean baseline Mutuality score was 3.13, indicating a moderately high level of mutuality, the mean WHO-5 score was 61.0, indicating a moderate level of emotional well-being, and the mean QCPR score was 57.4, indicative of a good relationship. It is noteworthy that there were no significant differences in the mutuality, WHO-5 and QCPR scores between PLWD and the carers at baseline. There was, however, a significant difference between the mutuality scores of men and women at baseline ($p = .036$), with women having the higher scores. The main findings from the study were 1) statistically significant increases with large effect sizes in mutuality, quality of caregiving relationships and emotional wellbeing for participants living with dementia, from baseline to endpoint; 2) non-significant differences in Mutuality, QCPR, and WHO-5 scores for the carer participants from baseline to endpoint; and 3) a statistically significant difference in patterns of intervention effect across time, with the participants living with dementia attaining a higher pattern of scores.

The disparity in mutuality scores between PLWD and their carers has been reported elsewhere. Lyons et al. (2007) examined mutuality in 103 care-giving dyads, of whom 40% of the care recipients had mild to moderate dementia. The study reported a significant negative trend in the mutuality scores of care recipients over a 20-month period and a non-significant negative trend in the mutuality scores of caregivers over the same time period. An interesting finding reported by Lyons et al. was that cognitive status was not significantly related to mutuality scores at baseline nor change in mutuality over time. In contrast, the physical health status of care recipients was positively associated with carer mutuality.

Based on the results of the most rigorous clinical trial to date, the ETNA3 study which recruited 653 participants from 40 centres in France, Amieva et al. (2016) recommended that individual interventions should be considered to delay institutionalisation in Alzheimer's disease. Recognising the need for high quality intervention studies in dementia care (Amieva et al. 2016; Dassel et al. 2017), the individual specific reminiscence outlined in our study, appeared to have had therapeutic value in the context of mild to moderate dementia. However, cognisant of the recommendation that clinical outcomes at two years is a standard time-point in dementia research (Lyons et al. 2007; Amieva et al. 2016), further research is required to explore the stability or otherwise of these changes over time and perhaps on institutionalisation patterns.

Interaction with the InspireD app

The use of traditional reminiscence memory books and latterly digital systems to facilitate reminiscing has been shown to have some benefit for PLWD (Lazar et al. 2014). However, there is a paucity of research that explores how these individuals actually interact with digital reminiscence systems (Span et al. 2013). The main focus of research on the analysis of event logs for computing systems used in assistive technology has been to aid in usability analysis or to reveal usage patterns in web browsing behaviour (Woo and Mori, 2004). Research has also been carried out to explore how rehabilitation devices can have data or event logging incorporated, but this has been more to support the goal of device monitoring (Miller et al. 2015).

It is acknowledged that research engagement can pose a challenge to care-giving dyads in the context of dementia (Woods et al. 2016), and perhaps it was not surprising to find that for four (13%) dyads in our study, interaction with the app was on a frequency of less than once per week. We found non-significant positive correlations between numbers of days that participants interacted with the app and endpoint mutuality and QCPR scores but no relationship was discerned between the number of days that participants interacted with the iPad app and endpoint WHO-5 scores. We also compared the effectiveness of two different levels of app interaction (app interaction on 12 days or more versus app interaction on 11 or less days) for enhancing levels of mutuality but found no significant difference in effect between the two levels of interaction with the app on the endpoint mutuality scores of participants. This suggests that a degree of caution should be observed when drawing conclusions about the impact of a qualitative experience (reminiscence) using purely quantitative measures based around frequency of usage. The key issue perhaps is not the frequency of app usage but rather, the quality of the experience. This has been reported elsewhere (Lazar et al. 2014; Kerkhof et al. 2017) and was further supported in the qualitative phase of the study where almost all participants reported positively on their experience of using the app.

It was interesting to find that the mean number of days that PLWD interacted with the app while logged in was higher than for carers. Although the difference was not significant, this was encouraging and suggests that PLWD found value in using the app independently. The qualitative interviews in Phase 3 further supported this finding as carers appeared to gain a bit of ‘guilt free respite’ from their caregiving role, secure in the knowledge that their relative living with dementia was engaged in an independent and enjoyable experience. This was particularly evident in music where often there were differences in music preferences between PLWD and carers. Consistent with other studies (Sharne-Flecishmann and Tractinsky, 2008; Mulvenna et al. 2011; Lazar et al. 2014) there were more interactions with photographs in comparison to music and video clips. Reminiscing, with its history in photograph-based memory books, has tended to be been more about the image rather than the music, sound or video (Wright and Mulvenna, 2012) and this is supported by the data derived from our study. What is also interesting in this data is the popularity of music among people living with dementia. Again, this is supported in the literature (Sixsmith and Gibson, 2007; Raglio et al. 2008) with evidence to suggest the positive impact of music in addressing the effects of ‘sundowning’ for PLWD (Bruer et al. 2007).

Carer involvement

The need for carer support has been highlighted by Dassel et al. (2017) who recommend that all carers of PLWD should be offered early cognitive screening and psychosocial interventions designed to help them maintain their cognitive and physical health during and following intensive caregiving responsibilities. It is internationally acknowledged that family carers are the most important practical, personal and economic support for PLWD (Dassel et al. 2017; Farina et al. 2017), and perhaps interventions that demand the support of carers are adding additional burdens, that can impact on their emotional well-being. With the recent trend towards dyadic approaches in dementia research, Laver et al. (2016) conducted a systematic review of forty studies to compare the efficacy of carer focussed approaches and dyadic focussed interventions. The authors concluded that there was no significant difference in the effects of dyadic intervention in comparison with carer focused interventions on outcomes pertaining to depression, quality of life, carer impact, behavioural and psychological symptoms and caregiver upset.

Our findings support the premise that sharing memories and experiences may be able to support mutuality and quality of informal care-giving relationships (Subramaniam and Woods, 2012; Daly et al. 2013). In three recently completed randomised controlled trials of group delivered reminiscence (Amieva et al. 2016; Charlesworth et al. 2016; Woods et al. 2016), the results indicated no overall therapeutic effect. Woods et al.’s (2016) randomised controlled trial found that higher attendance at group reminiscence sessions was associated with improved autobiographical memory, quality of life and relationship quality among PLWD whereas higher attendance on the part of carers, was associated with increased caregiver stress.

Researchers who have investigated factors associated with carer quality of life have reported that carers who live with a PLWD have poorer quality of life than non-co-habiting carers (Farina et al. 2017). This may offer a plausible explanation for the different usage patterns among cohabiting and non-co-habiting participants in our study. That said, we found no statistically significant differences between endpoint Mutuality, WHO-5 and QCPR scores of co-habiting or non-cohabiting dyads. It is interesting to note that the mean number of days that there was interaction with the app in the 12-week period of home use was higher among non-co-habiting participants. Although, the difference was not statistically significant, it is possible that the app generated a focus of engagement for dyads that were non-co-habiting. Although the use of technology to support reminiscence has been explored in long-term care settings (Hamel et al. 2016; Subramaniam and Woods, 2016), this finding suggests that the app may have potential for use across a range of care settings, including nursing and residential homes, where family members often find it difficult to engage in meaningful activity during their visits.

It is important that high quality intervention trials are conducted in dementia (Voigt-Radloff et al. 2011; Westerhof and Bohlmeijer, 2014; Amieva et al. 2016). Individual specific interventions, such as the reminiscence intervention in our feasibility study, appear to be producing more positive impacts than group based approaches (Amieva et al. 2016; Huntley et al. 2017) but further research is required to explore if it is possible to improve quality of life for PLWD without adversely affecting the wellbeing of their family carers.

In the moment data

In order to try and capture participants' feelings while reminiscing 'in the moment', we programmed the InspireD app to automatically generate a subset of questions (5 items) from the primary outcome measure, the Mutuality scale (Archbold et al. 1990) used in the study. The underlying factor structure of the 5 item mutuality construct was examined for both the 'in the moment' reminiscence data and the pencil and paper format. Although the complete Mutuality scale comprises 15 questions, an alternative approach that uses fewer items is acceptable provided that the underlying construct represents the same dimension.

The views and opinions of the User Development Group in Phase 1 were also sought in relation to response options for the 'in the moment' questions. Option 1 was a 5 point Likert Scale (Totally Disagree - Disagree - Not Sure -Agree - Totally Agree). Option 2 was a 3-point scale (Agree - not sure – Disagree) and Option 3 was a sliding scale from 0-100. Consistent with the original mutuality scale (Archbold et al. 1990), the majority of the group (n=7) chose option 1. Three people chose Option 2 and no one felt that Option 3 was suitable due to its perceived complexity and range. Although a 5 category response scale was preferred by the User Development Group, this may have enhanced the skewness of the responses. This poses a challenge to researchers in trying to promote patient and public involvement in research and suggests that ease of instrument use by PLWD may be achieved at the expense of the scientific rigour of the study.

Because of the skewed nature of the 'in the moment' responses, the current analysis worked with the assumption that the data were ordinal. A difficult issue, which may well be solved in larger studies, was the strong tendency for respondents to use only two (3 and 4) of the five response points on the scale. In essence our five categories were being reduced to two. It would be useful if the variance in the response scale could be increased in order to better separate the responses. Initially there were some convergence difficulties, probably due to the sample size and the kurtotic nature of the data but this was successfully overcome through the use of a Bayesian estimator.

Given the limited nature of the data, a series of factor models were analysed. Reasonable correlations were obtained both between PLWD and the carers. The correlation between factors evaluated on the basis of responses to the items on a first and second occasion were also reasonably high, as might be expected. People living with dementia had a surprisingly low factor loading on item 12 '*How much do you confide in him or her'*? (-0.09) on the first occasion and to item 11 'How *much do the two of you laugh together'*? (0.15) on the second occasion. This appears to indicate a considerable degree of change between responses to these questions on two different occasions. In the carer group, a similar inconsistency appeared on item 5 '*How attached are you to him or her?* (0.29) on the second occasion. Factorial constraints were not placed on the factor loadings due to the limited sample. It is also of note that many of the factor loadings are reasonably high indicating that the items are good measures of the underlying construct and can be evaluated consistently on two different occasions.

The study was designed to collect 'pencil and paper' responses to the Mutuality scale at the beginning, mid–point and end of the intervention. This provided us with a form of external validation, where responses to 'in the moment' questions could be compared with the pencil and paper tests. This was done separately for PLWD and the carers. Amongst the PLWD, the association between the measures taken 'in the moment' on two different occasions was high. This was in contrast with the responses to the pencil and paper test at the three time-points which were fairly low. This reasonably low pattern of association was also apparent across the construct measures using different methods (pencil and paper and via the iPad). This indicates a considerable amount of change or inconsistency in terms of the underlying factors. The factor loadings were reasonable but there appeared to be an issue with item 12 on the Mutuality scale on some occasions as evident by responses to the pencil and paper data and via the iPad. This question asked about confiding in the other person and it may be the case that this issue was a challenge in the context of dementia where there may be a desire to protect a loved one from potentially upsetting information.

Selecting a primary outcome measure

A key challenge for the research team was the selection of a primary outcome measure that would be best able to reflect the changes, if any, that occurred in the relationship between a PLWD and his/her carer as a result of sharing individual specific and personal memories. While previous studies have included measures investigating cognition, quality of life, anxiety and depression (Woods et al. 2012; O Shea et al. 2014; Charlesworth et al. 2017), only a relatively small number of studies have explored changes in the caregiver/care recipient relationship as a result of reminiscence (Woods et al. 2012). We selected the Mutuality scale, not because we necessarily thought it was a perfect fit for our study but rather, because it was the best fit from a limited pool of tried and tested measures of relationship quality in dementia care. However, in retrospect and acknowledging that the scale did show a statistically significant improvement in mutuality from the perspective of the PLWD and a non-statistical improvement for carers, our view is that this instrument in its current format is not entirely appropriate for use in dementia studies. We were not surprised by the poor responses to item 12 which asked '*How much do you confide in him or her?'* Responses to the DEMQOL proxy used in the health economics component of the study suggested that carers no longer confided in the PLWD (e.g. about financial matters) so as not to worry them. On reflection, Item 14 of the Mutuality scale which asked '*To what extent do you enjoy the time the two of you spend together*?' may have been a better option for the 'in the moment' data but it is acknowledged that item 12 would still have emerged as problematic in the pen and paper data collection method. It is also important to note that, whereas during the pen and paper completion of the Mutuality scale, the PLWD and the carer were interviewed separately, this could not be guaranteed with the 'in the moment' questions. It is possible that respondents may not have been entirely frank or honest if they knew that their responses were being observed by the other dyad member.

The 'in the moment' responses via the InspireD app for both PWLD and their carers were compared to their responses to the Mutuality scale administered by the researchers using the pencil and paper method. In general, the factor loadings were higher and the correlations, both with data collected via the same method and that collected across different methods, were much higher. The carers gave a much more consistent set of responses both in terms of the underlying factors and in terms of the association between the factors. It is also evident that the response to question 12 regarding confiding in the other person was not in line with the response to the other questions. The issue of limited spread in responses to the questions was particularly evident amongst the carers where responses to some items had to be removed from the analysis because of the lack of variability, as everyone responded with a 4.

As evidenced by the 'in the moment' data, certain items were not performing as expected; for example, a number of poor factor loadings were recorded using different methods of data collection. This issue of the reliability and validity of measures becomes more important for PLWD as it is possible that less reliable and valid items may place an extra cognitive burden on them. More culturally and condition specific pilot work is required, as reports of reliability and validity are almost always sample specific. Over-reliance on reported validity and reliability may therefore not be sufficient, particularly in the context of studies such as this, involving people living with dementia.

In terms of responding to the five questions relating to the construct of mutuality, both the PLWD and the carers provided reasonably consistent responses, but some questions appeared to be more problematic for PLWD. There also appears to be much more change in terms of the underlying construct for PLWD. This pattern of change in PLWD requires more detailed examination in further research. Is there something about certain type of statements or questions that leads to confusion amongst PLWD or are we actually seeing real change and is this just fluctuation over time? Either way it is likely that an 'in the moment' response via computer is the most likely method to provide answer to these types of questions.

One option by which this could be examined would be through the use of time series analyses such as a first-order autoregressive AR (1) model with both a random intercept and a random slope, as used in this study. Of course with such limited data, other options might be preferred, especially given the limited number of occasions available in the data. Nevertheless, the methods used here open up an avenue for the examination of change, especially for PLWD where change even in this limited study in terms of time constraints, appeared much more rapid. The nature of this change, however, remains an open question.

The 'in the moment' data strategy is certainly one way forward, as responses can be obtained on many occasions within a short period of time for the same individual. There is a need to understand what is relatively stable in responses especially for PLWD. Variability in response may be due to the type of the question, and some evidence was seen for this in terms of the relative stability of some responses to a number of the factor items. However, realistically there is a need to be able to change items and constructs over time, as certain types of constructs may have a limited 'life span', but this requires intensive longitudinal studies. While it is attractive to collect substantial material through repeated measurement using an 'in the moment' strategy, (and this may be even more important for individuals living with dementia), it seems likely, based on the current evidence from this study, that responses may not be reliable, and indeed that the nature of the questions themselves may be problematic, and hence require more experimentation. However, to examine difference between individuals, and possibly with experimental conditions, one needs to also increase the number of study participants. It is this interplay between change within the individual, and between the individuals, that can tell us much more about cognitive changes in PLWD and the possible steps that can be taken to ameliorate the social consequences of the condition.

Health economics and dementia

There is now a well-established body of evidence indicating that the costs of dementia care are substantial, soaring year on year, placing an unsustainable burden on health and social care (Banjaree et al. 2009; Wimo et al. 2011; Connolly et al. 2014; Prince et al. 2014). As Bond and colleagues point out however, it is the family who often bears the greatest burden (Bond et al. 2012). In the most comprehensive review of dementia in the UK, the London School of Economics (LSE) and King's College London (KCL) estimated that the cost of dementia in the UK was around £26 billion per year (or £32,250 per individual living with dementia), with £11.6 billion representing the economic value contributed by unpaid carers (Prince et al., 2014).

High quality economic evidence exists outlining the costs associated with dementia, the distribution of these costs and the groups and individuals in society who bear these costs (Knapp et al. 2013). Knapp stresses the ever pressing need to ensure individuals living with dementia and their carers get the most effective and cost effective treatment, care and support. However, the key question is '*What do these costs buy?'*

In assessments of new technologies and interventions by the National Institute of Health and Care Excellence (NICE), health economics plays a central role within the Guideline Development Group, which makes decisions about the best available evidence relating to clinical and cost-effectiveness. In relation to health economic analyses, NICE specifies a 'Reference Case' which is considered to be the most appropriate method of technology appraisal, and which should be used as a template for health economic analyses aimed at influencing NICE guidance. The Reference Case for example specifies that the perspective of the intervention should consider, not only the direct health costs/effects, but also the wider implications for family member or informal carers, when relevant. Furthermore, health effects should be expressed in QALYs, with the EQ-5D instrument as the preferred measure of health related quality of life (NICE, 2013)

In a review of dementia care costs and outcomes, Knapp et al. (2013) concluded that the vast majority of cost-effectiveness evidence was based on pharmacological interventions, with a high quality evidence base emerging and informing NICE clinical guidance. By contrast, there were few examples of cost effectiveness studies on non-pharmacological interventions for people living with dementia or interventions targeting informal carers. However, a number of researchers have incorporated a health economics component in their studies. These include a cost-effectiveness analysis of cognitive stimulation therapy for people living with dementia (Knapp et al. 2006); a cost-effectiveness study of occupational therapy for older people living with dementia and their carers (Graff et al. *2*008); and most closely related to the current study, the REMCARE study by Woods et al. (2016). This study assessed the cost effectiveness of reminiscence groups for people living with dementia and their caregivers but found no evidence to suggest the intervention was effective or cost-effective.

Our feasibility study on the impact of individual specific reminiscence facilitated through the use of an iPad app (InspireD) paves the way for the development of a larger effectiveness and cost-effectiveness study, which in turn could contribute to the currently small cost-effectiveness evidence base that exists in relation to non-pharmacological treatments in dementia care. This study estimated the costs directly associated with the intervention and associated health and social care costs, including the economic value of informal care, at baseline and during the 3-month intervention. In addition, in keeping with the 'Reference Case' specified by NICE, our study assessed health related quality of life using the EQ-5D, as well as the DEMQOL instruments for comparison.

The cost of the intervention

The estimated costs of the intervention, which included training, equipment, software development and travel were £77,112 or £2570 per dyad. This figure is substantially higher than the intervention costs reported in the REMCARE project which were £964 per dyad, involving 12 2-hour group reminiscence sessions and 7 monthly maintenance sessions (Woods et al. 2016). The costs of the current intervention were also higher than those reported by

Graff et al. (2008) in their cost-effectiveness study of occupational therapy (OT) for PLWD and their caregivers, involving 10 session of OT over five weeks.

Our study found that total costs of health and social care for PLWD increased from an average of £29,728 per person at baseline to £33,436 per person after 3 months. This increase was largely accounted for by an increase in the estimated economic cost of informal caregiving and is to be expected given the assumed progression of dementia and associated increase in caregiver support required. Hospital costs were also higher at follow-up with an average cost of £670 per person at T0 and £969 at T2. This increase in costs reflects a small number of individuals who underwent complex inpatient procedures. Medication profiles and costs were very similar at both time points. This finding may suggest that the follow-up time period was insufficient in detecting changes in medication. This factor merits considerations in the design of a full effectiveness intervention.

Estimated community health and social care costs were lower at follow-up (£305.18 per person at T0 and £268.68 per person at T2). A rough calculation shows that these community health and social care costs are similar to those reported in the REMCARE study, which estimated 10 month costs of £1,071 in the intervention and £1,170 among the control group (Woods et al. 2016). There was a notable reduction in the cost of GP services between the two time points and also lower psychiatrist and mental health nurse costs which may reflect an improvement in general wellbeing which is also mirrored by health-related quality of life results (to be discussed later). Interpretation of findings, however, in terms of the potential effects of the intervention is not appropriate, given the lack of randomisation in this feasibility study. Trends may be impacted by the progression of the dementia and/or by other external factors including the intervention itself.

The proportional breakdown of overall costs echoes findings from previous studies indicating that the greatest burden falls on family carers and loved ones (Connolly et al. 2014; Prince et al. 2014). Informal care accounted for 96% and 95% of overall costs at T0 and T2 respectively. These proportions were much higher than figures from other economic costing studies. Connolly et al. (2014) for example, estimated informal care costs to be 48% of overall costs associated with dementia, while the Dementia UK report estimated a figure of 44% (Knapp et al. 2013). The notable discrepancy between figures from previous studies and those reported in the current study reflect the exclusion of residential care costs for PLWD from the current home-based study. There are also however notable variations in estimated informal caregiver hours reported in this study relative to other studies. The current study estimated an average of 1,189 informal caregiver hours over three months at T0 and 1,332 hours over three months at T2, roughly equating to an average of 13 and 14.8 hours per day respectively. A series of Irish studies estimated informal caregiver time to be 11.6 hours per day (O'Shea, 2003); 5.06 hours (Gallagher et al. 2011) and 8.33 hours (Connolly et al. 2014). In a German based study examining the costs of dementia by disease stage, Leicht et al. (2011) reported much lower figures of 9.14 hours *per week*, 18.74 hours *per week* and 20.25 hours *per week* of informal care for people living with mild, moderate and severe dementia respectively. Beesley (2006) presents a detailed discussion of methods and difficulties in the measurement and valuation of informal care, concluding that the majority of studies do not use robust instruments or methods. The wide variation in estimates may to some degree reflect differences in the structure of healthcare systems, but raise important questions about resource use measurement in relation to informal care, which needs to be considered in the development of a full cost-effectiveness study.

In their review of literature on costs and outcomes, Knapp et al. (2013) point to the common unacceptable omission of informal care costs in cost-effectiveness analyses. Referring back to the NICE 'Reference Case' for health economic studies and considering the findings from the current study and wider evidence base on the intensity and associated costs of informal caregiving, it is clear that the long-term strategy for supporting and caring for PLWD must consider cost-effectiveness evidence which includes the economic impact on informal caregivers.

Findings on health related quality of life from the current feasibility study raise some important issues for discussion and planning for a future effectiveness and cost-effectiveness study. For PLWD, preference based indices (on a scale from 0 to 1) generated using both the DEMQOL and EQ5D instruments suggested an increase in quality of life across the three time points, while figures from the DEMQOL Proxy showed an increase between T0 and T1 and decrease at T2. EQ-5D based preference indices found in this study (0.649, 0.652 and 0.719

across the 3 time points) are lower than those reported by Woods et al. (2016) who estimated indices across different age categories among a control and intervention group: 0.80, 0.77, 0.75 0.72, 0.71 for 55-64, 65-74 and 75+ age groups among the control group; and 0.76 for 55-64, 65-74 and 75+ age groups among the intervention group). The REMCARE study also used the EQ-5D and found no significant difference between health-related quality of life among the intervention and control groups. They also concluded that their estimated indices were substantially lower than the UK norms and questioned the suitability of the EQ-5D instrument for their study.

The most striking finding from the current study in relation to quality of life, was that the index scores generated by the DEMQOL instrument were strikingly higher than those generated from the other two instruments. Total score generated by the DEMQOL (86.73, 90.43 and 91.50) appear to have credibility in comparison to other studies. Aguirre et al. (2011) for example reported scores of 93.4 before and 92.4 after Cognitive Stimulation Therapy. While total DEMQOL scores from the current study are comparable to other figures, quality of life indices generated from the DEMQOL instrument (0.8445, 0.9679 and 0.9013) are inexplicably high and raise questions about the appropriates of the selected response items from the DEMQOL proxy in truly capturing health related quality of life in this subgroup.

The views and experiences of participants

A key aspect of our study was to explore participants' views on the intervention and its impact on their relationships. Individual interviews with study participants revealed how positively the intervention was viewed by both the PLWD and their carers. Dempsey et al. (2012, p. 12) described reminiscence as an intervention which *"permits intrapersonal evaluation and fosters interpersonal relationships and self-esteem, while additionally reinforcing one's own sense of competence and well-being".* This was evident in the interviews as the PLWD described how the reminiscence training created a space to focus on their memories and in doing so, enabled them to concentrate on the significant aspects of their life. The reminiscence training sessions were positively evaluated by all interviewees as they created opportunities to identify and share memories which were defining to their relationship and their history. Evidenced in the sub theme '*It makes you remember',* the PLWD articulated that the intervention revealed how much they could still remember about their lives which had considerable impact, bringing joy, insight and a good feeling about and within, themselves. Carers described how the process helped them to learn things about their relative that they had not previously known and they appeared to see the person within the dementia rather than the dementia within the person. A similar finding was reported by Cooney et al.*'s* (2014, p. 3568) who used the term *"seeing me through my memories"* to describe the way in which a process of joint reminiscence revealed the PLWD as a unique human being.

For the PLWD, the interaction with the reminiscence facilitator appeared to help them to feel valued by virtue of the fact that somebody else was interested in hearing aspects of their life story. However, crucially for the carers, watching the facilitator interact with their relative demonstrated a new way of communicating. Melunsky et al. (2015) argued that carers often experience increased stress if new skills gained in group reminiscence sessions cannot be successfully implemented leading to self-criticism about their ability to care. However, findings from our study resonated with Beuscher and Grando's (2009, p.9) view that the work of reminiscence can act as a *"valuable interview strategy"* which can be modelled to ensure memories significant to an individual's life history can be elicited and with Kurz et al. (2010) who argued that such skills are more easily implemented in a more individualised approach to reminiscence.

Perspectives on training and usability

In general, the IT training was valued by participants. However, some PLWD relied on their carers to initiate usage and most carers felt that additional IT training would have improved their ability to use the device to its maximum potential. Although PLWD felt nervous about using the iPad, results from Phase 2 indicated a higher level of independent use by PLWD than by carers suggesting that while carer support was required, it was assistive rather than continuous. For the minority of dyads who struggled to use the app or exhibited infrequent usage, carers openly admitted they had not adapted well to this type of technology or had felt this type of medium was not appropriate for their relative. If carers were not engaged in the process, due to preconceived views about technology, the acceptability of the app was significantly impaired. According to Bowen et al. *(*2009), acceptability and implementation are key issues in feasibility studies and these have been shown to be directly connected to the ability to perceive and imagine how something can be used (Karlsson et al. 2014). This finding concurred with O'Connor et al. (2016) who proposed that negatively held carer views on technology was, not only a significant limitation on the development of technological programmes for PLWD, but reduced the potential for their relationship to be enhanced or supported through such a shared activity.

For the majority of dyads, the usability of the app was a significant reason why they remained engaged in the study. Carers highlighted that the convenience of the app provided a means of interaction with the PLWD and their wider social circle. All dyads fully availed of the mobility and convenience of the app, thus it became a social companion which accompanied them for family meals, holidays or day trips. The app also appeared to represent a virtual space in which precious memories could be preserved and protected. According to Lorenz et al. (2017, p. 10), technology can "*support safety and security"* through monitoring and assisted living devices. However, our findings tentatively suggest that the physical safety and secured afforded by modern technology can also be extended to emotional safety and security achieved through the protection of precious memories and life stories.

Consistent with the findings of Astell et al. (2011), individual interviews with participants indicated that using the app to look at photographs of significance to them, was a particularly enjoyable experience. This suggests that the individualised nature of the memories chosen for reminiscence must be validated by the full engagement of PLWD in the selection of memorabilia. This was further supported by Lazar et al. (2014) who asserted that personal memories selected by family members without involvement of the PLWD can lead to distress and confusion. In keeping with the findings of other studies, music was particularly important to the PLWD and could trigger specific life memories and relaxation. This resonated with McDermott et al.*'s* (2014) assertion that music chosen by PLWD not only tapped into a sense of personhood but to a wider connection to their world and history.

The home-based nature of the entire intervention, incorporating reminiscence and IT training and the 12-week period of home use was recognised by all participating dyads as key to their initial and continued involvement with the study. All participants indicated a strong preference for the home-based nature of this intervention and described how it created a feeling of privacy, and safety which were integral to their involvement. This suggests that a sense of personal and emotional safety can be facilitated through an individualised approach to reminiscence rather than navigating the challenges of a group based activity (Melunsky et al. *2*015; Subramanian and Woods, 2012). The home based nature of the intervention facilitated the PLWD to feel relaxed and able to share personal and intimate memories in a safe and secure environment while also enabling the meaning connected to a specific memory to be positively integrated within their own life story (Cosley et al. *2*009, Westerhof and Bohlmejer, 2014).

As this was a feasibility study, we were interested in hearing participants' views about the outcome measures used in the data collection procedures. The interviews revealed that in general, participants considered the outcome measures appropriate and sensitive. While as a research team, we had concerns about asking people questions about intimate aspects of their relationship, these were largely without foundation as most participants reported that the questions posed were thought provoking and triggered them to think about aspects of their relationship that they would not normally consider. A minority of carers felt that the questions did not capture the challenges posed by a life with dementia. However, this was not a key focus of this particular study.

The timing and impact of the intervention

Many of the participants in our study resided in rural areas and the isolation of the diagnosis was compounded by the social isolation they experienced. Participating dyads described receiving minimal support from external agencies. However, this could also be attributed to the increased demands of caring and the reduction in the ability to sustain supportive social networks as dyads may initially socially withdraw following diagnosis (McHugh et al. *2*012). Participants described a number of appointments and assessments corresponding with the initial diagnosis which began to dissipate as their journey progressed. This was acutely felt in rural areas with some dyads citing involvement in our study as the only ongoing contact they experienced. During these period of isolation, engagement with this intervention appeared to present a different way of caring for each other and exploring shared memories. The PLWD identified that the vivid recollection of memories significantly impacted their self-esteem and self-perception (Dempsey et al. *2*012). From the carers' perspectives, seeing such a positive response in their loved one was not only very encouraging but also caused them to value the life that their relative had lived and continued to live. Melunksy et al. (2015) argued that while a personalised approach to reminiscence may yield positive outcomes for carers, such as was seen in this study, it is also possible that carer may miss the supportive network associated with a group setting. However, it is our contention that the individualised approach used in this study recognised the importance of the relationship between the PLWD and their carers in such a way as to focus on what still remained and what they had gained rather than a continued focus on loss and what McHugh et al. (2012, p.227) described as the *"disappearance"* of their relationship.

The pain of memory

While significant memories for our dyads included families, family holidays and their early life together, not all defining memories were happy. As reported elsewhere, (Astell et al. *2*011; Lazar et al. *2*014), this was particularly challenging for carers as the nature of the memory, for example the loss of a child, although painful for them was significant for the PLWD. How the memory of the event is recalled can often differ in the event details or the emphasis placed on a specific aspect of memory. According to Condon et al. (2015), this lack of memory conformity is not related to how much trust or familiarity exists between the couple, but is more reflective of the context in which the memory is recalled. While dyadic reminiscence through verbal discussion, may impact memory conformity (Condon et al. *2*015), it could be argued that painful memories do not need to be recalled identically but rather, the meaning attached to the memory can be integrated into the dyads life story (Westerhof and Bohlmejer, 2014).

This has implications for the integration of the InspireD app, and the dyadic reminiscence it facilitated, into the lives of participating dyads. Participants acknowledged that the recall of painful memories facilitated a discussion around past events which had not taken place at the time of the trauma. Whether this led to a corrective process on perceived distorted memories (Condon et al. 2015*)* was not explored and did not emerge from our findings, but instead, the recollection provided the opportunity for internal reconciliation with the experience. For a minority of carers, the memories of the PLWD were not shared as they did not involve them or they belonged to an earlier part of the life of the PLWD. This corresponds to Astell et al.*'s* (2011) view that when asked to recall memories, the PLWD will often cite 'bump' memories, those experienced between the ages of 10-30 years old. This suggests that shared memories, regardless of their nature, are essential for connection and closeness to be established or enhanced through individual and specific reminiscence. This has implications for societal trends in relation to marriage, divorce and longevity of relationships.

Impact on relationships

The interviews revealed that for the PLWD, involvement in our study had a significant impact on self and their relationship with their carer as they felt more content, more in control of their memories and more confident in their ability to learn new skills. For the carers, this created an opportunity to celebrate the life they had lived, accessing a way for caring for their loved one which was relationship focused. This was significant as Quinn et al. (2009) found that caregivers experienced the loss of a reciprocal relationship and redefined their relationship within the context of their caregiving role. To minimise the likelihood of this, Vernooij-Dassen et al. (2011) suggested that carers need to cognitively reframe their caregiving role and responsibilities in order to alleviate stress and minimise the adverse consequences on their relationships.

Findings from our study can be further aligned to Quinn et al.*'s* (2009) assertion that the nature of the pre morbid caregiving relationship can be indicative of the challenges encountered adjusting to the new demands of a caregiving role. This was noted by the research team who observed that some dyads who were less enthusiastic about the intervention, particularly in the early phases, occasionally referred to strained relationships or to their difficulty in adapting to a caregiving role. Study findings, therefore, reaffirmed Lazar et al.*'s* (2014, p. 575) view that "*easing the burden of therapy delivery*" through the use of personalised material, the reduction of travel requirements for participants and the bespoke and tailored nature of the intervention is crucial in supporting dyads encountering challenges. A transgenerational impact was also evident as PLWD indicated that engagement with the iPad enhanced their contemporary relevance to younger generations within their wider family (Mulvenna et al. (2011).

All participants were asked about their greatest achievement as a result of their participation in the study. Findings suggested that the nature of this achievement was dependent on their role within the dyad. Carers described their achievements as relationship and outcome focused, whereas PLWD considered their biggest achievement to be more process focused in the context of mastering modern technology and learning a new skill. Westerhof and Bohlmeijer (2014) argued that gender can determine the focus of reminiscence work with women more likely to concentrate on interpersonal and emotion based memories, whereas men tend to focus on past achievements in their life history. The majority of carers in our study were female and the PLWD were male. However, with such a relatively small sample size, it was not possible to attribute any findings to gender differences.

Strengths and Limitations of the Study

A key strength of our study is that PLWD and their carers informed the development and testing of the InspireD reminiscence app. The Alzheimer's Society Home Support Network was the recruitment source for Phase 1 of our study and it is possible that this may have biased the results. While the User Development Group (n=12), included individuals with varying degrees of technology and computer experience, all were interested in the idea of using technology in dementia research. It is possible that PLWD and carers with more sceptical views about technology were therefore underrepresented in Phase 1 of the study.

The sample size in the User Development Group was ideal for standard usability testing and the transferability of findings has been demonstrated by providing a detailed outline of the data collection process. Although the workshops were facilitated in such a way as to encourage the sharing of experiences and the acceptance of differing views, some carers were more vocal than the PLWD. It is acknowledged that separate workshops and interviews may have moderated this tendency.

The number of participants recruited to and retained in Phase 2 of the study is a major strength. Only one dyad did not complete and we had a low percentage of missing data. The missing data were treated on an intention to treat basis using the standard expectation-maximization. The advantage to this technique is that a participant with missing data at one time-point only, could be included in the reporting of findings. A disadvantage is that there is no guarantee that the values imputed are those that the participant would have responded with.

The researchers promoted inclusivity in the selection of participants. Individuals with a diagnosis of mild to moderate dementia were recruited from the WHSCT Community Mental Health Team for Older People. It is acknowledged that the stage, type of dementia and other factors such as health or sensory impairments and caregiver stress, may have had a bearing on outcomes. This is recognised as a potential limitation of the study and an important issue to consider in a future RCT.

There are limitations to our quasi-experimental design. Chief amongst these is the lack of control and random assignment which limits the generalisability of the results to a larger population. In addition, it is possible that pre-existing factors may have influenced the results. Conclusions therefore have to be interpreted with caution.

A limitation in the user events logs is that they were logged locally on each iPad using a database technology (called SQLite) and later collected in person from the iPads using a pen-drive. As such, user events were not logged in real time and stored on a remote web server. As a result, we could not control for lost local data due to operating system failures, app crashes, bugs and updates.

A limitation of our study was the duration of IT training and the relatively short timeframe of the intervention. The third IT training session took place half way through the 3 –month period of home use and it is possible that there was insufficient time for the effect of using the reminiscence app more skilfully to impact on end-point measurement scores. The absence of follow-up data is a further limitation.

The primary and secondary outcome measures that we used (Mutuality, WHO-5 and QCPR) have been extensively tested for validity and reliability, and were sufficiently sensitive to deliver some statistically significant results. However, some of the questions (e.g. relating to the extent to which people confided in one another) merit further testing.

The qualitative phase of the feasibility study enabled both the carer and the PLWD to volunteer for one-to-one interviews with their involvement not contingent on the participation of the other dyad member. This was a significant strength of the study as it afforded participants the freedom to discuss their *own* individual experience of the intervention in an open and honest manner.

The interview schedule used in Phase 3 was informed by Phase 1 ensuring that patient and public involvement was a key driver in the dynamic nature of the research design. To elicit participants’ views on the key components of a feasibility study, this interview schedule required a structured design. While this could be perceived as a limitation of the qualitative phase of the study, it was necessary to include some closed questions (for example on previous experience of reminiscence and technology) to provide contextual information relative to this phase of the study.

A marginally higher number of carers participated in Phase 3 and while this could be perceived as a limitation, the team believe that this was more likely attributable to awareness on the part of PLWD of their cognitive and communication challenges. However, all efforts were made by the research team to ensure that such challenges were addressed which may be reflected in the considerable number of PLWD who took part in the interviews.

An additional strength of our study was the involvement of other members of the research team, in addition to the Research Associate, in the qualitative interviews. This was important as the Research Associate played a key role in all other aspects of data collection and had established a rapport with all participants. The involvement of other team members limited the likelihood of bias and facilitated a more honest appraisal of the intervention on the part of participants.

Chapter 11 -

Recommendations

Personal and Public Involvement

Pathway to Impact

Conclusions

Practice, Policy and Research Implications and Recommendations

Recommendations from the study findings are presented and arranged to reflect the core practice and policy implications and future research considerations.

Practice and Policy Recommendations

- It is anticipated that NICE will continue to emphasise the value of tailored specific psychosocial interventions in the updated guideline Dementia: supporting people with dementia and their carers in health and social care (CG42), which is due for publication in June 2018. There is a need to raise awareness of the benefits of individual and specific reminiscence using a relationship-centred approach to the general population through dissemination of our research findings.
- Educational programmes aimed at PLWD, their families and health and social care practitioners should be easily accessible to facilitate the use of bespoke technology support.
- The research team propose to actively engage with, and disseminate research findings to service user organisations and advocacy groups such as Dementia NI, the Alzheimer's Society and AgeNI to ensure our pathway to impact leads us to those who may benefit most.
- At a broader level, it is proposed that health and social care practitioners are cognisant of the importance of shared memories when engaging in this type of activity and receive appropriate training to maximise the benefits while ensuring that any distressing memories can be responded to appropriately.
- The most popular reminiscing modality was personal photographs. The PLWD may need support from someone to curate the photographs, save them in digital format and add them to the app. In InspireD, this role was undertaken by the carers, with IT training support in their homes. Therefore, for future use, it is recommended that those who care for PLWD are offered training on how to carry out this task.
- IT training was an important part of our study and, recognising the variation in the IT skills of participants, we recommend a bespoke approach to the length and frequency

of IT training sessions to enable the InspireD app to travel with dyads throughout their dementia journey.

- On a broader strategic level, the use of ICT applications require Wi-Fi enabled environments, the lack of which is most acutely experienced in rural areas. The research team propose that consideration must be given to a connected health approach and therefore recommend the digitalisation of care and home environments to facilitate technological developments in the care of *all* PLWD and their families.

Research Recommendations

- The InspireD research team are committed to the principle of ‘Nothing About Us Without Us’ and, therefore, recommends the involvement of those living with dementia and their carers in the co-creation, refinement and testing of technology used in dementia research and caring interventions.
- Our study findings illustrate the considerable benefit of collaborative working. Future research should consider a strengths and abilities based approach, in which those living with dementia and their carers are involved in each stage of the research process from design to dissemination.
- An important feature of our home-based intervention was the use of the InspireD reminiscence app hosted on touch screen software. We recommend a large randomised controlled trial of home-based individual specific reminiscence to test our findings further.
- Future research should consider 1) our calculations of an appropriate sample size for a follow-up RCT 2) further refinement of the InspireD app to incorporate the learning gained from this study and 3) researchers must consider how to incentivise use on a more frequent basis.
- It is recommend that the InspireD app code base should be used in a future RCT as this provides full control over the app design and development roadmap. This is an important precursor of any ‘route to market’ consideration.
- Our phase 1 results indicate that common usability testing protocols such as the SUS instrument, think-aloud protocols and external mobile macro cameras attached to the mobile testing device may not be suitable for evaluating apps whose target users are

PLWD. It is recommended that further research is conducted to develop appropriate usability metrics to facilitate the full engagement of those living with dementia in technology design and refinement.

- While there is evidence to suggest that reminiscence can be used to enhance quality of life in dementia, there is a need to address the challenges posed by a lack of standardisation in research in the context of different types of reminiscence, diverse care environments and varying stages of dementia.
- Our analysis of repeated measures data suggested that the intervention had preliminary efficacy on mutuality, subjective well-being and quality of carer-patient relationship for PLWD. A recommendation for future research would be to repeat data collection at 5-6 month intervals across a two-year period to see if the short-term gains attained in mutuality are in fact maintained over time.
- This reminiscence intervention relied on the involvement of family members, more research is warranted to explore the outcomes of such involvement on their health and wellbeing.
- Consideration should be given to a follow up study with InspireD participants since the original study was completed to assess the impact of the intervention over an extended period of time.
- Future research on individual specific reminiscence should give consideration to the significance of the shared life history and the relevance of specific shared memories and their impact within the dyadic relationship.
- The provision of individual and specific reminiscence training by a skilled facilitator was positively evaluated by all participants in our study and the involvement of such expertise is recommended in future studies of this kind.
- Given the use of the app in everyday situations, the emphasis on creativity could be further developed in future research. To this end, a follow-up study with a theoretical focus on 'everyday creativity' could help to frame and enhance participants' response to the 'InspireD'app.
- As the results indicate that higher baseline mutuality scores were related to better outcomes from usage of the InspireD app, this is an area that warrants consideration. In a future RCT, it would be important to observe whether there are similar

associations in respect of WHO-5 and Quality of Care Giving Relationship data. In the statistical powering of future studies, the intention will be to examine the individual profiles of each study participant and the factors that shape these responses.

- Future research should consider the suitability of instruments used in dementia research. The research team identified one item on the Mutuality scale that posed a challenge in the context of a dementia diagnosis and further testing of this instrument would be required with this population group.
- The observed ceiling effect researchers observed in both the Mutuality Scale and the DEMQOL instrument, warrants consideration of their use in a follow-up trial.
- To allow for remote telematics and to minimise data loss, we recommend logging responses and user events using 4G sim cards. This would enable the analysis of logs over the duration of the study. Remote logging could also facilitate the use of adaptive features to motivate PLWD and carers by sending personalised notifications and motivational messaging at moments of low app usage.
- Results of the health economics component of our study indicate a need to review the appropriateness of health related quality of life instruments for those living with dementia in the development of a future cost-effectiveness study, paying particular attention to the suitability of indices derived from the DEMQOL instrument.
- Future cost effective analysis should also be preceded by a review of instruments/methods used to measure and estimate informal carer costs and resource usage specific to dementia to ensure appropriateness.
- It is recommended that all studies exploring the cost effectiveness of interventions in dementia research should use the adapted CSRI developed in this research study. Future use of this instrument should identify British National Formulary Paragraph, Chapter and Section; distinguishing between medication types and should differentiate between elective and non-elective inpatient procedures to facilitate accurate assignment of unit costs.

Personal and Public Involvement

The term ‘Nothing About Us Without Us ‘reflects the view that no policy should be decided by any representative without the full and direct participation of members of the group affected by that policy. In the context of research, this is operationalised through personal and public involvement (PPI) with the aim of aligning research more closely with the public's needs while also making it more effective and cost effective. As previously stated, a Lead User dyad comprising a person living with dementia (Graeme Skelton) and his carer (Ashleigh Davis) were involved in all stages of the project including the preparation of the original funding proposal and the various stages of testing and developing the app. Both of these individuals were also members of the project steering group. Ashleigh later joined Dementia NI, an advocacy group established by PLWD to promote the rights of people living with dementia to be involved in decisions that affect their lives, thereby strengthening the voice of PLWD and their carers in our study. PPI was further promoted through the composition of our steering group which included representatives from Dementia Together NI, the Alzheimer's Society and the Reminiscence Network Northern Ireland (RNNI).

Findings from our study reinforce the immeasurable benefit of working collaboratively with PLWD and their carers to co-create and test the InspireD app. This collaboration ensured that the app was sensitive to the needs of the user group and provided an intuitive design which facilitated the engagement of both the PLWD and their carer. Valuable insights have been gained about the suitability (or otherwise) of standardised usability protocols for PLWD. Equally, lessons have been learnt about the reliability and validity of standardised questionnaires and scales (e.g. the Mutuality Scale) in the context of a dementia diagnosis. The recruitment and retention rates for our study coupled with the positive feedback from interviews confirm that that many people living with dementia and their carers are genuinely interested in contributing to research. However, our experience has also taught us that organisational barriers, paternalism and risk averse attitudes are in danger of preventing this from becoming a reality.

A barrier to PPI has been the ability to access (as opposed to recruit) PLWD and their carers. While the research team fully acknowledges the necessary protective measures required for a potentially vulnerable sample, some measures can act as a barrier to engagement and involvement. It has been the research teams' experience, that when engaged, service users made a very significant contribution to the design, testing and use of the reminiscence app. Participants also reported that their involvement in the study was an enjoyable and empowering social activity, which enhanced their self-esteem and feelings of worth. While access to our sample was initially problematic, it is important to note that the research team overcame this barrier through the assistance of the steering group, in particular Caroline McCaughey from the Alzheimer's Society Home Support Network.

Another major challenge to PPI is the different priorities of individuals involved in the research process. Our initial ethics application for Phases 2 and 3 of the study, and in particular the design and content of participant information materials, were heavily influenced by the User Development Group involved in Phase 1. User involvement resulted in very helpful guidance about font type and size and about language and content. Feedback from users emphasised the importance of keeping the information "*concise and not too long".* However, when we took this information on board in the design of the final information materials, we were informed by our regional ethics committee that '*the Participant Information Sheet did not outline to potential participants the full extent of what was involved in the study*. Our revised submission included very detailed participant information materials but as a team, we felt that this ran contrary to the advice of our users. While we fully accept the role of ethics committees in protecting the public and ensuring informed consent, our experience suggests that it may be difficult for researchers to reconcile the different views of users and others involved in the research process. This suggest the need to debate ways of promoting a more genuine approach to user engagement.

The study is now complete and our plan is to involve participants in the dissemination of our findings at seminars, conference presentations and to the student body at Ulster University. Together with some of the participants in our study, we are currently working with a local playwright to inform a play reflecting the real-life stories of individuals living with dementia and their families. This will be discussed in more detail under the 'Pathway to Impact' section of the report.

Pathway to Impact

Our study represents a productive collaboration between statutory (WHSCT), third sector (Alzheimer's Society Home Support Network and Reminiscence Network Northern Ireland) and academic organisations (Ulster University). The team has worked very closely with the RNNI in the planning and delivery of the reminiscence training for the facilitators involved in this study and with the WHSCT and the Alzheimer's Society in recruitment and implementation. This has resulted in mutually beneficial knowledge exchange activities. We have presented details of our study at the Alzheimer's Society Dementia Cafés. Staff, individuals living with dementia and their carers, have attended these events which provided everybody with an opportunity to learn about the use of technology to reminisce and about the reminiscence and training support available from the RNNI. The WHSCT also provided dementia training to members of the research team to improve their communication skills and to maximise the impact of the intervention.

Pathway to Publication Impact

This was a complex study involving 6 discrete aspects of data collection. The findings of our study are encouraging and suggest that technology can be successfully used to facilitate a more personalised approach to reminiscence which can positively impact the lives of PLWD and their carers. We have published from Phase 1 but as the results of Phases 2 and 3 were only finalised in the last few months, we have not been in a position to publish these as yet. However, the report has been written in such a way as to facilitate ease of publication in the context of the stand-alone data collection and analysis chapters (5-9). We have an impact and communications strategy which incorporates dissemination and publication activities, targeting a breadth and depth of journals and conferences/seminars pertaining to psychosocial interventions, technology and dementia. We have 2 publications to date, with a further 3 publications pending (including a book chapter). Other papers are at various stages of preparation. Preliminary findings from the study have been presented at 14 national and international conferences and the research has been well received by academics and practitioner alike.

Publications

Gibson A, McCauley CO, Mulvenna MD, Ryan AA, Laird EA, Curran KJ, Bunting B, Ferry F, Bond R In: Fardoun HM, Penichet VMR, Alghazzawi DM, Gamito P (2016) Assessing Usability Testing for People with Dementia, Proceedings of the 4th Workshop on ICTs for improving Patients Rehabilitation Research Techniques, ACM Digital Library, ISBN 978-1-4503-4765-5.

Mulvenna MD, Gibson A, McCauley C, Ryan A, Bond R, Laird EA, Curran KJ, Bunting B and Ferry F. (2017) *Behavioural Usage Analysis of a Reminiscing App for People Living with Dementia and their Carers.* In: European Conference on Cognitive Ergonomics 2017 (ECCE 2017), Umeå, Sweden. ACM Digital Library. 4 pp.

Ryan A (2016) Forward: *Sharing Memories Building Communities Report*. Belfast, Reminiscence Network Northern Ireland, Belfast.

Ryan A (2017) The Contribution of Information Technology to Reminiscence, Life Review and Life Story Work. IN Gibson, F (Editor) *Reminiscence, Life Review and Life Story Work*. London: Jessica Kingsley Publishers (In press).

Papers under review

Laird EA, Ryan A, McCauley CO, Gibson A, Mulvenna MD, Curran K, Bunting BP, Ferry F, Bond R. 'Individual specific reminiscence for adults living with dementia and their family carers: An appraisal of outcomes from a quasi-experimental study'. (Under review by Journal of Medical Internet Research)

Ryan A, Laird EA, McCauley C, Gibson A, Mulvenna MD, Curran KJ, Bunting BP, Ferry F and Bond R. "There is still so much inside": The impact of home-based, personalised reminiscence, facilitated through an iPad app, on people living with dementia and their family carers. (Under Review by Dementia, The International Journal of Social Research and Practice).

Conference Presentations

Laird EA, Ryan A, McCauley C, Gibson A, Mulvenna M, Bunting B, Ferry F, Curran K, Bond R (2018) 'A quasi-experimental study of individual specific reminiscence'. Oral Presentation. Alzheimer's Society Annual Conference, London, 23rd May 2018.

Ryan A, McCauley C, Laird EA, Gibson A, Mulvenna M, Bunting B, Ferry F, Curran K, Bond R (2018) '*Technology facilitated reminiscence*: *impact on people living with dementia and their family carers*. Dementia: Transforming the Journey – Prevention, Treatments and Quality of Life. Hilton Hotel, Templepatrick. 17th May 2018.

Ryan A, McCauley C, Laird EA, Gibson A, Mulvenna M, Bunting B, Ferry F, Curran K, Bond R (2018) '*Technology facilitated reminiscence in dementia – the InspireD story'.* Memory Service Seminar, Gransha Hospital, Co Londonderry, 25th April 2018.

Laird EA, Ryan A, McCauley C, Gibson A, Mulvenna M, Bunting B, Ferry F, Curran K, Bond R (2018) '*A quasi-experimental study of individual specific reminiscence'*. RCN International Research Conference 2018, Birmingham, 16th April 2018.

Ryan A, McCauley C, Laird EA, Gibson A, Mulvenna M, Bunting B, Ferry F, Curran K, Bond R (2018) '*Technology facilitated reminiscence in dementia'*. Growing Excellence in Dementia Care, 10th International Dementia Conference, Dublin City University 16th -17th April 2018.

Laird EA, Ryan A, McCauley C, Gibson A, Mulvenna M, Bunting B, Ferry F, Curran K (2017) '*A Strengths based approach in a study of facilitated reminiscence'*. Oral Presentation. 18th Nursing Ethics Conference and 3rd International Ethics in Care Conference, Centre of Biomedical Ethics and Law, KU Leuven. 15 – 16 September 2017.

Laird EA, Ryan A, McCauley C, Gibson A, Mulvenna M, Bunting B, Ferry F, Curran K, Bond R. (2017) *Individual Specific Reminiscence in Dementia*. All Ireland Gerontological Nurses Association 9th International Conference, Waterford. 18 May 2017.

Gibson A, Ryan A, McCauley C, Laird EA, Mulvenna M, Bunting B**,** Ferry F, Curran K, Bond, R (2016). *Accessing Usability Testing for People with Dementia*. 4th Annual Rehab Workshop, 13-Universidade Lusófona de Humanidades e Tecnologias, Campo Grande, 376, 1749-024 Lisbon, Portugal. 14th October 2016.

McCauley C, Ryan A, Laird E, Mulvenna M, Curran K, Bunting B, Gibson A, Ferry F, Bond R. (2016) '*InspireD: Facilitated Reminiscence in Dementia'*. ARK: Research on Ageing Symposium, The Playhouse Theatre, Derry/Londonderry. 13th October 2016.

McCauley CO, Ryan AA, Laird E, Mulvenna M, Curran K, Bunting B, Gibson A, Ferry F, Bond R. (2016) '*Individual Specific Reminiscence in Dementia: The InspireD Study'*. The Reminiscence Network Northern Ireland AGM and Conference, Antrim. 21st September 2016.

McCauley CO, Ryan AA, Laird E, Mulvenna M, Curran K, Bunting B, Gibson A, Ferry F, Bond R. (2016) *Individual Specific Reminiscence in Dementia'*. Seminar for visiting USA students, Ulster University, Magee Campus, Derry/Londonderry. 8th August 2016.

Ryan A, Laird EA, Gibson A, Mulvenna M, Bunting B, Curran K, Ferry F. (2015) *Individual Specific Reminiscence in Dementia*. Integrated Care in Dementia Conference, 2015, Ulster University, Jordanstown. 5th November 2015

Laird EA, Ryan A, Mulvenna M, Curran K, Bunting B, Gibson A, McCauley CO, Ferry F (2015) '*Individual Specific Reminiscence in Dementia'*. Poster Presentation. C-TRIC/TMED7 – 7th Annual Translation Medicine Conference Derry/Londonderry, 26-27 October 2015.

Laird EA, Ryan A, Mulvenna M, Curran K, Bunting B, Gibson A, McCauley CO, Ferry F (2015*) 'Individual specific reminiscence in dementia'.* International Training Programme on Ageing, held in Trinity College, Dublin 22 – 24 September 2015.

Ryan AA, Bunting B, Curran K, Laird EA, Ferry F, Mulvenna M, Gibson A, McCauley C, (2015) '*Research in Reminiscence'.* Reminiscence Network Northern Ireland Conference 'Sharing Memories Building Communities', Dunsilly Hotel, Antrim. 8th May 2015.

Pathway to Policy Impact

Professor Ryan has worked very closely with Dementia Together Northern Ireland which was established to transform the commissioning, design and delivery of dementia services in line with the recommendations of the NI Regional Strategy 'Improving Dementia Services in Northern Ireland' (DHSSPSNI, 2011). The Dementia Together NI regional implementation group includes people living with dementia and their family carers as well as representatives from the statutory, voluntary and academic sectors, many of whom have been consulted about different aspects of our study. Professor Ryan delivered the opening address at a conference which showcased the achievements of Dementia Together NI which was held on 30th November 2017.

We will also maximise the impact of our research by presenting our findings at the Knowledge Exchange Seminar Series (KESS) in Stormont. The promotion of evidence-led policy and law-making within Northern Ireland is the underlying aim of the Knowledge Exchange Seminar Series (KESS). KESS is the first of its kind in the United Kingdom, formally partnering a legislative arm of government, the Assembly, with academia. KESS aims to encourage debate and improve understanding, providing a forum to present and disseminate academic research findings in a straightforward format, on issues that are relevant to governance in Northern Ireland (NI). Significantly, it seeks to bring the findings to the attention of key participants and decision-makers in the policy and law-making processes in Northern Ireland, such as MLAs and Assembly committees, as well as the wider public sector.

Embedded in the KESS model are: the local universities *via* their academics; Assembly committees *via* their Chairpersons; the Assembly's Research and Information Service (RaISe) *via* its Researchers; and, a broad spectrum of attendees. Attendees include: MLAs and their staff; political party staff; Assembly and Departmental officials; others from the public and private sectors; academics; voluntary and community groups; and, members of the public. For this reason, KESS creates unique engagement opportunities; and importantly provides a 'pathway' for more, in-depth discussion at a later date about findings presented at KESS. The KESS seminars are free and all delegates receive a seminar pack that includes the academics' policy briefings and power point presentations, including contact information. All presentations are recorded and available on the KESS website, further extending the potential reach and impact of the seminars.

Pathway to Societal Impact

Reminiscence, as a shared activity, has the potential to provide PLWD with new opportunities to interact and communicate with family and friends. At the commencement of this study, the Reminiscence Network Northern Ireland had no reminiscence facilitators based in the western part of the province. As a direct result of this study, we now have 6 fully trained facilitators in the WHSCT area. This is a significant capacity building achievement. It is also impactful for future research and practice development initiatives in the field of reminiscence as the personalised and relationship-centred approach to reminiscence modelled by these facilitators was significant in maintaining participants' engagement with our study and the development of "*an enjoyable way to care".*

On a different note, we have been approached by a Donegal-based playwright Guy LeJeune, (Theatre Artist in Residence, An Grianán Theatre, Donegal) who heard our study presented at a Reminiscence Network Northern Ireland conference in 2016. Subsequent meetings between Professor Ryan, Dr McCauley and the playwright centred on the possibility of writing a play to reflect the real-life stories of individuals living with dementia and their families, as opposed to a play solely about dementia. The playwright's previous work has aimed to offer a true reflection of the communities he worked with in order to celebrate the voices and stories that may never have been heard, or might have been lost in time. Professor Ryan and Dr McCauley have provided information about the proposed play to InspireD study participants and have also facilitated introductions for those interested in collaborating with Mr LeJeune. By drawing on the memories and experiences of individuals, the aim of the play is to create a piece of drama that will challenge the stigma and increase understanding and awareness of the impact of a dementia diagnosis on individuals and families. The play is due to be completed in 2018 and we are currently trying to source additional funding to extend the run to include Northern Ireland and the Republic of Ireland.

Pathway to Web-Dissemination Impact

From the commencement of the project, we have been using every opportunity to maximise communications and impact. The team maintained a project blog at https://inspiredappblog.wordpress.com. The team also maintained a Twitter feed at https://twitter.com/inspiredappproj.

Awards

The impact of our study is also evidenced by the success of our team members. Dr Liz Laird was nominated for the RCN Nurse of the Year, Nursing Research Award 2017 in recognition of her significant contribution to the InspireD project. Dr Claire McCauley, our Research Associate won the Healthy Communities Award and the overall Early Career Researcher Award at Ulster University's Communications Awards ceremony in 2016. These awards received considerable coverage within Ulster University and have led to Dr McCauley being invited to take part in the 'Be Seen, Be Heard' media communication training for early career female researchers to ensure the research they are involved in and the expertise they have receives equitable media coverage. Dr McCauley was also nominated for Alzheimer's Society Dementia Research Leaders Award –Rising Star Award in 2017. http://www.ulster.ac.uk/insight/news/2016/11/inaugural-research-communication-awards/

Conclusions

Reminiscence has been promoted internationally as a means of enhancing standards of care and quality of life for people living with dementia. Our study comprised a novel intervention of home-based and personalised reminiscence, facilitated by an iPad app (InspireD) which was co-created by people living with dementia and their family carers. The findings of this study indicate statistically significant enhancements in mutuality, emotional well-being and quality of care-giving relationship with large effect sizes from baseline to endpoint for the participants living with dementia, and non-significant differences in mutuality, emotional wellbeing, and quality of care-giving relationship from baseline to endpoint for carers. This suggests that a more individual relationship-centred approach to reminiscence, facilitated through the bespoke software, has the potential to generate a positive impact on people living with dementia without negative consequences for family caregivers. These findings support an emerging body of evidence that purports that individual specific psychosocial interventions have efficacy in the context of dementia care. It is important to highlight that our study is not without limitations and that pre-existing factors may have influenced the results. Nonetheless, our intervention, comprising a programme of training and use of an iPad app, has a significant contribution to make to ongoing development in the context of technology-facilitated reminiscence. A robust randomised controlled trial, drawing on the strengths and weaknesses of this feasibility study, is warranted.

References

AgeNI (2017) *Dementia.* Available from: http://www.ageuk.org.uk/northernireland/health--wellbeing/dementia/ (Accessed 7 October 2017).

Aguirre E, Spector A, Streater A, Burnell K, Orrell M. (2011) Service users' involvement in the development of a maintenance cognitive stimulation therapy (CST) programme: A comparison of the views of people with dementia, staff and family carers. *Dementia,* 10(4), 459-473.

Alm N, Astell A, Gowans G, Dye R, Ellis M, Vaughan P, Riley P (2009) Engaging multimedia leisure for people with dementia. *Gerontechnology,* 8, 236-246.

Alzheimer's Disease International. *A global Voice on dementia.* World Alzheimer's Report (2015). The global impact of dementia: an analysis of prevalence, incidence, cost and trends. Executive Summary. London: Alzheimer's Disease International.

Alzheimer's Research UK (2015). *The power to defeat dementia*. Dementia in the family. The impact on carers: Cambridge: Alzheimer's Research UK.

Alzheimer's Society (2017) *United against dementia.* What is Dementia. Fact sheet 400 London: Alzheimer's Society.

Amieva H, Robert PH, Grandoulier AS, Meillon C, De Rotrou J, Andrieu S, Berr C, Desgranges B, Dubois B, Girtanner C, Joël ME, Lavallart B, Nourhasherni F, Pasquier F, Rainfray M, Touchon J, Chêne G, Dartiques JF (2016) Group and individual cognitive therapies in Alzheimer's disease: the ETNA3 randomized trial. *International Psychogeriatrics,* 28 (5), 707-17. doi: 10.1017/S1041610215001830.

Ancient C, Good A, Wilson C, Fitch T (2011) Can ubiquitous devices utilising reminiscence therapy be used to promote well-being in dementia patients? An exploratory study. Available from:
https://researchportal.port.ac.uk/portal/files/209627/HCI_international_Ancient_et_Al.pdf
(Accessed 3 October 2017)

Archbold PG, Stewart BJ, Greenlick MR, Harvath T (1990) Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health,* 13, 375-384.

Astell A, Alm N, Gowans G, Ellis M, Dye R, Vaughan, P. (2009) Involving older people with dementia and their carers in designing computer based support systems – some methodological considerations. *Universal Access in the Information Society,* 8, 49-58.

Astell A, Ellis M, Bernardi L, Alm N, Dye R, Gowans G, Campbell J (2007) *Developing technology to support the relationship between people with dementia and caregivers*. Proceedings of the 22nd conference of Alzheimer's Disease international, Berlin, pp30-33.

Astell AJ, Ellis M, Bernardi L, Alm N, Dye R, Gowans G, Campbell J (2010) Using a touch screen computer to support relationships between people with dementia and caregivers. *Interacting with Computers,* 22, 267-275.

Astell AJ, Joddrell P, Groenewoud H, (2016) Does familiarity affect the enjoyment of touchscreen games for people with dementia? *International Journal of Medical Informatics,* 1-3. doi: 10.1016/j.ijmedinf.2016.02.001

Astell AJ, Purves B, Phinney A. (2011) 'Story of my life?' The contents and functions of reminiscing. *CHI.* ACM 978-1-4503-0268-5/11/05.

Aydin MN, Harmsen F, Slooten van K, & Stegwee RA. (2005) On the Adaptation of an Agile Information (Suren) Systems Development Method. *Journal of Database Management*, 16 (4), 20-24.

Ayres S (2013) How digital technology is supporting people living with dementia. Nominet Trust. Available from: http://www.nominettrust.org.uk/knowledge-centre/blogs/how-digital-technology-supporting-people-living-dementia (Accessed 29 September 2017)

Azcurra DJLS (2012) A reminiscence programme intervention to improve the quality of life of long-term care residents with Alzheimer's disease. A randomised controlled trial. *The Journal of Brazilian Psychiatric Association*, 34(4),422-433.

Banerjee S, Samsi K, Petrie C D, Alvir J, Treglia M, Schwam EM and del Valle M. (2009) What do we know about quality of life in dementia? A review of the emerging evidence on the predictive and explanatory value of disease specific measures of health related quality of life in people with dementia. *international Journal of Geriatric Psychiatry*, 24(1), 15-24.

Bangor A, Kortum PT, Miller JT. (2008) An empirical evaluation of the System Usability Scale. Int. J. Hum. *Comput. Interact.* 24(6):574-594.

Bannon W. (2015) Missing data within a quantitative research study: How to assess it, treat it, and why you should care. *Journal of the American Association of Nurse Practitioners*, 27 (4) doi/10.1002/2327-6924.12208/pdf.

Bech P, Olsen LR, Kjolle, M, Rasmussen NK (2003) Measuring well-being rather than the absence of distress symptoms: a comparison of the SF-36 Mental Health subscale and the WHO-Five Well-Being Scale. *Methods Psychiat Res,* 12, 85-91.

Beecham J, Knapp M (1992) Costing psychiatric interventions. In *Measuring Mental Health Needs.* Edited by Thornicroft G, Brewin C, Wing J. London: Gaskell; 163–183.]

Beesley L (2006). *Informal Care in England*. London, Kings Fund.

Beuscher L. & Grando VT (2009) Challenges in conducting qualitative research with individuals with dementia. *Research in Gerontological Nursing,* 2(1), 6-11.

Bleakley CM, Charles D, Porter-Armstrong A, McNeill MDJ, McDonagh SM, McCormack, B (2015) Gaming for health: A systematic review of the physical and cognitive effects of interactive computer games in older adults. *Journal of Applied Gerontology*, 34, NP166-NP189.

Bond M, Rogers G, Peters J. (2012) The effectiveness and cost-effectiveness of donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease (review of

Technology Appraisal No. 111): a systematic review and economic model. *Health Technology Assessment*, 16, 1–470.

Bowen DJ, Kreuter M, Sprin B, Cofta-Woerpel L, Linnan L, Weiner D, Bakken S, Kaplan C, Squiers L, Fabrizio C & Fernandez M (2009) How we design feasibility studies. *American Journal of Preventative Medicine,* 36(5), 452-457.

Boyd HD & Shenk D (2014) Beyond reminiscence: Using generic video to elicit conversational language. *American Journal of Alzheimer's Disease and Other Dementias,* 1-8. doi: 10.1177/1533317514534759.

Brankaert R & Ouden E D (2015) Design of a mobile interface: Reflections on an in-context evaluation. In *Proceedings of Participatory Innovation Conference 2015*, The Hague, The Netherlands.

Braun V. Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research In Psychology,* 3, 77-101

Bruer RA, Spitznagel, E, Cloninger, C (2007) The Temporal Limits of Cognitive Change from Music Therapy in Elderly Persons with Dementia or Dementia-Like Cognitive impairment: A Randomized Controlled Trial. *Journal of Music Therapy*, 44 (4) 308–328

Carers UK (2017) Making life better for carers. Available from: https://www.carersuk.org/help-and-advice/technology-and-equipment (Accessed 1 October 2017)

Carroll JM, Rosson MB (2007) Participatory design in community informatics. *Design Studies* 28(3): 243-261.

Carter J, Stewart B, Archbold P (1998) Living with a person who has Parkinson's disease: The Spouse's perspective by stage of disease. *Movement Disorders*, 13 (1), 20-28.

Charlesworth G, Burnell K, Crellin N, Hoare Z, Hoe J, Wenborn J, Knapp M, Russell L, Woods B. & Orrell M. (2016) Peer support and reminiscence therapy for people with dementia and their family carers: A factorial pragmatic randomised trial. *Journal of Neurology, Neurosurgery and Psychiatry*, 87(11),1218-1228.

Chisholm D, Knapp MR, Knudsen HC, Amaddeo F, Gaite L, van Wijngaarden B (2000) Client Socio-Demographic and Service Receipt Inventory--European Version: development of an instrument for international research. EPSILON Study 5. European Psychiatric Services: Inputs Linked to Outcome Domains and Needs.*Br J Psychiatry Suppl.* 2000;(39):28-33.

Cochrane Collaboration (2015) *Cochrane Dementia and Cognitive Improvement Group*. Available from http://dementia.cochrane.org/our-reviews (Accessed 14 June 2017)

Conden CE, Ritchie TD & Igou ER (2015) How dyads reminiscence moderates the relations between familiarity, trust, and memory conformity. *Social Psychology,* 46(2), 65-75.

Connolly S, Gillespie P, O'Shea E, Cahill S, & Pierce M. (2014). Estimating the economic and social costs of dementia in Ireland. Dementia 13(1), pp. 5-22.

Cooney A, Hunter A, Murphy K, Casey D, Devane D, Smyth S, Dempsey L, Murphy E, Jordan F & O'Shea E (2014) 'Seeing me through my memories': a grounded theory study on using reminiscence with people with dementia living in long-term care. *Journal of Clinical Nursing,* 23,3564 3574.

Cosley D, Akey K, Alson B, Baxter J, Broomfield M, Lee S, Sarabu C (2009) Using technologies to support reminiscence. *Proceedings of the 23rd British HCl Group Annual Conference on People and Computers: Celebrating People and Technology,* Pages 480-484.

Cotelli M, Manenti R, Zanetti O (2012) Reminiscence therapy in dementia: A review. *Journal of Maturitas*. 72 (1) pp 203-205.

Creswell JW (2013) *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. 3rd ed. London: Sage.

Curtis L & Burns A (2016) *Unit Costs of Health and Social Care 2016.* Personal Social Services Research Unit, Canterbury: University of Kent

Daly L, McCarron M, Higgins A, McCallion P (2013) 'Sustaining Place' – a grounded theory of how informal carers of people with dementia manage alterations to relationships within their social worlds. *Journal of Clinical Nursing*, 22 (3-4), 501 – 512.

Damianakis T, Crete-Nishihata M, Smith KL, Baecker M, Marziali E (2010) The Psychosocial Impacts of Multimedia Biographies on Persons with Cognitive Impairments. *Journal of the Gerontologist,* 50 (1) pp 23-25.

Dassel, K.B., Carr, D.C., Vitaliano, P. 2017. Does Caring for a Spouse With Dementia Accelerate Cognitive Decline? Findings from the Health and Retirement Study. *Gerontologist,* 57 (2), 319-328.

de Wit M, Pouwer F, Gemke RJ, Delemarre-van de Waal HA, Snoek FJ (2007) Validation of the WHO-5 Well-Being Index in adolescents with type 1 diabetes. *Diabetes Care,* 30 (8), 2003-6.

Dechamps A, Fasotti L, Jungheim J, Leone E, Dood E, Allioux A (2011) Effects of different learning methods for instrumental activities of daily living in patients with Alzheimer's dementia : A pilot study. *Journal of Alzheimer's Disease and other Dementias*. 26, 273-281

DeLello JA & McWhorter RR (2015) Reducing the digital divide: Connecting older adults to iPad technology. Journal of Applied Gerontology. DOI 10.1177/0733464815589985.

Dempsey L, Murphy K, Cooney A, Casey D, O'Shea E, Devane D, Jordan F, Hunter A (2012) Reminiscence in dementia: a concept analysis. *Dementia,* 0 (0), 1-17.

Denzin NK and Lincoln YS. (Eds.) (2013) Strategies of Qualitative Inquiry 4th ed. London: Sage.

Department of Health, Social Services and Public Safety (2011) *Improving Dementia Services in Northern Ireland: A Regional Strategy.* Department of Health, Social Services and Public Safety: Belfast. Available from:

https://www.dhsspsni.gov.uk/sites/default/files/publications/dhssps/improving-dementia-services-2011.pdf (Accessed 10th November 2015)

Department of Health (2016) O'Neill/ launches dementia learning and development framework. Available from: https://www.health-ni.gov.uklnews/oneill-launches-dementia-learning-and- development-framework (Accessed 29 April 2017)

Dewar B & Nolan M (2013) Caring about caring Developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies* 50 (9), 1247-1258

DiCicco-Bloom B. and Crabtree BF (2006), The qualitative research interview. *Medical Education,* 40: 314–321.

Dolan P. (1997). Modelling valuations for EuroQol health states. *Medical Care*, 35, 1095–1108.

Elfrink TR, Zuidema SU, Kunz M, Westerhof G (2017) The effectiveness of creating an online life story book on persons with early dementia and their informal caregivers: a protocol of a randomized controlled trial. *BMC Geriatrics.* 17, 95 DOI: 10.1186/S12877-017-0471-Y.

Farina N, Page TE, Daley S (2017) Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimer's & Dementia,* 13 (5), 572-581.

Gallagher D, Ni Mhaolain A, Crosby L, Ryan D, Lacey L, Coen RF, Walsh C, Coakley D, Walsh JB, Cunningham C, Lawlor BA (2011). Dependence and caregiver burden in Alzheimer's disease and mild cognitive impairment. *American Journal of Alzheimer's Disease & Other Dementias.* 26(2)110-4. doi: 10.1177/1533317510394649.

Gallagher-Thompson D, Dal Canto PG, Jacob T, Thompson L (2001) A comparison of marital interaction patterns between couples in which the husband does or does not have Alzheimer's disease. *Journal of Gerontology,* 56B (3), S140-S150.

Gibson A, McCauley CO, Mulvenna MD, Ryan AA, Laird EA, Curran KJ, Bunting B, Ferry F, Bond R (2016) Assessing Usability Testing for People with Dementia, REHAB-2016 Workshop – 4th Workshop on ICTS. Improving Patients' Rehabilitation Research Techniques, ACM Digital Library, ISBN 978-1-4503-4765-5, DOI: http://dx.doi.org/10.1145/3051488.3051492.

Glaser B. & Straus AL (1967) *The Discovery of Grounded Theory.* Chicago: Aldine.

Gonzalez J, Mayordomo T, Torres M, Sales A, Melendez C. (2015). Reminiscence and dementia: A therapeutic intervention. *Journal of International Psychogeriatric,* 27(10), 1731-1737.

Good A, Wilson C, Ancient C, Sambhanthan A (2012) A proposal to support wellbeing in people with borderline personality disorder: Applying reminiscent theory in a mobile app. In: *The ACM conference on designing interactive systems.* ACM Press, New York.

Gowans G, Campbell J, Alm N, Dye R, Astell A, Ellis, M (2004). Designing a multimedia conversation aid for reminiscence therapy in dementia care environments. In *CHI'04 extended abstracts on human factors in computing systems (CHI EA 04)* (PP. 825-836). New York, ACM Press.

Graff M, Adang E, Vernooij-Dassen M, Dekker J, Jönsson L, Thijssen M, (2008) Community occupational therapy for older patients with dementia and their caregivers: cost effectiveness study. *British Medical Journal.* 336:134–138.

Green J & Thorogood N. (2014) *Qualitative Methods for Health Research.* 3rd ed. London: Sage Publications.

Groenewoud JHH & de Lange JJ (2014) *Evaluation of personalised happy games on the iPad for people with dementia*]. Rotterdam: Kenniscentrum zorginnovatie.

Group EQ: EuroQoL (1990) A new facility for the measurement of health related quality of life. *Health Policy* ,16:199–208.

Haesner M, Steinert A, O Sullivan JL, Weichenberger M (2015) Evaluating an online cognitive training platform for older adults: User experience and implementation requirements. *Journal of Gerontological Nursing*, 41 (8), 22-31.

Hamel AV, Sims TL, Klassen D, Harvey T, Gaugler JE (2016) Memory Matters. A mixed methods feasibility study of a mobile aid to stimulate reminiscence in individuals with memory loss. *Journal of Gerontological Nursing*, 42(7), 15-24.

Hanson E, Magnusson L, Arvidsson H, Claesson A, Keady J, Nolan M (2007) Working together with persons with early stage dementia and their family members to design a user-friendly technology-based support service. *Dementia,* 6 (3), 411-434

Hardy P & Summer T (2010) Humanizing health-care. In. *Digital Storytelling; Capturing Lives, Creating Community,* 3rd edn. (ed. Lambert, J) pp 143-156. Berkeley, CA, Digital diner Press

Hayes J, Zimmerman MK, Boylstein C (2010) Responding to symptoms of Alzheimer's disease: Husbands, wives, and the gendered dynamics of recognition and disclosure. *Qualitative Health Research,* 20 (8), 1101–1115.

Health and Social Care Business Services Organisation (2015) Prescription Cost Analysis Northern Ireland 2015. Available from: https://www.nidirect.gov.uk/contacts/contacts-az/health-and-social-care-business-services-organisation. (Accessed 3 October 2017)

Hellstrom I, Nolan M, Nordenfelt L, Lundh U (2007) Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics* 14, 608-619

Henkel V, Mergl R, Kohnen R, Allgaier AK, Möller HJ, Hegerl U. (2004) Use of brief depression screening tools in primary care: consideration of heterogeneity in performance in different patient groups. *Gen Hospital Psychiatry*. 26, 190-198.

Huntley JD, Hampshire A, Bor D, Owen A, Howard RJ (2017) Adaptive working memory strategy training in early Alzheimer's disease: randomised controlled trial. *Br J Psychiatry,* 210, 61–66.

Intille SS, Rondoni, J, Kukla C, Anacona I, & Bao L. (2003). A context-aware experience sampling tool. In *Proceedings of the Conference on Human Factors and Computing Systems:* Extended Abstracts: ACM Press.

Karlsson E, Axelsson K, Zingmark K & Savenstedt S (2011) The challenge of coming to terms with the use of a new digital assistive device: a case study among two persons with mild dementia. *The Open Nursing Journal*, 5 102-110. DOI: 10.2174/18744346011050100102

Karlsson E, Axelsson K, Zingmark K, Fahlander K, Savenstedt S (2014) "Carpe Diem" Supporting conversations between individuals with dementia and their family members. *Journal of Gerontological Nursing,* 40 (2)38-46.

Kelly F (2010) Recognising and supporting self in dementia: a new way to facilitate a person-centred approach to dementia care. *Ageing and Society*, 30, 103-124

Kerkhof YJF, Bergsma A, Graff MJL, (2017) selecting apps for people with mild dementia: Identifying user requirements for apps enabling meaningful activities and self-management. *Journal of Rehabilitations and Assistive Technologies Engineering,* 4, 1-21

Kerssens C, Kumar R, Adams A, Knott C, Matalenas L, Sanford JA, Rogers A (2015) Personalized technology to support older adults with and without cognitive impairment living at home. *American Journal of Alzheimer's Disease & Other Dementias,* 30(1), 85-97.

Kitwood T (1997) *Dementia Reconsidered: the Person Comes First*. Open University Press, Buckingham, UK.

Knapp M, Iemmi V, Romeo R (2013) Dementia care costs and outcomes: a systematic review. *International Journal of Geriatric Psychiatry*, 28, 551-561

Knapp M, Thorgrimsen L, Patel, A, Spector A, Hallam A, Woods B, Orrell M (2006) Cognitive stimulation therapy for people with dementia: cost-effectiveness analysis. *British Journal of Psychiatry,* 18(8), 574-580.

Kretzschmar ,F Pleimling D, Hosemann J, Füssel S, Bornkessel-Schlesewsky I, Schlesewsky M (2013) *Subjective Impressions Do Not Mirror Online Reading Effort*: Concurrent EEG-Eyetracking Evidence from the Reading of Books and Digital Media. PLoS ONE 8(2): e56178. https://doi.org/10.1371/journal.pone.0056178

Kurz A, Wagenpfeil S, Hallauer J, Schneider-Schelte H & Jansen S. (2010) Evaluation of a brief educational program for dementia carers: The AENEAS Study. *International Journal of Geriatric Psychiatry,* 25 (8), 861-869.

Kvale S (1996) *Interviews: An Introduction to Qualitative Research Interviewing.* California: Sage Publications Ltd.

Larson R, & Csikszentmihalyi M. (2014). The experience sampling method. In *Flow and the Foundations of Positive Psychology: The Collected Works of Mihaly Csikszentmihalyi* (pp. 21-34). Springer Netherlands. doi: 10.1007/978-94-017-9088-8_2

Laver K, Milte R, Dyer S, Crotty M (2016) A Systematic Review and Meta-Analysis Comparing Carer Focused and Dyadic Multicomponent Interventions for Carers of People with Dementia. *Journal of Aging and Health.* doi/pdf/10.1177/0898264316660414.

Lawrence V, Fossey J, Ballard C, Moniz-Cook E, Murray J (2012) Improving quality of life for people with dementia in care homes: making psychosocial interventions work. *British Journal of Psychiatry*, 201 (5), 344-51.

Lazar A (2014) *Using technology to increase meaningful engagement in a memory care unit.* Group 14, November 9-12, 2014, Sanibel Island, Florida, USA. ACM. 978-1-4503-3043-5/14/11. http://dx.doi.org/10.1145/2660398.2660433.

Lazar A, Thompson H, Demiris G (2014). A systematic review of the use of technology for reminiscence therapy. *Health Education and Behaviour,* 41 (15) 515-615.

Leicht H, Heinrich S, Heider D, Bachmann C, Bickel H, van den Bussche H, Fuchs A, Luppa M' Maier W, Mösch E, Pentzek M, Rieder-Heller SG, Tebarth F, Werle J, Weyerer S, Wiese B, Zimmermann T, König HH (2011), Net costs of dementia by disease stage. *Acta Psychiatrica Scandinavica*, 124: 384–395.

Lewin K (1935) *A dynamic theory of personality.* New York: McGraw-Hill.

Lewis C (1982) *Using the 'thinking-aloud' method in cognitive interface design*. (IBM Research Report RC 9265, 2/17/82). Yorktown Heights, NY: IBM T.J. Watson Research Center.

Lim FS, Wallace T, Luszcz MA, (2013) Usability of tablet computers by people with early-stage dementia. *Gerontology,* 59: 174–182.

Lincoln YS & Guba EG (1985) *Naturalistic Inquiry.* Beverly Hills, CA: Sage Publications.

Liwowsky I, Kramer D, Mergl R, Bramesfeld A, Allgaier AK, Pöppel E (2009) Screening for depression in the older long-term unemployed. *Soc Psychiatry Psychiatr Epidemiol*, 44 (8), 622-7. doi: 10.1007/s00127-008-0478-y.

Logsdon RG, Gibbons LE, McCurry SM, Teri L (2002) Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine*, 64, 510 - 519.

Lorenz K, Freddolino P, Comas-Herrera A, Knapp M, Damant J (2017) Technology- based tools and services for people with dementia and carers: Mapping technology onto the dementia care pathway. *Dementia* 0(0) 1-17

Löwe B, Spitzer RL, Gräfe K, Kroenke K, Quenter A, Zipfel S, Buchholz C, Witte S, Herzog W (2004) Comparative validity of three screening questionnaires for DSM-IV depressive disorders and physicians' diagnoses. *J Affect disorders,* 78, 131-140.

Lyons KS, Sayer AG, Archbold PG, Hornbrook MC, Stewart BJ (2007) The enduring and contextual effects of physical health and depression on care-dyad mutuality. *Research in Nursing & Health.* 30 (1), 84-98.

Magnusson l, Hanson E & Savolinen L (2006) ACTION-*Person-centred care and support via IR. From an EU project to a mainstream support service for older people with chronic illness and their carers.* Final unpublished report to ITHS2, The Knowledge Foundation & Vardal Foundation, Stockholm (available from the first author, Lennart.magnusson@hb.se)

Mc Carthy S, Sayers H, Mc Kevitt P & McTear M. (2009). *"MemoryLane: Reminiscence for Older Adults."* Proceedings of the Reminiscence Systems Workshop at the 23rd British Human Computer Interaction (HCI) Conference. 1-5 September 2009. Churchill College Cambridge, UK, pp: 22-27.

Mc Carthy, S., Sayers, H, Mc Kevitt, P, McTear, M., Coyle, K. 2015. Intelligently Adaptive Mobile Interfaces for Older People*, International Journal of Ambient Computing and Intelligence,* doi: 10.4018/978-1-4666-7481-3.ch003

McCarthy S (2011) *Memory Lane: An Intelligent, Multimodal, Mobile Reminiscence Companion for Older Adults.* A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy http://www.paulmckevitt.com/phd/mccarthythesis.pdf.

McCormack, B .and McCance, T. (2016) *Person-Centred Practice in Nursing and Health Care:* Theory and Practice. Wiley. 94-401.

McDermott O, Orrell M &Ridder HM (2014) The importance of music for people with dementia: the perspectvies of people with dementia, family carers, staff and music therapists. *Aging and Mental Health,* 18(6), 706-716.

McDonnell E & Ryan A (2014) The experience of sons caring for a parent with dementia. *Dementia, The International Journal of Social Research and Practice, 13* (6), 788-802. DOI: 10.1177/1471301213485374

McHugh JE, Wherton JP, Prendergast DK, Lawlor BA (2012) Identifying opportunities for supporting caregivers of persons with dementia through information and communication technology. *Gerontechnology,* 10(4), 220-230.

McKeown J, Clarke A, Ryan T, Pepper J (2010) The use of life work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing.* 10 (1) pp 148-158.

Melunsky N, Crellin N, Dudzinski E, Orrell M, Wenborn J, Poland F, Woods B, Charlesworth G (2015) The experience of family carers attending a joint reminiscence group with people with dementia: A thematic analysis. *Dementia*, 14(6), 842-859.

Miles MB & Huberman MA (2014) Qualitative *Data Analysis-A Methods Sourcebook.* 3rd ed. Thousand Oaks, California: Sage Publications

Miller SD, Hubble MA, Chow D, Seidel J (2015) Beyond measures and monitoring: realizing the potential of feedback informed treatment. *Psychotherapy*, 52(4), 449-457.

Mulder I, ter Hofte GH, Kort J (2005): 'SocioXensor: Measuring user behaviour and user eXperience in ConteXt with mobile devices', in L.P.J.J. Noldus, F. Grieco, L.W.S. Loijens and P.H. Zimmerman (eds.): *Proceedings of Measuring Behavior. The 5th International Conference on Methods and Techniques in Behavioural Research*, August 30 – September 2, 2005, Wageningen, the Netherlands, pp. 355-358.

Mulhern B, Rowen D, Brazier J, Smith S, Romeo R, Tait R, Watchurst C, Chua KC, Loftus V, Young T, Lamping D, Knapp M, Howard R, Banerjee S (2013). Development of DEMQOL-U and DEMQOL-PROXY-U: generation of preference-based indices from DEMQOL and DEMQOL-PROXY for use in economic evaluation. *Health Technologies Assessment*, 17(5):v-xv, 1-140. doi: 10.3310/hta17050.

Mulvenna MD, Doyle L, Wright T, Zheng H, Topping P, Boyle K. & Martin S (2011) Evaluation of card-based versus device-based reminiscing using photographic images. *Journal of CyberTherapy and Rehabilitation,* 4(1), 57-66.

National Institute for Health and Care Excellence (2013) *Judging the cost effectiveness of public health activities.* London: NICE. Available from: https://www.nice.org.uk/advice/lgb10/chapter/judging-the-cost-effectiveness-of-public-health-activities. (Accessed 4 October 2017)

Newell AF and Gregor P (2000) *User sensitive inclusive design, in search of a new paradigm.* Proceedings on the 2000 conference on Universal Usability. http://web.mit.edu/16.459/Newell.pdf Accessed 25th April 2013.

Nielsen J, Landauer TK (1993) "A mathematical model of the finding of usability problems," *Proceedings of ACM INTERCHI'93 Conference* (Amsterdam, The Netherlands, 24-29 April 1993), pp. 206-213.

Nijhof N, van Gemert-Pijnen JEWC, Burns CM, (2013) A personal assistant for dementia to stay at home safe at reduced cost. *Gerontechnology,* 11: 469–479.

Nolan, MR, Brown J, Davies, S, Nolan J. & Keady J. (2006). *The Senses Framework: improving care for older people through a relationship-centred approach. Getting Research into Practice (GRiP) Report No 2.* Project Report. University of Sheffield.

O Neill E & Hardy P (2008) *Designing patient-shaped healthcare: hearing patient voices*. White Rose Health Innovation Partnership Technology Bulletin. Available at: http://www.whiterose.ac.uk/sites/default/files/Patient%20 Shaped %20Healthcare.pdf (accessed 5 October 2011)

O Shea E (2003). Costs and consequences for the carers of people with dementia in Ireland. *Dementia,* 2(2), 201-219.

O'Cathain A, Hoddinott P, Lewin S, Thomas K, Young B, Adamson Y, Jansen JFM, Mills N, Moore G & Donovan JL. (2015) Maximising the impact of qualitative research in feasibility studies for randomized controlled trials: guidance for researchers. *BioMed Central,* 1:32. doi 10.1186/s40814-015-0026-y.

O'Connor S, Bouamrane MM, O'Donnell CA & Mair FS (2016) Barriers to co-designing mobile technology with persons with dementia and their carers. *Nursing Informatics,* doi: 10.3233/978-1-61499-658-3-1028.

O'Rourke J, Tobin F, O'Callaghan S, Sowman R & Collins DR. (2011) "YouTube": a useful tool for reminiscence therapy in dementia? *Age and Ageing*, 40(6), 742-744.

Orpwood R, Sixsmith A, Torrington J, Chadd J, Chalfont G (2007) Designing technology to support quality of life of people with dementia. *Technology and Disability*, 19, 103-112

O'Shea E, Devane D, Cooney A, Casey D, Jordan F, Hunter A, Murphy E, Newell J, Connolly S & Murphy K (2014) The impact of reminiscence on quality of life of residents with Dementia in long stay care. *International Journal of Geriatric Psychiatry*, 29, 1062-1070.

Pallant J (2010). *SPSS Survival Manual.* New York: McGraw Hill.

Palmer SB, Wehmeyer ML, Davies DK, Stock SE (2012) Family members' reports of the technology use of family members with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 56(4) 402-414.

Parahoo K (2006) Nursing *Research: Principles, Process and Issues.* 2nd ed. Basingstoke: Palgrave Macmillan.

Peisah C, Lawrence G, Reutens S (2011) Creative solutions for severe dementia with BPSD: A case of art therapy used in an inpatient and residential care setting. *International Psychogeriatrics* 23, 1011-1013.

Polit DF & Beck CT. (2012) *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. 9th Edition, Lippincott, Williams & Wilkins, Philadelphia.

Prince M (2014) *Dementia UK: Update, Second Edition Report.* London: King's College and the London School of Economics for the Alzheimer's Society.

Pringle A & Somerville S. (2013) Computer-assisted reminiscence therapy developing practice. *Mental Health Practice*, 17(4), 34.

Quinn C, Clare L, Woods B (2009). The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. *Aging and Mental Health,* 13 (2), 143-154.

Raglio A, Bellelli G, Traficante D, Gianotti M, Ubezio MC, Villani D, Trabucchi M. (2008). Efficacy of music therapy in the treatment of behavioural and psychiatric symptoms of Dementia. *Alzheimers Disease & Associated Disorders.* 22(2), 158-162.

Regier NG & Gitlin LN. (2017) Dementia-related restlessness: Relationship to characteristics of persons with dementia and family caregivers. *International Journal of Geriatric Psychiatry,* doi: 10.1002/gps.4705

Riley P, Alm N, Newell A (2009) An interactive tool to promote musical creativity in people with dementia. *Computers in Human Behaviour,* 25, 599-608.

Robinson L, Brittain K, Lindsay S, Jackson D, Olivier P (2009) Keeping In Touch Everyday (KITE) project: developing assistive technologies with people with dementia and their carers to promote independence. *International Psychogeriatrics,* 21 494-502.

Rowen D, Mulhern B, Banerjee S, Hout BV, Young TA, Knapp M, Smith SC, Lamping DL, Brazier JE. (2012) Estimating preference-based single index measures for dementia using DEMQOL and DEMQOL –Proxy. *Value Health* 15(2), 346-56

Ryan A & McKenna H. (2013) Familiarity as a key factor influencing rural family carers experience of the nursing home placement of an older relative: a qualitative study. *BMC Health Services Research*, 13:252. doi: 10.1186/1472-6963-13-252

Sarne-Fleischmann V & Tractinsky N (2008) Development and evaluation of a personalised multimedia system for reminiscence therapy in Alzheimer's patients. *International Journal of Social and Humanistic Computing,* 1(1), 8195.

Sauro J (2011) Measuring Usability with the System Usability Scale. Available at: http://www.measuringu.com/sus.php (Accessed 24 September 2015).

Sauro J, Lewis JR. (2012) *Quantifying the user experience: Practical statistics for user research*. London: Elseiver

Sauro J., and Dumas, J.S., (2009) Comparison of three one-question, post-task usability questionnaires. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (CHI '09). ACM, New York, NY, USA, 1599-1608.

Sauro, J. (2016) How to Conduct a Usability Test On a Mobile Device, http://www.measuringu.com/blog/mobile-usability-test.php, (Accessed 10 May 2016)

Savage C (2016) Harnessing new technologies to improve mood and wellbeing. *Care Analysis* 18(2), 98-100

Schumacher KL, Stewart BJ, Archbold PG (2007) Mutuality and preparedness moderate the effects of caregiving demand on cancer family caregiver outcomes, *Nursing Research,* 56, 425-433.

Selwood A, Johnston K, Katona C, Lyketsos C, Livingston G. (2007) Systematic Review of the effect of Psychological Interventions on family Caregivers of people with dementia. *Journal of Affective Disorders*. 101 pp 75-89.

Sixsmith A & Gibson G (2007) Music and the wellbeing of people with dementia, *Ageing and Society*, 27 (1), pp. 127-145

Smith KL, Crete-Nishihata, M, Damianakis T, Baecker R, Marziali E (2009) Multimedia biographies: a reminiscence and social stimulus tool for persons with cognitive impairment. *Journal of Technology in Human Services*. 27(4), 287-306

Smith SC, Lamping DL, Banerjee S, Harwood A, Foley B, Smith P, Cook JC, Murray J, Prince M, Levin E, Mann A, Knapp M (2005) Measurement of health related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technology Assessment* 9:1112.

Smith SC, Lamping DL, Banerjee S, Harwood R, Foley B, Smith P, Cook JC, Murray J, Prince M, Levin E, Mann A, Knapp M (2007) Development of a new measure of health-related quality of life for people with dementia: DEMQOL. *Psychological Medicine* 37 (5), 737-46.

Smith SK, Mountain GA (2012) New forms of information and communication technology (ICT) and the potential to facilitate social and leisure activity for people living with dementia. *International Journal of Computers in Healthcare*, 1 (4), 332-45.

Smith. G (2016) *Dementia Care. A Practical Approach*. London: CRC Press.

Snoek F (2006) The DAWN Study. Available from http://www.dawnstudy.com/content/dam/Dawnstudy/AFFILIATE/www-dawnstudy-com/Home/TOOLSANDRESOURCES/Documents/WHO-5.pdf (Accessed 4 April 2017)

Span M, Hettinga M, Vernooij-Dassen M, Eefstinge J, Smits C (2013) Involving people with dementia in the development of supportive IT applications: A systematic review. *Ageing Research Reviews*, 12, 535–551. doi.org/10.1016/j.arr.2013.01.002

Spruytte N, Van Audenhove C, Lammertyn F, Storms G (2002) The quality of the caregiving relationship in informal care for older adults with dementia and chronic psychiatric patients. *Psychology & Psychotherapy: Theory, Research & Practice*, 75, 295-311.

Stenhouse R, Tait J, Hardy P, Sumner T (2013) Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early stage dementia. *Journal of Psychiatric and Mental Health Nursing,* 20, 134-141

Subramaniam P & Woods B (2012) The impact of individual reminiscence therapy for people with dementia: systematic review. *Expert Rev. Neurother,* 12(5), 545-555.

Subramaniam P & Woods B. (2016). Digital life storybooks for people with dementia living in care homes. *Clinical Interventions in Aging,* 11, 1263-1276.

Tamura T, Ohsumi M, Oikawa D, Higashi Y, Fujimoto T, Suenaga T and Kuwhara N (2007) Reminiscence – A comparison of conventional therapeutic and computer-based interactive methods. *Journal of Robotics and Mechatronics,* 19 (6), 724-726

Tetz KB, Archbold PG, Stewart BJ, Messecar D, Hornbrook MC, Lucas SA (2006) How Frail Elders Evaluate Their Caregiver's Role Enactment - A Scale to Measure Affection, Skill, and Attentiveness. *Journal of Family Nursing,* 12 (3), 251-275.

Thiry E (2013) Designing a Digital Reminiscing System for Older Adults. SIGACCESS Access. *Comput.,* 105: 24–28. doi:10.1145/2444800.2444805.

Topp CW, Østergaard SD, Søndergaard S, Bech P (2015) The WHO-5 Well-Being Index: a systematic review of the literature. *Psychother Psychosom,* 84 (3), 167-76.

United Natinos (2008) *Convention on the Rights of Persons with Disabilities.* Available from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html (Accessed 3 October 2017)

Upton D, Upton P, Jones T, (2011). *Evaluation of the impact of touch screen technology on people with dementia and their carers within care home settings*. Worcester: University of Worcester

van Kordelaar V, Kuin KA, Westerhof GJ (2007) *Tijdreizen: Een Handleiding en Werkboek Voor Intergenerationele Gesprekken* (Time Traveling: A Manual for Intergenerational Groups). Nijmegen, the Netherlands: Centre for Psychogerontology.

van Tilborg IA, Kessels RPC, Hulstijn W (2011) How should we teach everyday skills in dementia? A controlled study comparing and explicit training methods. *Clinical Rehabilitation* 25, 638-648

Vernooij-Dassen M, Draskovic I, Mc Cleery J, Downs, M (2011) Cognitive reframing for carers of people with dementia. *The Cochrane Database of Systematic Reviews.* Issue 11.

Voigt-Radloff S, Graff M, Leonhart R, (2011). A multicentre RCT on community occupational therapy in Alzheimer's disease: 10 sessions are not better than one consultation. *BMJ Open*. doi:10.1136/bmjopen-2011-000096

Wayman L (2017) *A Loving Approach to Dementia Care. Making Meaningful Connections with the person who has Alzheimer's Disease or Other Dementia or Memory Loss*. 2nd ed. Maryland: John Hopkins University Press.

Webster J D, Bohlmeijer ET, Westerhof GJ (2010) Mapping the Future of Reminiscence. A Conceptual Guide for Reminiscence. A Conceptual Guide for Research and Practice. *Journal of Research on Aging.* 34 (4) pp 527-564.

Werner P & Heinik J (2008) Stigma by association and Alzheimer’s disease. *Aging & Mental Health*. 12, 92-99

Westerhof GJ & Bohlmeijer ET (2014) Celebrating fifty years of research and applications in reminiscence and life review: State of the art and new directions. *Journal of Aging Studies,* 29, 107-114.

Whitlatch J & Menne H (2009) Don’t’ forget about me. Decision making by people with dementia. *Journal of the American Society on Ageing.* 33, 66-71

Whitlatch CJ, Feinberg LF, Tucke SS (2005) Accuracy and consistency of responses from persons with dementia. *Dementia: The International Journal of Social Research and Practice,* 4 (2), 171-183.

Wiebe K D, Mason-D'Croz T, Sulser N, Cenacchi S, Islam R, Robertson T (2016) Agriculture *and food security in 2050: socioeconomic and climate challenges and options.* International Food Policy Research Institute (IFPRI), Washington, DC.

Wilmer HH, Sherman LE, Chein JM (2017) Smartphones and cognition: A review of research exploring the links between mobile technology habits and cognitive functioning. *Frontiers in Psychology* 8, 605 DOI: 10.3389/fpsy.2017.00605.

Wimo A, Jönsson L, Gustavsson A, McDaid D, Ersek K, Georges J, Gulácsi L, Karpati K, Kenigsberg P, Valtonen H. (2011) The economic impact of dementia in Europe in 2008-cost estimates from the Eurocode project. I*nt J Geriatr Psychiatry.* 26(8):825-32.

Woo D & Mori J (2004) Accessibility: A tool for usability evaluation. In Masoodian M, Jones S, Rogers B, (eds.) *APCHI.* Volume 3101 of LNCS, New York: Springer 531–539.

Woods B, Spector AE, Jones CA, Orrell M, Davies SP (2005) Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews 2005* Issue 2. Art. No.: CD001120. DOI: 10.1002/14651858.CD001120.pub2.

Woods R, Bruce E, Edwards R, Elvish R, Hoare Z, Hounsome B, Russell I (2012). REMCARE: Reminiscence Groups for People with dementia and their family caregiver's effectiveness and cost-effectiveness Pragmatic multicentre randomised trial. *Health Technology Assessment.* 16 (1) PP 1-116.

Woods RT, Orrell M, Bruce E, Edwards RT, Hoare Z, Hounsome B, Keady J, Moniz-Cook E, Orgeta V, Rees J, Russell I. (2016) REMCARE: Pragmatic Multi-Centre Randomised Trial of Reminiscence Groups for People with Dementia and their Family Carers: Effectiveness and Economic Analysis. *PLoS ONE [Electronfo Resource*}, 11(4) pp 1-19.

World Health Organisation Collaborating Centre in Mental Health (1998) WHO (Five) Well-Being Index. Available from https://www.psykiatri-regionh.dk/who-5/Documents/WHO5_English.pdf (Accessed 1 February 2014)

Wright T & Mulvenna MD (2012) The Memory Game: an iPad-based interactive reminiscence programme to aid those with dementia. *Gerontologist,* 52 (1), 274-274.

Yasuda K, Kuwabara K, Kuwahara N, Abe S, Tetsutani N. (2009) Effectiveness of personalised reminiscence photo videos for individuals with dementia. *Neuropsychological Rehabilitation,* 19(4) 603-619.

Appendices

Appendix 1

Invitation to participate in research

(Phase 1)

Usability of an app for supporting reminiscence with people living with dementia and their carers

Assumpta Ryan
Chief Investigator
Tel: 02871675350
Email:
aa.ryan@ulster.ac.uk

Liz Laird
Researcher
Tel: 02871675006
Email:
ea.laird@ulster.ac.uk

Can you help with a research study?

You have been given this invitation because you are a member of the Alzheimer’s Society Foyle Support Network. We would like you to consider helping our research team to develop and test technology that could assist people with dementia to reminisce.

Your involvement will require attendance at 4 to 6 meetings and workshops with the research team in Ulster University, Magee Campus, Derry-Londonderry.

During the workshops you will be shown how to use the technology and the researchers will be observing as you are doing this. Your views and feedback will be very important and will assist us to improve the technology.

If you are interested, then please contact Liz or Assumpta by telephone or email. Our details are provided. If you prefer, you can complete the form on the following page and post this to Liz. You do not have to decide today to take part, only that we can contact you.

Thank you for considering this important study.

Declaration of Interest

Usability of an app for supporting reminiscence with people with dementia and their carers

(Phase 1)

I confirm that I am giving the researchers permission to contact me about taking part in this reminiscence study.

I understand that I am under no obligation to take part in this study.

The information that I provide below can be used to contact me about this study only and will be confidential to the researchers.

NAME:…………………………………………………………………

SIGNATURE:…………………………………………………………

PHONE NUMBER:..…………………………………………………………

Please post this form to Liz Laird, School of Nursing, Ulster University, Northland Rd, Londonderry, BT47 3YJ

Appendix 2

Participant Information Leaflet

(Phase 1)

Usability of an app for supporting reminiscence with people living with dementia and their carers

Assumpta Ryan
Chief Investigator
Tel: 02871675350
Email:
aa.ryan@ulster.ac.uk

Liz Laird
Researcher
Tel: 02871675006
Email:
ea.laird@ulster.ac.uk

You have been given this information booklet, because you are interested to help us to test out a software device that we are developing to assist reminiscence activity.

Reminiscence in this study will involve activities that support people to remember pleasurable events and experiences in their lives, and share these memories with their carer.

Please read this booklet carefully

A team of researchers at Ulster University led by two qualified nurses (Assumpta Ryan and Liz Laird) is interested in exploring the effect of technology assisted reminscence for people with dementia and their family carer.

You are being invited to take part in a testing out phase of this study. Before you decide whether or not you wish to take part, it is important that you understand what the research is for and what it will involve. Please read the following information carefully.

What is the purpose of the study?

The aim of this study is to find out what your needs and your capabilties are, as you try out the technology that we are developing.

What will participation in the study involve?

This study will involve you being part of a small group that will help the research team to test and refine the technology. You will be invited to take part in 4 to 6 meetings or workshops that will be held in Ulster University, Magee Campus, Derry-Londonderry.

You will be supported to complete a short questionnaire that provides us with some information about you, such as your age, and previous experiencence using IT. In the workshops you will be shown how to use the technology.

Once you feel comfortable with it, you will be observed as you complete some tasks. The technology will be able to store information about how you are using the device and this will help us to make further improvements to it. We will ask you for your views about how we can improve the device, as we want to make the device more user friendly.

When you are content with your ability to use the technology, you will be given an opportunity to try it out at home. Your views are important to us. You will be supported to complete a short questionnaire about the usability of the device, and this will help us to make further improvements.

Why have you been chosen?

You have been chosen because you are a member of the Alzheimer's Society Foyle Support Network.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign a consent form. If you do choose to take part, you can change your mind at any time and withdraw from the study, without giving a reason.

Are there any possible benefits of taking part?

It is hoped that the information we obtain from you taking part in this study will help us to test and refine technology that will assist reminiscence activity for people with dementia and their family carer.

Will my taking part in this study be kept confidential?

If you agree to take part in this study your name or any identifying characteristics will not appear in any reports or publications. All information associated with this study will be stored securely and only accessed by the research team.

What will happen to the results of the study?

The results from this study are likely to be published and presented at conferences. You will not be identified in any report, presentation or publication. You can request a copy of the findings following completion of the research.

What you can expect from the Researcher?

You can expect that a member of the research team will be easily accessible and contactable to discuss any aspect of the study with you.

Who has reviewed this study?

Ethical approval has been attained from Ulster University’s Research Ethics Committee to conduct the study.

Contacts for further information

Dr Assumpta Ryan Reader in Nursing Room MG105, Ulster University, Northland Rd, Derry-Londonderry BT48 7JL T 02871675350	Ms Liz Laird, Lecturer of Nursing Room MG207e, Ulster University, Northland Rd, Derry-Londonderry BT48 7JL T 02871675006	Mr Nick Curry Research Governance Room 26A17 Ulster University Shore road, Newtownabbey BT37 0QB T 02890366629

Thank you for taking time to read this information booklet

Appendix 3

Consent Form (Phase 1)

Study Title: Usability of an app for supporting reminiscence with people living with dementia and their carers

1. I confirm that I have read and understood the information about this study and have received answers to any questions I asked. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving a reason and without my rights being affected. ☐
3 I understand that video and audio recording will be used in observations of how I am using the technology ☐
4. I understand that the researchers will hold all information collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study. ☐
5. I agree to take part in the above study. ☐

Name of Participant:	Name of Researcher obtaining consent:
…………………………………………………	…………………………………………………..
Signature:	Signature:
………………………………………………..	…………………………………………………
Date: ……………………………………	Date: ……………………………………..

Appendix 4

Ethical Approval (Phase 1)

Ulster University
Sl1ore Road
Newtownabbey
County Antrim
BT37 DQB
Northern Ireland

T: + 44 (0)28 9036 6552/6518/6629
F: + 44 (0)28 9036 6479

ulster.ac.uk

Our Ref: NC:GOV

11 September 2015

Dr A Ryan

Room MG105

School of Nursing Ulster University Magee

Dear Dr Ryan

Research Ethics Committee Application Number: REC/15/0082

Study Title: Usability of an app for supporting reminiscence with people with dementia and their carers

Thank you for your recent response to matters raised by the committee. This has been considered and the decision of the committee is that the research should proceed.

Please also note the additional documentation relating to research governance and indemnity matters, including the requirements placed upon you as Chief Investigator.

The committee's decision is valid for a period of three years from today's date (this means that the study should be completed by that date). If you require this period to be extended, please contact the Research Governance section.

1. **Please complete and return the Chief Investigator Statement of Compliance prior to commencing the study and keep a copy for your file.**
2. **Please retain all other documents.**

Further details of the University's policy along with guidance notes, procedures, terms of reference and forms are available at the following web address:

http://research.ulster.ac.ukloffice/rofficeeg.html

If you need any further information or clarification of any points, please do not hesitate to contact me.

Yours sincerely

CJL

Lf Nick Curry

Senior Administrative Officer

Research Governance

028 9036 6629

n.curry@ulster.ac.uk

Appendix 5

Letter of Invitation

(Phase 2, Version 1: 01/02/2016)

A Feasibility Study of Facilitated Reminiscence for People Living with Dementia

Dear (Participant)

You are being invited to take part in a study exploring what it is like to experience reminiscence in your own home.

Reminiscence involves remembering pleasurable events in your life and sharing these memories with others.

In this study we will be using an iPad to help people and their family carers to share the reminiscence experience.

The staff would like to ask your permission to pass on your contact details to us, so that we can contact you about the study. You do not have to decide today to take part, only that we can contact you.

If you would prefer not to be contacted, this will not affect your care in any way.

Thank you for taking the time to read this letter and consider taking part in this research study.

Professor Assumpta Ryan Chief Investigator Ulster University Derry/Londonderry BT48 7JL Tel: 02871 675350 Email:aa.ryan@ulster.ac.uk	Dr Claire McCauley Researcher Ulster University Derry/Londonderry BT48 7JL Tel: 02871 675293 Email:c.mccauley2@ulster.ac.uk

Declaration of Interest

(Phase 2)

A Feasibility Study of Facilitated Reminiscence for People Living with Dementia

I confirm that I am giving permission for the researchers to contact me about taking part in this reminiscence study.

I understand that I am under no obligation to take part in the study.

This information below will only be used to contact me about this study and will be treated as confidential by the researchers.

Name:	Signature:
Address:	Phone no:
Carer’s name:	Signature:
Carer’s address:	Carer’s phone no:

Please return this completed page to a member of staff who will store it securely for the research team

Appendix 6

Reminiscence Training Manual

A Feasibility Study of Facilitated Reminiscence for People Living with Dementia

Purpose of the Project

RNNI will provide training for carers in the 'basics of reminiscence work' – good listening skills, and responding sensitively to their loved ones efforts to communicate with them. It will highlight to carers the pleasure that they can still gain from reminiscing with their loved one who has dementia about their good times together. This also helps their loved one with dementia rediscover their sense of identity and belonging which helps them feel more confident as they use one of their remaining strengths – their long- term memory. It offers a way for carers to make the most of their relationship with their person as they are now and stimulates positive feelings which will reinvigorate the relationship between the carer and the person with dementia.

This project is innovative in its use of an iPad to store memories of enjoyable events both visually and audibly i.e. photos, extracts of films, songs/hymns, storytelling and poetry so that they are easily accessed and enjoyed together. They will also be shown how to add new information on their iPad whenever they want to in the future.

The outcome of this training for the carer and the person with dementia has the potential of far-reaching implications for families, society and public spending as it may prevent the breakdown of the care-giving relationship that can lead to the person with dementia needing alternative care, such as a residential or nursing home.

Programme Outline

Session1: Introductions and Overview of Life Story

Resources needed: memories life clock

1. Introduce self and explain the aims of the project e.g. how reminiscence can be helpful to both the carer and the person with dementia……you hope that they will both have fun and enjoy reminiscing over the 5 sessions……after that it is hoped they will continue to reminisce together.
2. Explain proposed number of visits and negotiate time
3. Ask carer to help ensure that their loved one is fully involved in the reminiscence work – they are the 'memory carrier' for their loved one and can choose relevant triggers to stimulate happy memories – remembering that they may have experienced events differently. (Relevant triggers may include photographs, maps, school reports, certificates, tickets/concert programmes, postcards, lists of favourite music/songs).
4. Use Life Memories Clock – a circle divided into 4 quarters to represent 4 quarters of their life time. Discuss with them significant experiences/events for them during each quarter of their lives and write these around the circle to give an overview of their lives.
5. At the end of the visit, give them the Timeline on which the carer can work with their loved one to see their life in the context of Northern Ireland events and International events. They can add to their Life Memories Clock additional memories if they want. Explain that during your next visit the focus will be on early years in the family. Family photos or a map of where the person lived would be very helpful for the next visit.

Session 2: Early Years

Resources needed: paper, pens and pencils and selection of objects from school, a leather school bag, pen, pencil, rubber, ink, exercise book, a skipping rope, marbles, crayons, writing script.

1. Happy Home - helpful starting questions are: Who was part of your home? Where was home to you as a child? Then go on to a question such as 'Discuss family photos.
2. Then ask them to draw the outside of the home where they were happiest or the floor plan of inside their home. Encourage the person with dementia to remember the colours, sounds and family members in the home. (Facilitator may need to do the drawing)
3. School - How far was Primary School away from home? How did they get there?
4. Provide a pen and paper if person with dementia wants to show off their best handwriting....or they recite a poem or sing a song they have 'learnt by heart'?
5. Food - Ask person about their favourite childhood food. Where did their family eat meals?...Did people have particular places around the table? ….Was there a prayer to God to give thanks before starting a meal?.... Were the children reminded about table manners e.g. no elbows on the table? ….Who did the cooking? Who cleared the dishes from the table?..Who washed the dishes?
6. Explain that during your next visit you plan to focus on Outings/Holidays/Leisure activities. Ask carers to assemble some souvenirs and photographs from holidays.

Session 3: 0utings/Holidays/Leisure activities

Resources needed: sand, seaweed old postcards, old camera, holiday photographs, shells, foreign currency, train or plain tickets. Blank maps of Ireland, British Isles and the World.

1. Begin with showing the photograph of the five ladies paddling in the sea and then develop this into a reflection of personal holiday memories. The aim is to recall enjoyable holiday memories but begin with destinations and chart them on the maps. The family carer can help prompt memories. Include in this the type of things the loved one liked to do on holiday – dancing, fishing, cycling, painting, reading or walking. Bear in mind that many people visited other family members for their holidays and may not have travelled very far so be sensitive to this. Everyone however will have experienced a trip to the seaside.
2. Using the other physical prompts
3. Encourage the feel of sand running through fingers or the smell and touch of slimy seaweed and can evoke powerful memories. Although some people may not be able to articulate their memories, the introduction of physical activities will help to transport them back to remembered pleasures.
4. Encourage the recall the songs that were often sung during outings or day trips: Show me the way to go home/My bonnie lies over the ocean/ Summer holiday.
5. Explain that during your next visit you plan to focus on work. Ask carers to assemble some relevant material.

Session 4: Work

Resources needed: Plain A4 paper, pencil and coloured pens

Topics to explore under this theme might include first jobs, the first pay packet, the journey to work, the working day and friendships at work. For some a session on work provides an opportunity to show the skills and capabilities they have had in the past and allows the carer to appreciate the whole person and their achievements. This is a good opportunity to show any certificates or ‘congratulations on your retirement’ letters.

1. The facilitator can begin with miming some of the jobs they have done and get the loved one and their carer to guess the activity.
2. Then go on to ‘This is the hand activity’
3. This activity involves touching the loved one’s hand so please make sure that this is acceptable.
4. Place their hand in the centre of the paper and draw round it carefully and gently. Use this outline to begin to build a picture of the work undertaken with these hands. Write any comments or memories using the coloured pens either inside or outside the hand.
5. Remind the couple that the next visit will be your last one and the focus then will be on putting their memories into the App on the iPad.

Session 5: Uploading Memorabilia

IT Trainer to join this session to put memorabilia into the App on the iPad.

1. Record stories with iPad
2. Food could be continued
3. Childhood play could be continued
4. Suggest to carer other topics which they may want to discuss with their loved one are as follows:
    - Fashion/clothes
    - Hairstyles
    - Going out
    - Courtship and weddings
    - Celebrations

Appendix 7

Ethical Approval Phases 2 and 3

HSC Business Services Organisation

Office for Research Ethics Committees Northern Ireland (ORECNI)

Customer Care & Performance Directorate
Lissue Industrial Estate West
Rathdown Walk
Moira Road
Lisburn
BT28 2RF
Tel: 028 95361400
www.orecni.hscni.net
HSC REC B

HSC REC B
15 March 2016

Professor Assumpta Ryan
Professor of Ageing and Health, Institute of Nursing and Health Research
School of Nursing, Ulster University
Northland Road
Derry
BT48 7JL

Dear Professor Ryan

Study title:	**A Feasibility Study of Facilitated Reminiscence for People Living with Dementia**
REC reference:	**16/NI/0035**
IRAS project ID:	**156499**

The Research Ethics Committee reviewed the above application at the meeting held on 10 March 2016. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Mr Matthew Mills, recb@hscni.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave **a favourable ethical opinion** of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

Ethical issues raised by the Committee in private discussion, together with responses given by the researcher when invited into the meeting.

The Committee was joined by Dr Assumpta Ryan and Mrs Elizabeth Laird to discuss the application.

Social or scientific value; scientific design and conduct of the study

The Committee agreed that upon the initial study submission they had been convinced that the study was of very high social and scientific value. It was noted that the study design as outlined within the re-submission had been greatly clarified and was now largely satisfactory. Some Committee members noted that it was good that people with no internet access would be allowed to participate as an IPAD would be provided, however it was still unclear how the participant would be able to access the internet if they had no WIFI connection. The researchers advised that this had been taken into consideration and although most participants should have an internet connection, the research organisations IT department had provided assurance that internet access could be arranged whether this was a 3G sim card or by other means. The Committee acknowledged that the study was a feasibility study and as assurance had been provided that every step would be taken to provide those participants who needed it with an internet connection, this was considered satisfactory.

Upon response to a question from the Committee, the researchers confirmed that the compliance of a carer using the application was not going to be measured formally.

Recruitment arrangements and access to health information, and fair participant selection

It was noted that the recruitment procedures appeared to be appropriate and explanations and a clear rationale had been provided. It was noted that recruitment for phase 2 would be taken from phase 1. The Committee questioned what scales would be used to measure the diagnosis of people with dementia for inclusion in the study. The researchers advised that they would be using the clinical dementia rating already assigned to a patient by their care team. Participants with mild to moderate dementia would be included whereas those with a diagnosis of “extreme” would be considered outside of the inclusion criteria.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Brochure]	Version 1	15 December 2015
Covering letter on headed paper [Cover Letter & HSC REC B Letter]	1	02 February 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Indemnity]	Version 1	18 November 2015
Interview schedules or topic guides for participants [Interview Schedule Phase 2]	Version 1	01 February 2016
IRAS Checklist XML [Checklist_03022016]		03 February 2016
Letter from funder [Letter from Funder]	Version 1	25 July 2014
Letter from sponsor [Letter from Sponsor]	Version 1	18 November 2015
Letters of invitation to participant [Letters of Invitation]	Version 1	01 February 2016
Other [Lone Worker Protocol]	Version 3	01 February 2016
Other [Distress Protocol]	Version 3	01 February 2016
Other [Support Pack]	Version 3	01 February 2016
Other [Reminiscence Training Programme]	Version 1	01 February 2016
Participant consent form [Participant Consent Forms]	Version 1	01 February 2016
Participant information sheet (PIS) [Participant Information Sheets]	1	01 February 2016
REC Application Form [REC_Form_03022016]		03 February 2016
Referee's report or other scientific critique report [Referees' Reports]	Version 1	09 October 2015
Research protocol or project proposal [Research Protocol]	Version 5	03 February 2016

Summary CV for Chief Investigator (CI) [Summary CV A Ryan]	2	03 February 2016
Validated questionnaire [Outcome Measurements]	Version 1	02 February 2016

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

16/NI/0035	**Please quote this number on all correspondence**

With the Committee’s best wishes for the success of this project.

Yours sincerely

Matthew Mills

pp Professor Patrick Murphy
HSC REC B Chair

E-mail: recb@hscni.net

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments* *"After ethical review – guidance for researchers"* [*SL-AR2 for other studies]*
Copy to:	*Mr Nick Curry, Ulster University* *Mrs Sally Doherty, Research Governance*

HSC REC B

Attendance at Committee meeting on 10 March 2016

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Ronald Atkinson	Retired Consultant in Medical Oncology	No	
Mrs Karen Cardwell	Community Pharmacist	Yes	
Dr Elinor Johnston	Research Assistant (Clinical Studies Coordinator)	Yes	
Ms Rejina Mariam Verghis	Junior Biostatistician	No	
Mrs Siobhan McCullough	Nurse / Lecturer	No	
Mrs Cliona McDowell	Statistician	No	
Mr John Edward Mone	Retired (Former Executive Director of Nursing)	No	
Dr Sarah Anne Moorhead	Lecturer in Health & Interpersonal Communication	No	
Ms Aine Morrison	Service Manager, Community Treatment & Support Services for Learning Disability	Yes	
Professor Patrick Murphy	Advisor on Social & Economic Policy	Yes	Chair of the meeting
Dr Seamus O'Brien	Outcomes Manager, Primary Joint Unit	Yes	
Mr Leon O'Hagan	Pharmacist	Yes	
Dr Mark Reid	Retired Consultant Paediatrician	Yes	
Ms Marilyn Trimble		No	
Ms Sue Trouton	Community Midwifery Sister	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Mr Matthew Mills	REC B Manager

Appendix 8

Participant Information Leaflet (PLWD)

(Phase 2, Version 1: 01/02/2016)

A Feasibility Study of Facilitated Reminiscence for People Living with Dementia

We would like to invite you to take part in our study exploring how people and their family carers can be supported to engage in reminiscence activity in their own home.

Reminiscence involves the use of prompts such as photographs, music and films to trigger memories that have a special meaning for a person.

You have indicated that you are interested in finding out more about the study and this information sheet will provide you with details about the study and what your involvement would entail.

Thank you for reading this information

The aim of our study is to investigate the impact of home based reminiscence using an iPad App on people living with dementia and their carers.

What will happen if I take part?

If you decide to take part, you and your carer will receive 5 reminiscence training sessions. These will be provided by facilitators from the Reminiscence Network Northern Ireland. These training sessions will take place in your own home at a time that suits you and your carer.

At the end of these training sessions, you will be given an iPad to use the App to reminisce. An IT trainer will then provide you and your carer with 3 training sessions on how to use the App. This will take place in your own home at a time that suits you and your carer. You will also be provided with contact details for the IT trainer if you have any problems using the App.

Once the training is complete, the iPad will be left for you and your carer to use for reminiscence activity for a period of 3 months. It is important for our study that you try and use the iPad on at least 3 occasions each week.

The App will collect information about your pattern of usage in terms of how often and how long you use the App. This information will be stored on the iPad and will be sent automatically to a secure email address in the university.

Each time you use the App, a short question will appear on the screen for you to answer. The question will help us to understand the impact of reminiscence on your relationship with your carer. You do not have to answer this question if you do not want to.

In this research study, we would like to understand how this approach to reminiscence works for you. Our researcher will visit you on 3 occasions to ask questions which will help us to understand the impact of reminiscence on relationships, quality of life and use of services.

If you decide that you would like to take part in the study we will ask you to sign a consent form before it begins.

Do I have to take part?

No, you do not have to take part in this study if you do not want to and you do not need to give any reason if you decide not to take part.

If you choose to take part in the study you will be free to withdraw at any stage without needing to give a reason for doing so.

If you do choose to withdraw, it is important that you are aware that we will use information that we have already gathered from you up to that point, to inform our study reports and findings.

What are the possible benefits of taking part and what are the possible disadvantages?

By taking part in this study, you will be contributing to research that will help improve our understanding of how reminiscence can be used by people with dementia and their family carers.

We hope that participation in this study will be an engaging and enjoyable process for you. Your views and contributions are very important to us.

It is possible some memories may be upsetting. If this happens, you should let the researcher know immediately. You will be free to ask for breaks or can withdraw at any point.

You will have access to a list of names and phone numbers of people you can contact for support.

Confidentiality

We have a duty to protect participants and to keep all information you give us confidential. Therefore the research team will fully comply with the Ulster University Data Protection Policy. Any information you share during the course of the study will be treated in strict confidence.

Information collected will only be seen by members of the research team and will be stored safely and securely. Any information you give that is used in publications will be made anonymous.

What will happen to the results of the research study?

The information we gather will be used by us to prepare a report and research papers about facilitated reminiscence for people with dementia and their family carers. Their publication in journals will enable professionals to increase their knowledge about supporting reminiscence at home.

We will provide a summary of the study findings to Reminiscence NI and the Alzheimer's Society and the WHSCT. If you would like to be provided with a summary of the overall research findings, you may provide contact details to a member of the research team and we will send you a summary leaflet at the end of the project.

Who is organising the research?

The project is funded by the Health and Social Care Research and Development Office and Atlantic Philanthropies. The research will be led by Assumpta Ryan, Professor of Ageing and Health at Ulster University in partnership with Reminiscence NI, the Alzheimer's Society and the Western Health and Social Care Trust.

Further information

If you would like any further information, please contact:

Dr Claire McCauley
Researcher
School of Nursing
Ulster University Northland Road
Derry/Londonderry
BT48 7JL

Tel: 02871 675293
Email: c.mccauley2@ulster.ac.uk

Thank you kindly for your interest in this study and for taking the time to read through this information sheet

Appendix 9

Participant Information Leaflet (Carer)

(Phase 2, Version 1: 01/02/2016)

A Feasibility Study of Facilitated Reminiscence for People Living with Dementia

We would like to invite you to take part in our study exploring how people with dementia and their family relatives can be supported to engage in reminiscence activity in their own home.

Reminiscence involves the use of prompts such as photographs, music and films to trigger memories that have a special meaning for a person.

You have indicated that you are interested in finding about more about the study and this information sheet will provide you with details about the study and what your involvement would entail.

Thank you for reading this information

The aim of our study is to investigate the impact of home based reminiscence using an iPad App on people living with dementia and their relatives.

What will happen if I take part?

If you decide to take part, you and your relative will receive 5 reminiscence training sessions. These will be provided by facilitators from the Reminiscence Network Northern Ireland. These training sessions will take place in your own home at a time that suits you and your relative.

At the end of these training sessions, you will be given an iPad to use the reminiscence App. An IT trainer will then provide you and your relative with 3 training sessions on how to use the App. This will take place in your own home at a time that suits you and your relative. You will also be provided with contact details for the IT trainer if you have any problems using the App.

Once the training is complete, the iPad will be left for you and your relative to use for reminiscence activity for a period of 3 months. It is important for our study that you support your relative to use the App on at least 3 occasions per week.

The iPad will collect information about your pattern of usage in terms of how often and how long you use the iPad. This information will be stored on the iPad and will be sent automatically to a secure email address in the university.

Each time you use the App, a short question will appear on the screen for you to answer. The question will help us to understand the impact of reminiscence on your relationship with your relative. You do not have to answer this question if you do not want to.

In this research study, we would like to understand how this approach to reminiscence works for you. Our researcher will visit you on 3 occasions to ask question which will help us to understand the impact of reminiscence on relationships and quality of life. We will also provide you with a Service Use Log to record all the services you and your relative have used during the study.

If you decide that you would like to take part in the study we will ask you to sign a consent form before it begins.

Do I have to take part?

No, you do not have to take part in this study if you do not want to and you do not need to give any reason if you decide not to take part. If you choose to take part in the study you will be free to withdraw at any stage without needing to give a reason for doing so.

If you do choose to withdraw, it is important that you are aware that we will use information that we have already gathered from you up to that point, to inform our study reports and findings.

What are the possible benefits of taking part and what are the possible disadvantages?

By taking part in this study you will be contributing to research that will help improve knowledge of how professionals can best support reminiscence activity for people with dementia and their family carers.

We hope that participation in this study will be an engaging and enjoyable process for you. Your views and contributions are very important to us.

It is possible that some memories may be upsetting. If this happens, you should let the researcher know immediately. You will be free to ask for breaks or can withdraw at any point.

You will have access to a list of names and phone numbers of people you can contact who can provide you with the support.

Confidentiality

We have a duty to protect participants and to keep all information you give us confidential. Therefore the research team will fully comply with the Ulster University Data Protection Policy. Any information you share during the course of the study will be treated in strict confidence.

Information collected will only be seen by members of the research team and will be stored safely and securely. Any information you give that is used in publications will be made anonymous.

What will happen to the results of the research study?

The information we gather will be used by us to prepare a report and research papers about facilitated reminiscence for people with dementia and their family carers. Their publication in journals will enable professionals to increase their knowledge about supporting reminiscence at home.

We will provide a summary of the study findings to the Reminiscence Network Northern Ireland, the Alzheimer's Society and the Western Health and Social Care Trust. If you would like to be provided with a summary of the overall research findings, just let us know and we will send this to you at the end of the project.

Who is organising the research?

The project is funded by the Public health Agency, research and development Office and Atlantic Philanthropies. The research will be led by Professor Assumpta Ryan, Professor of Ageing and Health at Ulster University in partnership with Reminiscence Network NI, the Alzheimer's Society and the Western Health and Social Care Trust.

Further information

If you would like any further information, please contact:

Dr Claire McCauley Research Assistant

School of Nursing

Ulster University

Derry/ Londonderry BT48 7JL

Email: c.mccauley2@ulster.ac.uk

Telephone: 028 71675293

Thank you kindly for your interest in this study and for taking the time to read through this information sheet

Appendix 10

Consent form (PLWD)

(Phase 2, Version 1: 01/02/2016)

Ulster University

Study Title: A Feasibility Study of Facilitated Reminiscence for People Living with Dementia

1. I confirm that I have read and understood the information about this study and have received answers to any questions I asked. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving a reason and without my rights being affected. ☐
3. I understand that if I chose to withdraw at any stage from the study, that information already collected from me will be used to inform the findings of the study. ☐
4. I understanding that the researchers will hold all information collected securely and in confidence. All efforts will be made to ensure that I cannot be identified as a participant in the study. ☐
5. I understand that information about the usage of the App will be recorded and sent to the research team throughout the duration of the project. ☐

6 I agree to take part in the study. ☐

Name of Participant:	Name of Researcher:
………………………………………………	………………………………………………
Signature:	Signature:
………………………………………………	………………………………………………
Date:	Date:
………………………………………………	……………………………………………….

Appendix 11

Consent Form (Carer)

(Phase 2, Version 1: 01/02/2016)

Study Title: A Feasibility Study of Facilitated Reminiscence for People Living with Dementia

1. I confirm that I have read and understood the information about this study and have received answers to any questions I asked. ☐
2. I understand that I will be required to support my relative to use the reminiscence App. ☐
3. I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving a reason and without my rights being affected. ☐
4. I understand that if I chose to withdraw at any stage from the study, that data already collected from me will be used to inform the findings of the study. ☐
5. I understanding that the researchers will hold all information collected securely and in confidence. All efforts will be made to ensure that I cannot be identified as a participant in the study. ☐
6. I understand that information about the usage of the App will be recorded and sent to the research team throughout the duration of the project. ☐

7. I agree to take part in the study. ☐

Name of Participant:	Name of Researcher:
………………………………………………	………………………………………………
Signature:	Signature:
………………………………………………	………………………………………………
Date:	Date:
………………………………………………	………………………………………………

Appendix 12

The Mutuality Scale

(Archbold PG, Stewart BJ, Greenlick MR, Harvath T. (1990) Mutuality and preparedness as predictors of caregiver role strain. Res Nurs Health, 13, 375-84.

Ulster
University

Participant Code:____________________Date: _____________

We would like you to let us know how you and your family member feel about each other at the current time.

No.	**Item**	**Not at all**	**A little**	**Some**	**Quite a bit**	**A great deal**
1.	To what extent do the two of you see eye to eye (agree on things)?	**0**	**1**	**2**	**3**	**4**
2.	How close do you feel to him or her?	**0**	**1**	**2**	**3**	**4**
3.	How much do you enjoy sharing past experiences with him or her?	**0**	**1**	**2**	**3**	**4**
4.	How much does he or she express feelings of appreciation for you and the things you do?	**0**	**1**	**2**	**3**	**4**
5.	How attached are you to him or her?	**0**	**1**	**2**	**3**	**4**
6.	How much does he or she help you?	**0**	**1**	**2**	**3**	**4**
7.	How much do you like to sit and talk with him or her?	**0**	**1**	**2**	**3**	**4**
8.	How much love do you feel for him or her?	**0**	**1**	**2**	**3**	**4**
9.	To what extent do the two of you share the same values?	**0**	**1**	**2**	**3**	**4**
10.	When you really need it, how much does he or she comfort you?	**0**	**1**	**2**	**3**	**4**
11.	How much do the two of you laugh together?	**0**	**1**	**2**	**3**	**4**
12.	How much do you confide in him or her?	**0**	**1**	**2**	**3**	**4**
13.	How much emotional support does he or she give you?	**0**	**1**	**2**	**3**	**4**
14.	To what extent do you enjoy the time the two of you spend together?	**0**	**1**	**2**	**3**	**4**
15.	How often does he or she express feelings of warmth towards you?	**0**	**1**	**2**	**3**	**4**

Appendix 13

The WHO-5 Well-Being Index (1988 version)

Psychiatric Research Unit
WHO Collaborating Centre in Mental Health

[redacted]

Please indicate for each of the five statements which is closest to how you have been feeling over the last two weeks. Notice that higher numbers mean better well-being.

Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, put a tick in the box with the number 3.

	Over the last two weeks	All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
1	I have felt cheerful and in good spirits	5	4	3	2	1	0
2	I have felt calm and relaxed	5	4	3	2	1	0
3	I have felt active and vigorous	5	4	3	2	1	0
4	I woke up feeling fresh and rested	5	4	3	2	1	0
5	My daily life has been filled with things that interest me	5	4	3	2	1	0

Scoring:

The raw score is calculated by totaling the figures of the five answers. The raw score ranges from 0 to *25,* 0 representing worst possible and 25 representing best possible quality of life.

To obtain a percentage score ranging from 0 to 100, the raw score is multiplied by 4. A percentage score of 0 represents worst possible, whereas a score of 100 represents best possible quality of life.

Interpretation: It is recommended to administer the Major Depression (ICD-10) Inventory if the raw score is below 13 or if the patient has answered 0 to 1to any of the five items. A score below 13 indicates poor wellbeing and is an indication for testing for depression under ICD-10.

Monitoring change: In order to monitor possible changes in wellbeing, the percentage score is used. A 10% difference indicates a significant change (ref. John Ware, 1995).

Appendix 14

The Quality of Carer Patient Relationship

(Spruytte *et al.,* 2002)

Please think about your *relationship with the person who is caring for you* and answer the following questions by circling your responses.

No.	Question	Totally disagree	Disagree	Not sure	Agree	Totally agree
1.	My relative and I often spend time together in an enjoyable way	1	2	3	4	5
2.	My relative and I often disagree	1	2	3	4	5
3.	There is a big distance in the relationship between my relative and myself	1	2	3	4	5
4.	My relative and I accept each other as we are	1	2	3	4	5
5.	If there are problems my relative and I can usually resolve these easily	1	2	3	4	5
6.	I get on well with my relative	1	2	3	4	5
7.	My relative and I are tender towards each other	1	2	3	4	5
8.	My relative often annoys me	1	2	3	4	5
9.	I feel very good if I am with my relative	1	2	3	4	5
10.	My relative and I often try to impose our opinions on each other	1	2	3	4	5
11.	I blame my relative for the cause of my problems	1	2	3	4	5
12.	My relative and I appreciate each other as people.	1	2	3	4	5
13.	My relative does not appreciate enough what I do for him/her	1	2	3	4	5
14.	I am always glad to see him/her if I have not seen him/her for some time.	1	2	3	4	5

Appendix 15

The Quality of Carer Patient Relationship (Carer)

(Spruytte *et al.,* 2002)

Please think about your relationship with the person you are caring for and answer the following questions by circling your responses.

No.	Question	Totally disagree	Disagree	Not sure	Agree	Totally agree
1.	My relative and I often spend time together in an enjoyable way	1	2	3	4	5
2.	My relative and I often disagree	1	2	3	4	5
3.	There is a big distance in the relationship between my relative and myself	1	2	3	4	5
4.	My relative and I accept each other as we are	1	2	3	4	5
5.	If there are problems my relative and I can usually resolve these easily	1	2	3	4	5
6.	I get on well with my relative	1	2	3	4	5
7.	My relative and I are tender towards each other	1	2	3	4	5
8.	My relative often annoys me	1	2	3	4	5
9.	I feel very good if I am with my relative	1	2	3	4	5
10.	My relative and I often try to impose our opinions on each other	1	2	3	4	5
11.	I blame my relative for the cause of my problems	1	2	3	4	5
12.	My relative and I appreciate each other as people.	1	2	3	4	5
13.	My relative does not appreciate enough what I do for him/her	1	2	3	4	5
14.	I am always glad to see him/her if I have not seen him/her for some time.	1	2	3	4	5

Appendix 16

DEMQOL

Study ID ☐☐☐☐☐

DEMQOL (version 4)

Instructions: Read each of the following questions (in bold) verbatim and show the respondent the response card.

I would like to ask you about your life. There are no right or wrong answers. Just give the answer that best describes how you have felt in the last week. Don't worry if some questions appear not to apply to you. We have to ask the same questions of everybody.

Before we start we'll do a practice question; that's one that doesn't count. *(Show the response card and ask respondent to say or point to the answer)* **In the last week, how much have you enjoyed watching television?**

a lot	**quite a bit**	**a little**	**not at all**

Follow up with a prompt question: **Why is that?** *or* **Tell me a bit more about that.**

For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask about <u>your feelings</u>. In the last week, have you felt…….

1. **cheerful? ****	a lot	quite a bit	a little	not at all
2. **worried or anxious?**	a lot	quite a bit	a little	not at all
3. **that you are enjoying life? ****	a lot	quite a bit	a little	not at all
4. **frustrated?**	a lot	quite a bit	a little	not at all
5. **confident? ****	a lot	quite a bit	a little	not at all
6. **full of energy? ****	a lot	quite a bit	a little	not at all
7. **sad?**	a lot	quite a bit	a little	not at all
8. **lonely?**	a lot	quite a bit	a little	not at all
9. **distressed?**	a lot	quite a bit	a little	not at all
10. **lively? ****	a lot	quite a bit	a little	not at all
11. **irritable?**	a lot	quite a bit	a little	not at all
12. **fed-up?**	a lot	quite a bit	a little	not at all
13. **that there are things that you wanted to do but couldn't?**	a lot	quite a bit	a little	not at all

Next, I'm going to ask you about <u>your memory</u>. In the last week, how worried have you been about……….

14. **forgetting things that happened recently?**	a lot	quite a bit	a little	not at all
15. **forgetting who people are?**	a lot	quite a bit	a little	not at all
16. **forgetting what day it is?**	a lot	quite a bit	a little	not at all

17. **your thoughts being muddled?**	a lot	quite a bit	a little	not at all
18. difficulty making decisions?	a lot	quite a bit	a little	not at all
19. poor concentration?	a lot	quite a bit	a little	not at all

Now, I'm going to ask you about <u>your everyday life</u>. In the last week, how worried have you been about……….

20. **not having enough company?**	a lot	quite a bit	a little	not at all
21. **how you get on with people close to you?**	a lot	quite a bit	a little	not at all
22. **getting the affection that you want?**	a lot	quite a bit	a little	not at all
23. **people not listening to you?**	a lot	quite a bit	a little	not at all
24. **making yourself understood?**	a lot	quite a bit	a little	not at all
25. **getting help when you need it?**	a lot	quite a bit	a little	not at all
26. **getting to the toilet in time?**	a lot	quite a bit	a little	not at all
27. **how you feel in yourself?**	a lot	quite a bit	a little	not at all
28. **your health overall?**	a lot	quite a bit	a little	not at all

We've already talked about lots of things: your feelings, memory and everyday life. Thinking about all of these things in the last week, how would you rate……….

29. **your quality of life overall? ****	very good	good	fair	poor

****** items that need to be reversed before scoring

Appendix 17

DEMQOL (Carer Version)

Ulster University

Study

DEMQOL (version 4)

Study ID ☐☐☐☐☐

DEMQOL - Carer *(version 4)*

Instructions: *Read each of the following questions (in bold) verbatim and show the respondent the response card.*

I would like to ask you about__________*(your relative's)* **life, as you are the person who knows him/her best. There are no right or wrong answers. Just give the answer that best describes how__________***(your relative)* **has felt in the last week. If possible try and give the answer that you think______________***(your relative)* **would give. Don't worry if some questions appear not to apply to__________***(your relative).* **We have to ask the same questions of everybody.**

Before we start we'll do a practise question; that's one that doesn't count. *(Show the response card and ask respondent to say or point to the answer***).** **In the last week how much has _________** *(your relative)* **enjoyed watching television?**

a lot **quite a bit** **a little** **not at all**

Follow up with a prompt question: **Why is that?** *or* **Tell me a bit more about that.**

For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask you about__________*(your relative's)* **feelings. In the last week, would you say that __________** *(your relative)* **has felt .**

1. **cheerful? ****	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
2. **worried or anxious?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
3. **frustrated?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
4. **full of energy? ****	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
5. **sad?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
6. **content? ****	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
7. **distressed?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
8. **lively? ****	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
9. **irritable?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
10. **fed-up**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
11. **that he/she has things to look forward to? ****	☐ a lot	☐ quite a bit	☐ a little	☐ not at all

Next, I'm going to ask you about__________*(your relative's)* **memory. In the last week, how worried would you say __________** *(your relative)* **has been about .**

12. **his/her memory in general?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
13. **forgetting things that happened a long time ago?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
14. **forgetting things that happened recently?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
15. **forgetting people's names?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
16. **forgetting where he/she is?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
17. **forgetting what day it is?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all

18. **his/her thoughts being muddled?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
19. **difficulty making decisions?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
20. **making him/herself understood?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all

Now, I'm going to ask about__________*(your relative's)* everyday life. In the last week, how worried would you say __________ *(your relative)* has been about .

21. **keeping him/herself clean (eg washing and bathing)?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
22. **keeping him/herself looking nice?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
23. **getting what he/she wants from the shops?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
24. **using money to pay for things?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
25. **looking after his/her finances?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
26. **things taking longer than they used to?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
27. **getting in touch with people?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
28. **not having enough company?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
29. **not being able to help other people?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
30. **not playing a useful part in things?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
31. **his/her physical health?**	☐ a lot	☐ quite a bit	☐ a little	☐ not at all

We've already talked about lots of things:__________*(your relative's)* **feelings, memory and everyday life. Thinking about all of these things in the last week, how would you say__________***(your relative)* **would rate ..**

32. his/her quality of life overall? **	☐ very good	☐ good	☐ fair	☐ poor

****** items that need to be reversed before scoring

Appendix 18

Client Service Receipt Inventory

Client Service Receipt Inventory

A feasibility study of facilitated reminiscence for people with dementia

2016

Adapted Client Service Receipt Inventory – for participant with dementia.

Section 1: Study participant/patient

1. How many people are there in the participant's household?

	Number
Number of adults including study participant	☐☐
Number of children under the age of 16 years	☐☐

2. **What kind of accommodation does the study participant live in at the moment?** *(tick* ***one*** *box)*

1. Council-rented housing ☐

2. Housing-association rented housing ☐

3. Private rented housing ☐

4. Owner-occupied housing ☐

5. Other housing (please describe in box) ☐ ☐

3. Is the participant's accommodation "sheltered" housing (has a warden or scheme manager on-site)?

1. Yes ☐

2. No ☐

4. Has the participant lived anywhere else during <u>the last 3 months</u> (excluding hospital stays)?

1. **Yes** ☐ → ***Go to Q5***

2. **No** ☐ → ***Go to Q6***

5. What type of accommodation did the participant stay in at that time?

If participant reports a stay in a care/nursing home or other location, complete the questions in that row.

For 'Participant or family contribution', ask: 'Did the participant or a family member pay for this accommodation?' *and tick yes if the person reports having paid all or part of the costs*

Service	**No**	**Yes**	**Reason for using service (e.g. respite)**	**Name of home (not to be entered into database)**	**Number of days**	**Participant or family contribution** **No**	 **Yes**	**Provider (*see note**)**
Residential care home	☐	☐	☐	☐	☐☐	☐	☐	☐
Nursing home	☐	☐	☐	☐	☐☐	☐	☐	☐
Other - please describe using 'Name of home' box	☐	☐	☐	☐	☐☐	☐	☐	☐

*[*Note: Use the "Name of home" information to complete the Provider box, using WHO codes, after the interview]*

WHO codes

1	Local authority/Social Services/Council
2	NHS
3	Voluntary/charitable organisation
4	Private company or insurance company
5	Self or family members
6	Other
7	Researcher unable to classify response
8	Not completed

Community health and social services

6. In the <u>last 3 months</u>, has the study participant used any of the services below?
[SHOW CARD 1]

Note: please tick the ‘no’ box if participant has not used the service

Service	**No**	**Yes**	**No. of home visits**	**No. clinic or office visits**	**Average duration of contact (minutes)**
GP	☐	☐	☐☐	☐☐	☐☐☐
Practice nurse (at GP surgery)	☐	☐	☐☐	☐☐	☐☐☐
Community/District Nurse	☐	☐	☐☐	☐☐	☐☐☐
Community psychiatric / Community Mental Health Nurse	☐	☐	☐☐	☐☐	☐☐☐
Psychiatrist	☐	☐	☐☐	☐☐	☐☐☐
Social worker or care manager	☐	☐	☐☐	☐☐	☐☐☐
Psychologist	☐	☐	☐☐	☐☐	☐☐☐
Physiotherapist	☐	☐	☐☐	☐☐	☐☐☐
Occupational therapist	☐	☐	☐☐	☐☐	☐☐☐
Dietician	☐	☐	☐☐	☐☐	☐☐☐
Counsellor	☐	☐	☐☐	☐☐	☐☐☐
Mental health team worker	☐	☐	☐☐	☐☐	☐☐☐
Specialist nurse (e.g. Admiral Nurse, palliative care nurse, respiratory nurse) - *please describe in box*	☐	☐	☐☐	☐☐	☐☐☐

7. In the <u>last 3 months</u>, has the participant used any of the services below?
[SHOW CARD 2]
Note: please tick the 'no' box if participant has not used the service

For 'Participant or family contribution', ask: 'Did you or a family member pay for this service?' *and tick yes if the person reports having paid all or part of the costs*

Service	**No**	**Yes**	**Number of home visits**	**No. of clinic / office visits**	**Average duration of contact (minutes)**	**Participant or family contribution**	
						No	**Yes**
Home care/home help	☐	☐	☐☐☐	▨▨	☐☐☐	☐	☐
Home care/home help: additional organisation	☐	☐	☐☐☐	▨▨	☐☐☐	☐	☐
Home care/home help: additional organisation	☐	☐	☐☐☐	▨▨	☐☐☐	☐	☐
Cleaner	☐	☐	☐☐☐	▨▨	☐☐☐	☐	☐
Meals on wheels	☐	☐	☐☐☐	▨▨	▨▨▨	☐	☐
Laundry service	☐	☐	☐☐☐	▨▨	▨▨▨	☐	☐
Sitting service (e.g. Crossroads)	☐	☐	☐☐☐	▨▨	☐☐☐	☐	☐
Carer's support worker	☐	☐	☐☐☐	▨▨	☐☐☐	☐	☐
Optician	☐	☐	☐☐☐	☐☐	▨▨▨	☐	☐
Chiropodist	☐	☐	☐☐☐	☐☐	▨▨▨	☐	☐
Dentist	☐	☐	☐☐☐	☐☐	▨▨▨	☐	☐
Other health or social care services:							
1. …………………	☐	☐	☐☐☐	☐☐	☐☐☐	☐	☐
2. …………………	☐	☐	☐☐☐	☐☐	☐☐☐	☐	☐

Day services

8. In the last 3 months has the participant used any of the day services below?

[SHOW CARD 3] *Note: please tick the 'no' box if participant has not used the service*

For 'Participant or family contribution', ask: 'Did you or a family member pay for this service?' *and tick yes if the person reports having paid all or part of the costs*

Service	**No**	**Yes**	**Number of times per week**	**Number of times in last 3 months**	**Name of service (not to be entered into database)**	**Did participant or family pay or contribute**		**Provider (*see note**)**
						No	**Yes**	
Day centre	☐	☐	☐☐	☐☐☐	☐	☐	☐	☐
Lunch club	☐	☐	☐☐	☐☐☐	☐	☐	☐	☐
Patient education group (e.g. reminiscence) *please describe:* ……………………	☐	☐	☐☐	☐☐☐	☐	☐	☐	☐
Other health or social care day services:								
1. ………………	☐	☐	☐☐	☐☐☐	☐	☐	☐	☐
2. ………………	☐	☐	☐☐	☐☐☐	☐	☐	☐	☐

*[*Note: Use the "Name of service" information to complete the Provider box, using WHO codes, after the interview]*

Direct Payments

9. Has the participant been in receipt of direct payments, individual budget or personal budget* **in the last 3 months**? (* see Q9 definitions card)

Direct payments / Personal Budgets	**No**	**Yes**	**Total weekly value in £**
Direct payments	☐	☐	☐
Individual budget / Personal budget	☐	☐	☐

Hospital services

10. <u>In the last 3 months</u> has the participant used any of the following hospital services?

Note: please tick the 'no' box if participant has not used the service

Service	No	Yes	Name of ward, clinic hospital or centre	Reason for using service (condition, specialty)	Unit of measurement	No. of days/ attend	NHS Trust code*
Accident & Emergency Department (A&E)	☐	☐	☐	☐	Attendance	☐☐	☐
Inpatient ward admission 1	☐	☐	☐	☐	Inpatient day	☐☐	☐
Inpatient ward admission 2	☐	☐	☐	☐	Inpatient day	☐☐	☐
Inpatient ward admission 3	☐	☐	☐	☐	Inpatient day	☐☐	☐
Inpatient ward admission 4	☐	☐	☐	☐	Inpatient day	☐☐	☐
Inpatient ward admissions 5	☐	☐	☐	☐	Inpatient day	☐☐	☐
Outpatient Department (OPD) Attendance 1	☐	☐	☐	☐	Appointment	☐☐	☐
OPD Attendance 2	☐	☐	☐	☐	Appointment	☐☐	☐
OPD Attendance 3	☐	☐	☐	☐	Appointment	☐☐	☐
OPD Attendance 4	☐	☐	☐	☐	Appointment	☐☐	☐
OPD Attendance 5	☐	☐	☐	☐	Appointment	☐☐	☐
Day hospital Attendance 1	☐	☐	☐	☐	Day attendance	☐☐	☐
Day hospital Attendance 2	☐	☐	☐	☐	Day attendance	☐☐	☐

*[*Note: Use 'name of hospital' information to assign NHS Trust code after the interview]*

Equipment and adaptations

11. In the last 3 months has the participant had any adaptations or equipment to meet their needs? [SHOW CARD 4]

1. Yes ☐

2. No ☐

If yes, *tick the box for each type of change or equipment that the participant has had and ask* 'who or which organisation paid for these'.

Type of adaptation or equipment	Tick if yes	Who/Which organisation paid for this?				
		Council	NHS	Self	Volunt./ charity	Other
Medication reminder dispenser	☐	☐	☐	☐	☐	☐
Calendar clock	☐	☐	☐	☐	☐	☐
Falls detector/falls alarm	☐	☐	☐	☐	☐	☐
Community/personal alarm (inc. pull-cord and pendant alarms)	☐	☐	☐	☐	☐	☐
Outdoor railing	☐	☐	☐	☐	☐	☐
Grab rail/Stair rail	☐	☐	☐	☐	☐	☐
Walking stick	☐	☐	☐	☐	☐	☐
Walking frame	☐	☐	☐	☐	☐	☐
Walk-in shower/shower cubicle replacing bath	☐	☐	☐	☐	☐	☐
Over-bath shower	☐	☐	☐	☐	☐	☐
Bath seat/shower seat	☐	☐	☐	☐	☐	☐
Kitchen stool	☐	☐	☐	☐	☐	☐
Bed lever/rail	☐	☐	☐	☐	☐	☐
Toilet frame/raised toilet seat	☐	☐	☐	☐	☐	☐
Commode	☐	☐	☐	☐	☐	☐
Continence pads	☐	☐	☐	☐	☐	☐

12. <u>In the last 3 months</u> has the participant had any other adaptations or equipment for his/her condition? Please describe.

Prompt for memory aids: *e.g. bath overflow and temperature alarms, also: gas and carbon monoxide sensors and smoke alarms <u>that are monitored by a telecare centre</u>*

If yes, *tick the box for each type of adaptations or equipment that the participant has had and ask* 'who or which organisation paid for these'.

Type of adaptation or equipment	**Tick if yes**	**Who/which organisation paid for this?**				
		Council	**NHS**	**Self**	**Volunt./ charity**	**Other**
1.________________	☐	☐	☐	☐	☐	☐
2.________________	☐	☐	☐	☐	☐	☐
3.________________	☐	☐	☐	☐	☐	☐
4.________________	☐	☐	☐	☐	☐	☐
5.________________	☐	☐	☐	☐	☐	☐
6.________________	☐	☐	☐	☐	☐	☐

Medications

13. Has the participant taken any medications for his/her condition <u>over the last 3 months</u>?

Tradename	First day	Last day (if applies)	Ongoing (if applies)	Dose	Medication unit code	Frequency code	Medication code*
DEMENTIA DRUGS	dd/mm/yy	dd/mm/yy					
______________	__/ /	/ /_	☐	☐☐☐	☐☐	☐☐	☐☐
______________	__/ /	/ /_	☐	☐☐☐	☐☐	☐☐	☐☐
______________	__/ /	/ /_	☐	☐☐☐	☐☐	☐☐	☐☐
______________	__/ /	/ /_	☐	☐☐☐	☐☐	☐☐	☐☐
______________	__/ /	__/ /_	☐	☐☐☐	☐☐	☐☐	☐☐
OTHER MENTAL HEALTH DRUGS							
______________	__/ /	/ /_	☐	☐☐☐	☐☐	☐☐	☐☐
______________	__/ /	/ /_	☐	☐☐☐	☐☐	☐☐	☐☐
______________	__/ /	/ /_	☐	☐☐☐	☐☐	☐☐	☐☐
______________	__/ /	/ /_	☐	☐☐☐	☐☐	☐☐	☐☐
______________	__/ /	/ /_	☐	☐☐☐	☐☐	☐☐	☐☐

*[*Note: Use ‘Tradename’ information to assign medication code after the interview]*

Tick if participant does not take any medications for his/her condition ☐

Medication unit codes

1	Mg	7	Drops
2	microgram	8	Sprays (spray)
3	Gram	9	Bottles
4	Ml	10	Packs
5	Tubs/tubes	11	IU (injections)
6	Puffs (inhalers)	99	Other – give details

Medication frequency codes

1	Once daily	7	Once a week
2	Twice daily	8	Once every two weeks
3	Three times daily	9	Once every three weeks
4	Four times daily	10	Once every four weeks
5	Three times a week	11	Once every five weeks
6	Twice a week	88	As required / “PRN”

Section 2: Carer

1. Do you live with your relative (the service user/participant)?

1. **Yes** ☐ → ***Go to Q5***

2. **No** ☐ → ***Go to Q2***

2. How many people are there in your household?

	Number
Number of adults (including responder)	☐☐
Number of children under the age of 16	☐☐

3. **What kind of accommodation do you live in at the moment?** *(tick* ***one*** *box)*

Council-rented housing ☐

Housing-association rented housing ☐

Private rented housing ☐

Owner-occupied housing ☐

Other housing ☐

Please describe ☐

4. Is your accommodation "sheltered" housing (has a warden or scheme manager on-site)?

1. Yes ☐

2. No ☐

Employment

5. Which of the following best describes your current employment situation?

(*Tick the one box that applies best to carer's situation*)

In paid employment	☐ →	***GO TO Q6***
Retired	☐ →	***Go to Q8***
Unable to work	☐ →	
Unemployed and looking for work	☐ →	
At home and not looking for work (e.g. housewife/husband)	☐ →	
Doing voluntary work	☐ →	
Student (full or part-time)	☐ →	
Other *(Please describe)*	☐ →	

If carer is employed:

6. What is your current job(s)/occupation(s)?

☐

7. Number of hours you work per week in all the jobs you do ☐☐

If carer is unemployed, unable to work, 'at home' or retired:

8. When were you last employed? (Month/Year)

☐☐ ☐☐
mm y y

9. What was/were your most recent job(s)/occupation(s)?

☐

10. Have you given up or cut down on work in order to provide care for the study participant?

Yes, given up work	☐ →	***Go to Q11***
Yes, cut down	☐ →	
No	☐ →	***Go to Q13***

If carer gave up or cut down work*:*

11. When did this happen? (Month/Year)

☐☐ ☐☐
mm yy

12. If carer cut down on work:

By how much did you cut down on work each week? Hours per week ☐☐

If the carer lives with the study participant, ask Q13

If the carer does <u>not</u> live with the study participant, ask Q14

13. On a typical day, how much time do you spend looking after/providing help for the study participant? (*Tick if yes*)

Provides no help in a typical day	☐
Less than 1 hour	☐
More than 1 hour and up to 2 hours	☐
More than 2 hours and up to 3 hours	☐
More than 3 hours and up to 5 hours	☐
More than 5 hours and up to 10 hours	☐
More than 10 hours, but not overnight	☐
More than 10 hours *and/including* overnight	☐
Other, describe:	☐

☐

14. How many hours do you spend each week looking after/providing help to the study participant?
(If the carer does not live with the service user)

Hours per week ☐ ☐ ☐

15. On a typical day, what tasks do you usually help your relative with? (*Tick as many as apply*)

Personal care	☐
Helping with finances	☐
Practical help	☐
Taking the person to appointments	☐
Medications	☐
Keeping the person company	☐
Making sure the person is safe (supervision)	☐
Other, describe:	☐

☐

Other carers

16. Other than yourself, do other friends or relatives regularly help/provide care for the study participant?

1. **Yes** ☐ → ***Go to Q17***

2. **No** ☐ → ***Go to Q19***

17. Thinking about an average week, how many such carers help/provide care for the study participant?

☐☐

18. Thinking about an average week, and about all such carers, for how many hours do they help/provide care for the study participant?

Hours per week ☐ ☐ ☐

19. Have any **friends and relatives** taken time off paid work over the last 3 months to help/provide care for the study participant?

1. **Yes** ☐

2. **No** ☐

20. **If yes,** can you estimate the total number of days that relatives/friends have taken off work over the last 3 months to help/provide care for the study participant? *(If no, write 0 in boxes)*

Total days ☐ ☐ ☐

TRAVEL COSTS

21. In the last 3 months, have you accompanied your relative to any clinic, hospital, or day services for his/her condition?

1. **Yes** ☐ → ***Go to Q22***

2. **No** ☐ → ***No further questions***

22. If yes, over the last 3 months, how many times did you accompany your relative?

	Number of times per week	**Number of times in last 3 months**
Accompanied respondent	☐☐	☐☐

23. How did you normally travel to get to the services your relative used (*e.g. to go to your GP surgery or hospital)*? **If you used more than one form of transport please say how you travelled for the main/longest part of your journey.**

[use TRANSPORT code] ☐

TRANSPORT codes

1	Walked	7	Took hospital transport
2	Cycled	8	Went by ambulance
3	Took the bus	9	Other
4	Took the train		
5	Took a taxi		
6	Drove the car		

24. How long did it normally take to travel there from home?

	Hours	Minutes
Number of	☐☐	☐☐

25. If you normally travelled by public transport, what was the cost of the fare in one direction (cost of a one-way ticket)?

	£	pence
Cost of one-way fare	☐☐	☐☐

26. If you normally travelled by taxi, what was the cost of the fare in one direction (cost of a one-way journey)?

	£	pence
Cost of one-way fare	☐☐	☐☐

27. If you normally travelled by car, how many miles/kilometres did you travel to get there (one-way journey)? *(write in underlined space whether using miles or kilometres)*

Number of_________one-way ☐☐☐

28. If you normally travelled by car, if you had to pay for parking, how much did you pay?

	£	pence
Expenditure on parking	☐☐	☐☐

Appendix 19

EQ-5D Health Questionnaire

English version for the UK
(Validated for Ireland)

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility
I have no problems in walking about ☐
I have some problems in walking about ☐
I am confined to bed ☐

Self-Care
I have no problems with self-care ☐
I have some problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

Usual Activities (e.g. *work, study, housework, family or leisure activities)*
I have no problems with performing my usual activities ☐
I have some problems with performing my usual activities ☐
I am unable to perform my usual activities ☐

Pain/Discomfort
I have no pain or discomfort ☐
I have moderate pain or discomfort ☐
I have extreme pain or discomfort ☐

Anxiety/Depression
I am not anxious or depressed ☐
I am moderately anxious or depressed ☐
I am extremely anxious or depressed ☐

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state today

Best imaginable health state

Worst imaginable health state

Appendix 20

Unit Costs of Community Health and Social Services

Appendix 20: Unit Costs of Community Health and Social Care Services

Service	**Unit Cost (£)**	**Notes**	**Source**
General Practitioner	3.60	Per minute	PSSRU 2016
Practice Nurse	43.00	Per hr patient contact	PSSRU 2016
Community/District Nurse	40.00	Per hr patient contact	PSSRU 2016
Community Psychiatric/Mental Health Nurse	44.00	Per hr patient contact	PSSRU 2016
Psychiatrist	138.00	Per hr patient contact	PSSRU 2016
Social Worker/Care Manager	79.00	Per hr patient contact	PSSRU 2016
Psychologist	52.00	Per hr patient contact	PSSRU 2016
Physiotherapist	32.00	Per hr patient contact	PSSRU 2016
Occupational Therapist	44.00	Per hr patient contact	PSSRU 2016
Dietician	44.00	Per hr patient contact	PSSRU 2016
Counsellor	42.00	Per hr patient contact	PSSRU 2016
Mental health Team Worker	43.00	Per hr patient contact	PSSRU 2016
Specialist Nurse	44.00	Per hr patient contact	PSSRU 2016
Home Help/Home Care	24.00	Per hr patient contact	PSSRU 2016
Cleaner	7.20	per hr	https://www.gov.uk/national-minimum-wage-rates
Meals on Wheels	7.20	per hr	https://www.gov.uk/national-minimum-wage-rates
Laundry Service	7.20	per hr	https://www.gov.uk/national-minimum-wage-rates
Sitting Service (e.g. Crossroads)	7.20	per hr	https://www.gov.uk/national-minimum-wage-rates
Carer's Support Worker	52.00	per hour client related work	PSSRU 2016
Optician	17.35	per hr	NHS agenda for change payscales
Chiropodist/Podiatrist	32.00	per hr(Community based)	PSSRU 2016

Dentist	121.00	Per hr patient contact	PSSRU 2016

*One participant indicated the use of acupuncture in the ‘other’ services category. The cost was assumed to be equivalent to physiotherapy and a unit cost of £32 per hour applied.

Appendix 21

Prescribed Medication Unit Costs

Appendix 21: Prescribed Medication Unit Costs

Name of Drug	**Preparation**	**Ingredient Cost per prescription £[1]**
Adcal (1.5mg+ 600mg)	Tablet	6.92
Adcal D3 Chewable	Tablet	4.95
Alendronic Acid 70mg	Tablet	1.35
Amiodarone 200mg	Tablet	2.57
Amitriptyline 10mg	Tablet	1.84
Amlodipine 5mg	Tablet	1.49
Amlodipine 10mg	Tablet	1.54
Apixaban 2.5mg	Tablet	69.86
Aspirin Disp 75mg	Tablet	1.29
Aspirin E/C 75mg	Tablet	2.81
Atorvastatin 10mg	Tablet	1.89
Atorvastatin 20mg	Tablet	2.19
Atorvastatin 40mg	Tablet	2.44
Avodart 500mcg	Capsule	20.14
Bendroflumethiazide 2.5mg	Tablet	1.42
Betahistine Dihydrochloride 8mg	Tablet	1.54
Betahistine Dihydrochloride 16mg	Tablet	1.95
Bisacodyl E/C 5mg	Tablet	2.1
Bisoprolol fumarate1.25mg	Tablet	1.71
Bisoprolol fumarate 2.5mg	Tablet	1.63
Bisoprolol fumarate 5mg	Tablet	1.48
Bumetanide 1mg	Tablet	2.48
Buspirone 5mg	Tablet	11.09
Butrans 5mcg/hr	Transdermal Patch	17.61
Carbimazole 5mg	Tablet	59.52
Cilostazol 100mg	Tablet	19.43
Cinnarizine 15mg	Tablet	5.5
Citalopram 20mg	Tablet	1.36
Circadin 2mg MR	Tablet	23.6
Chlorpromazine 25mg	Tablet	5.09
Clopidogrel 75mg	Tablets	2.61
Co-codomal 15mg/500mg	Tablet	6.82
Colecalciferol 20mcg	Tablet	7.11
Dabigatran Etexilate 110g	Capsule	73.82
Dilzem SR 120mg	Capsule	14.05
Donepezil 5mg	Tablet	1.53

---

[1] Based on average prescription/pack size

Donepezil 10mg	Tablet	1.87
Duloxetine 30mg	Capsule	27.91
Eklira Genuair 322mcg	Inhaler	31.89
Enalapril Maleate 2.5mg	Tablet	2.77
Enalapril Maleate 5mg	Tablet	1.8
Ensure Plus Juice	Liquid	26.6
Feldene Gel	Gel	5.59
Ferrous Fumarate 305mg (Galfer)	Capsule	1.12
Finasteride 5mg	Tablet	2.42
Fluoxetine 20mg	Capsule	1.84
Folic acid 400mcg	Tablet	1.89
Folic acid 5mg	Tablet	1.28
Fortisip Compact	Liquid	65.42
Furosemide 20mg	Tablet	1.2
Gabapentin 300mg	Capsule	4.83
Galantamine 8mg MR	Capsule	67.69
Galantamine 16 MR	Capsule	71.78
Ganfort 300mcg/ml	Eye drop	23.03
Gliclazide 30mg	Tablet	6.61
Hydroxocobalamin 1mg/1ml	Injection (ampoule)	10.24
Hylo-Tear 0.1%	Eye drop	9.84
Ibuleve Cream	Cream	4.2
Indapamide 2.5mg	Tablet	2.37
Isosorbide Mononitrate 50mg	Capsules	6.64
Isotard XL 50mg	Tablets	10.83
Kapake 30mg/500mg	Tablets	6.44
Lansoprazole 30mg	Capsule	2.28
Laxido Sachets (orange)	Sachets	6.05
Levothyroxine 25mg	Tablet	5.13
Levothyroxine 50mg	Tablet	3.58
Lisinopril 5mg	Tablet	1.56
Loratadine 10mg	Tablet	1.35
Losartan 25mg	Tablet	1.76
Losartan 100mg	Tablet	2.44
Lyrica 150mg	Capsule	67.8
Mebeverine 135mg	Tablet	11.97
Memantine 20mg	Tablet	2.77
Metformin 500mg tabs	Tablet	6.09
Metformin 1g MR	Tablet	11.62
Midodrine hydrochloride 2.5mg	Tablet	25.27
Mirtazapine 15mg	Tablet	1.94
Mirtazapine 30mg	Tablet	1.68
Morphine 37.5mg (every 72 hours)	Transdermal patch	24.29

(likely fentanyl)		
Movical Powder	Sachets	10.79
Multivitamin	Capsule	.99[2]
Natecal D3 (1.5g+10mcg)	Tablets	4.16
Nebivolol 5mg	Tablet	2.4
Nicorandil 20mg	Tablet	9.83
Nitromin 400mcg (Nitrolingual Pumpspray)	Spray	3.02
Octasa MR 400mg	Tablet	26.09
Olanzapine 2.5mg	Tablet	1.28
Omeprazole 10mg	Capsule	1.86
Omeprazole 20mg	Capsule	1.92
Pantoprazole 20mg	Tablet	2.04
Paracetamol 500mg	Tablet	2.72
Perindopril 2mg	Tablet	1.74
Perindopril 4mg	Tablet	2.27
Pregabalin 25mg	Capsule	63.77
Quetiapine 25mg	Tablet	1.53
Ramipril 2.5mg	Capsule	1.67
Ramipril 5mg	Capsule	1.9
Ramipril 10mg	Capsule	2.08
Risedronate Sodium 35mg	Tablet	1.65
Risperidone 500mcg	Tablet	2.3
Rivaroxaban (no strength noted as dose varies)	Tablets	69.35
Rivaroxabin 15mg	Tablet	69.35
Rivastigmine 1.5mg	Capsule	6.67
Rivastigmine 4.6mg/24hr	Transdermal patch	77.04
Rivastigmine 9.5mg/24hr	Transdermal patch	28.95
Rosuvastatin 10mg	Tablet	28.9
Rosuvastatin 20mg	Tablet	40.39
Senna 7.5mg	Tablet	3.48
Seretide Accuhaler 500mcg	Inhaler	49.2
Sertraline 100mg	Tablet	2.51
Simbrinza (10mg/ml+2mg/ml)	Eye drop	11.53
Simpla Trident T1 sterile leg bag 370817 500ml bag	Device	30.31[3]

---

[2] Based on cost of 'Boots' multivitamins (pack size 30)

[3] Unit cost obtained on request from Bradbury Surgical

Simpla S2 non-drainable night drainage bag 320902 2 litre	Device	2.91[4]
Simvastatin 20mg	Tablet	1.54
Simvastatin 40mg	Tablet	1.78
Sitagliptin 100mg	Tablet	49.08
Spironolactone 25mg	Tablet	1.89
Tamsulosin 400mcg MR	Capsule	6.11
Thiamine 50mg	Tablet	4.68
Toviaz 4mg	Tablet	32.99
Trajenta 5mg	Tablet	41.89
Tramadol 200mg MR	Capsule	28.5
Uniphyllin Continus 200mg	Tablet	3.48
Ventolin Evohaler 100mcg	Inhaler	2.31
Victoza 6mg/1ml	Injection	100.22
Warfarin 1mg	Tablet	2.53
Zolpiderm tabs 5mg	Tablet	1.61
Zopiclone 3.75mg	Tablet	1.38

*Based on average prescription size

---

[3] Unit cost obtained on request from Bradbury Surgical

[4] Unit cost obtained on request from Bradbury Surgical

Appendix 22

Unit Costs of Hospital Services

Appendix 22: Unit Costs of Hospital Services

Hospital Service	**Unit Cost (£)**	**Notes**	**Source**
A& E attendance	139	Per A&E attendance	https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/577083/Reference_Costs_2015-16.pdf
Elective Inpatient Stay	3749	Average cost per finished consultant episode	https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/577083/Reference_Costs_2015-16.pdf
Non-elective Inpatient Stay	1609	Average cost per finished consultant episode	https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/577083/Reference_Costs_2015-16.pdf
Outpatient attendance	117	Average cost per attendance	https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/577083/Reference_Costs_2015-16.pdf
Day Hospital Attendance	733	Average cost per attendance	https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/577083/Reference_Costs_2015-16.pdf
More detailed Inpatient and Outpatient Costs (where sufficient detail provided)			
Inpatient Costs T0			
Triple Bypass	10176	Average cost of procedure	Based on national reference costs (assumed to be and elective procedure, complex coronary artery bypass graft- Code ED26B)
Inpatient Costs T2			
Pacemaker	2744	Average cost of procedure	Based on national reference costs (assumed to be Code EY08E)
Cardiac Bypass	10616	Average cost of procedure	Based on national reference costs (assumed to be standard coronary artery bypass graft, length of stay used as a guide- Code ED28A)

Outpatient Costs T0			
Gynae	133.01	Average cost of service	Based on national reference costs (the 'total outpatient attendances' tab provides average cost of inpatient services by service description)
Cardiac	127.67	Average cost of service (assumed cardiology)	Based on national reference costs (the 'total outpatient attendances' tab provides average cost of inpatient services by service description)
Eye Clinic	79.19	Average cost of service (assumed optometry)	Based on national reference costs (the 'total outpatient attendances' tab provides average cost of inpatient services by service description)
Optometry	79.19	Average cost of service	Based on national reference costs (the 'total outpatient attendances' tab provides average cost of inpatient services by service description)
Dermatology	101.63	Average cost of service	Based on national reference costs (the 'total outpatient attendances' tab provides average cost of inpatient services by service description)
Cardiac	127.67	Average cost of service (assumed cardiology)	Based on national reference costs (the 'total outpatient attendances' tab provides average cost of inpatient services by service description)
Outpatient Costs T2			
Gynae	133.01	Average cost of service	Based on national reference costs (the 'total outpatient attendances' tab provides average cost of inpatient services by service description)
hearing	58.33	Average cost of service (assumed audiology)	Based on national reference costs (the 'total outpatient attendances' tab provides average cost of inpatient services by service description)
Cardiac	127.67	Average cost of service (assumed cardiology)	Based on national reference costs (the 'total outpatient attendances' tab provides average cost of inpatient services by service description)

Cardiac	127.67	Average cost of service (assumed cardiology)	Based on national reference costs (the 'total outpatient attendances' tab provides average cost of inpatient services by service description)

Appendix 23

Interview Schedule

A Feasibility Study of Facilitated Reminiscence for People Living with Dementia - Phase 3

Over the past number of months, you and (name of wife/husband/daughter) have been involved in a study about reminiscence and sharing memories. This involved:

1) Training by (name of facilitator) on how to use memories to share meaningful past experiences.

2) Training in use of an iPad and app to help you to store and access your memories

3) Using the iPad to reminiscence in your home with xx

We are interested in hearing more about your experience of taking part in this research study.

Switch recorder on

1. Have you ever done any type of reminiscence activity before? (Prompt for similarities and difference between Inspired)
2. A Facilitator (name) visited you in your home to work with you on sharing memories that were important to you. What was this like for you? (Prompt for format, process and duration of reminiscence training)
3. The work that you conducted with (Facilitator) involved sharing memories that were personal and special to you. What effect did this have on you? (Prompt for challenges/benefits).
4. Can you tell me about your experience with technology such as mobile phones or tablets prior to this study?
5. What are you views about the training you received in using the iPad and App? (Prompt for frequency and durations of session, likes and dislikes)
6. Did the training encourage you to use the iPad App? Please explain your answer.
7. Can you tell me about your experience of using the iPad to reminiscence at home? (Prompt for frequency of use, preferred times/days, barriers and enablers to use, time demands, preferences e.g. photos, video)
8. What did you like about using the iPad to share your memories? (Prompt for differences between photo albums)

9. What did you not like about using the iPad to share your memories?

10. Would you like to keep using the iPad and app to reminisce? Why? How do you feel when you are using it?

11. Has it been important for you to share your memories with X? Tell me about this (Prompt for mutual understanding)

12. Can you tell me about the type of memories that are most important to you?

13. What did you like/dislike about sharing memories with X?

14. Has your relationship with X changed over the course of the study? Tell me more about this (Prompt for behavioural/mood changes, caregiver/care-recipient tension)

15. What impact has the reminiscence intervention had on your relationship with X?

16. Apart from X, did you share your memories with anybody else (Prompt for other family members using App)

17. This reminiscence project was designed to be delivered in your own home (rather than in a day centre). Do you feel that this was a good thing or a bad thing? Would you have been able to take part if the project had not been delivered in your home?

18. Would you recommend this reminiscence intervention for other people living with dementia and their carers? Please explain your answer?

19. Has your involvement in the study changed the way you feel about dementia?

20. Since taking part in the study, has your use of services changes (Prompt for increase/decrease service use, reasons why, voluntary/statutory/private)

21. On 3 occasions, we asked you questions about your relationship with X and your quality of life. What were your thoughts and feelings about these questions (Prompt for changes over time)

22. Overall, when you consider all that you have done during this study, what is your biggest achievement?

23. What advice would you give to other people with memory problems about being involved in research?

24. We have greatly appreciated your commitment to this research. If we were to conduct similar research in the future, what could we do better?

25. Is there any other comment you would like to make about the study?

Appendix 24

Letter of Invitation

(Phase 3, Version 1: 01/02/2016)

A Feasibility Study of Facilitated Reminiscence for People Living with Dementia

Dear (Participant)

You have been participating in a study about facilitated reminiscence. Your valued contribution has been greatly appreciated. This is an invitation to take part in an interview phase of that study.

We would like to ask your permission for us to contact you about the interview phase of the study. You do not have to decide today to take part, only that we can contact you.

Your participation will involve an interview of approximately 45 minutes with a researcher to help us to explore what it was like to experience training in reminiscence and sharing memories in your own home.

You do not have to agree and it will not affect your care in any way.

Thank you for taking the time to read this letter and consider taking part in this research study.

Professor Assumpta Ryan Chief Investigator Ulster University Derry/Londonderry BT48 7JL Tel: 02871 675350 Email:aa.ryan@ulster.ac.uk	Dr Claire McCauley Researcher Ulster University Derry/Londonderry BT48 7JL Tel: 02871 675293 Email:c.mccauley2@ulster.ac.uk

Declaration of Interest

Ulster University

A Feasibility Study of Facilitated Reminiscence for People Living with Dementia – Phase 3

I confirm that I am giving the researchers my permission to contact me about taking part in the interview phase of the reminiscence study.

I understand that I am under no obligation to take part in the study in any way.

This information will be used to contact us about this study only and will be confidential to the researchers.

Name ……………………………………Signature ……………..…………………

Phone number: ……………………………………………..…………

Please return this completed page to the researcher who will store it securely, or you may post it to:

Dr Claire McCauley
Researcher
Room MG106
School of Nursing
Ulster University
Northland Road
Derry/Londonderry
BT48 7JL

Appendix 25

Participant Information Sheet (PLWD)

A Feasibility Study of Facilitated Reminiscence for People Living with dementia – Phase 3

You have been participating in a study about facilitated reminiscence involving people with dementia and their family carer. This has involved you in several weeks of training and then the use of technology to support reminiscence activity in your home over a period of 3 months.

We would like to invite you now to take part in a second phase of this study, and that is an interview to explore your ideas and your experiences of the facilitated reminiscence activity. We are interested in hearing your views about being involved in this research study.

What will happen if I take part?

If you decide you would like to take part, we will arrange to carry out an informal interview with you to hear about your experiences and views.

The interview will be completed by a Lecturer of Nursing or a Researcher from Ulster University. The interviews will be carried out in your own home and a family member may also be present during the interview if you wish.

The interview will last around 45 minutes. The interview will be digitally recorded for analysis purposes only.

If you decide that you would like to take part in the study, we will ask you to sign a consent form.

Do I have to take part?

You do not have to take part in the interview phase of the study if you do not want to and you do not need to give any reason if you decide not to take part.

If you choose to take part in this phase of the study, you will be free to withdraw at any stage without needing to give a reason for doing so.

If you do choose to withdraw, it is important that you are aware that we will use information that we have already gathered from you up to that point, to inform our study reports and findings

What are the possible benefits of taking part and what are the possible disadvantages?

What are the benefits and possible disadvantages of taking part?

By taking part in this study you will be contributing to research that will help improve knowledge of how professionals can best support reminiscence activity at home for people with dementia and their family carer.

You may find talking about some aspects of your experience of the reminiscence intervention to be upsetting. Procedures are in place to support you in the event that you become upset or distressed.

Confidentiality

The Research Team will fully comply with the Ulster University Data Protection Policy. Any information you share during the course of the study will be treated in strict confidence.

Information collected will only be seen by members of the research team and will be stored safely and securely. Any information you give that is used in publications will be made anonymous.

What will happen to the results of the research study?

The information we gather will be used to inform a larger study about facilitated reminiscence for people with dementia in their own homes. If you would like to be provided with a summary of the overall research findings, you may provide contact details to a member of the research team and we will send you a summary leaflet at the end of the project.

Who is organising the research?

The project is funded by the Health and Social Care Research and Development Office and Atlantic Philanthropies. The research will be led by Dr Assumpta Ryan, Professor of Ageing and Health at Ulster University in partnership with Reminiscence NI, the Alzheimer’s Society and the Western Health and Social Care Trust.

Further information

If you would like any further information, please contact:

Dr Claire McCauley
Researcher
Ulster University Derry/Londonderry
BT48 7JL

Tel: 02871 675293
Email: c.mccauley2@ulster.ac.uk

Thank you for your interest in this study

Appendix 26

Participant Information Sheet (Carer)

A Feasibility Study of Facilitated Reminiscence for People Living with dementia – Phase 3

You have been participating in a study about facilitated reminiscence involving people with dementia and their family carer. This has involved you in several weeks of training and then the use of technology to support reminiscence activity in your home over a period of 3 months.

We would like to invite you now to take part in a second phase of this study, and that is an interview to explore your ideas and your experiences of the facilitated reminiscence activity. We are interested in hearing your views about being involved in this research study.

What will happen if I take part?

If you decide you would like to take part, we will arrange to carry out an informal interview with you to hear about your experiences and views.

The interview will be completed by a Lecturer of Nursing or a Researcher from Ulster University. The interviews will be carried out in your own home and a family member may also be present during the interview if you wish.

The interview will last around 45 minutes. The interview will be digitally recorded for analysis purposes only.

If you decide that you would like to take part in the study, we will ask you to sign a consent form.

Do I have to take part?

You do not have to take part in the interview phase of the study if you do not want to and you do not need to give any reason if you decide not to take part.

If you choose to take part in this phase of the study, you will be free to withdraw at any stage without needing to give a reason for doing so.

If you do choose to withdraw, it is important that you are aware that we will use information that we have already gathered from you up to that point, to inform our study reports and findings

What are the possible benefits of taking part and what are the possible disadvantages?

What are the benefits and possible disadvantages of taking part?

By taking part in this study you will be contributing to research that will help improve knowledge of how professionals can best support reminiscence activity at home for people with dementia and their family carer.

You may find talking about some aspects of your experience of the reminiscence intervention to be upsetting. Procedures are in place to support you in the event that you become upset or distressed.

Confidentiality

The Research Team will fully comply with the Ulster University Data Protection Policy. Any information you share during the course of the study will be treated in strict confidence.

Information collected will only be seen by members of the research team and will be stored safely and securely. Any information you give that is used in publications will be made anonymous.

What will happen to the results of the research study?

The information we gather will be used to inform a larger study about facilitated reminiscence for people with dementia in their own homes. If you would like to be provided with a summary of the overall research findings, you may provide contact details to a member of the research team and we will send you a summary leaflet at the end of the project.

Who is organising the research?

The project is funded by the Health and Social Care Research and Development Office and Atlantic Philanthropies. The research will be led by Dr Assumpta Ryan, Professor of Ageing and Health at Ulster University in partnership with Reminiscence NI, the Alzheimer's Society and the Western Health and Social Care Trust.

Further information

If you would like any further information, please contact:

Dr Claire McCauley
Researcher
Ulster University Derry/Londonderry
BT48 7JL

Tel: 02871 675293
Email: c.mccauley2@ulster.ac.uk

Thank you for your interest in this study

Appendix 27

Consent Form (PLWD)

Version 1: 01/02/2016

Study Title: A Feasibility Study of Facilitated Reminiscence for People Living with dementia–Phase 3

1. I confirm that I have read and understood the information about this study and have received answers to any questions I asked. ☐

2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving a reason and without my rights being affected. ☐

3. I understand that if I chose to withdraw at any stage from the study, that information already collected from me will be used to inform the findings of the study. ☐

4. I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study. ☐

5. I understand that the interview will be digitally recorded and that quotations from what I say with the researcher may be used but that no one will be able to identify me through the information presented. ☐

6. I agree to take part in the interview phase of the study. ☐

Name of Participant:	Name of Researcher:
………………………………………………	………………………………………………
Signature:	Signature:
………………………………………………	………………………………………………
Date:	Date:
………………………………………………	……………………………………………….

Appendix 28

Consent Form (Carer)

Version 1: 01/02/2016

Study Title: A Feasibility Study of Facilitated Reminiscence for People Living with dementia–Phase 3

1. I confirm that I have read and understood the information about this study and have received answers to any questions I asked. ☐

2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving a reason and without my rights being affected. ☐

3. I understand that if I chose to withdraw at any stage from the study, that information already collected from me will be used to inform the findings of the study. ☐

4. I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study. ☐

5. I understand that the interview will be digitally recorded and that quotations from what I say with the researcher may be used but that no one will be able to identify me through the information presented. ☐

6. I agree to take part in the interview phase of the study. ☐

Name of Participant:	Name of Researcher:
………………………………………………	………………………………………………
Signature:	Signature:
………………………………………………	………………………………………………
Date:	Date:
………………………………………………	……………………………………………….