

SHORT REPORT

A Feasibility Study of Facilitated Reminiscence for People Living with Dementia

**Professor Assumpta Ryan
Dr Liz Laird
Professor Maurice Mulvenna
Professor Brendan Bunting
Dr Finola Ferry**

**Dr Claire McCauley
Ms Aideen Gibson
Dr Raymond Bond
Professor Kevin Curran**

This report can be cited as: Ryan, A.A., McCauley, C.O., Laird, E.A., Gibson, A., Mulvenna, M.D., Bond, R., Bunting, B., Curran, K and Ferry, F. 2018. A Feasibility Study of Facilitated Reminiscence for People Living with Dementia. Belfast: HSC Public Health Agency, Research and Development Division.

June 2018

Contents

EVIDENCE BRIEF	3
Background	4
Aims and Objectives.....	6
Methods.....	6
Findings	7
Conclusion.....	10
Personal and Public Involvement (PPI)	10
Practice, Policy and Research Implications/Recommendations.....	12
Pathway to Impact	14
References	20

EVIDENCE BRIEF

Why did we start?

Reminiscence has been widely used as a therapeutic approach for people living with dementia and their carers. The literature suggests that an individualised approach 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 lack of research in this area. The aim of this study was to investigate the outcomes of a home based, individual specific reminiscence intervention using an iPad app for people living with dementia and their family carers.

What did we do?

The study design had 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 design and test the technology. **Phase 2:** The developed app was then tested with a paired sample of 30 people living with mild to moderate dementia and their family carers (n=60). A reminiscence trainer supported participants in gathering personal memorabilia and an IT trainer then provided training in the use of the reminiscence app. Participants used the app for 12 weeks at home. Questionnaires which 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 were collected at the beginning, middle and end points of the study. Health economics data were also collected to understand how cost effective this intervention would be in future work. **Phase 3:** Individual interviews were conducted with a sample of participants (n=32) to explore their experience of the intervention.

What answer did we get?

Results revealed that people living with dementia used the app independently and more frequently than their carers. Our results showed an increase in mutuality, quality of caregiving relationships, and emotional well-being for people living with dementia but no significant change for carers over the course of the study. However, the intervention had a significant impact on the caring relationship and was viewed as an enjoyable way to care for themselves and their loved one.

What should be done now?

- A large randomised controlled trial of technology facilitated and home delivered individual specific reminiscence is recommended.
- Raise public awareness of the benefits of individual and specific reminiscence using a relationship-centred approach.
- There is a need to address the challenges posed by research exploring different types of reminiscence delivered in diverse care settings at varying stages within the dementia journey.

Main body of report

Background

Dementia belongs to a range of progressive neurological 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). 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)

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 (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 problems (Selwood et al. 2007). 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 reduction in shared activities (Quinn et al. 2009; Damianakis et al. 2010).

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 understanding that the memories can be accessed in the early to moderate stages of dementia. It, therefore, draws on a person's strengths and abilities, rather than emphasising their difficulties (Woods et al. 2016). Reminiscence has the potential to improve mood, well-being, quality of life, social interaction, mental processing and autobiographical memory for people living with dementia (Subramaniam and Woods, 2012; Lazar et al. 2014).

Although reminiscence remains one of the most popular psychosocial interventions for people living with dementia and their families (Cotelli et al. 2012), the delivery of such therapeutic programmes has presented challenges. 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 benefit for people living with dementia must be balanced against possible 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. 2012).

It is now recognised that technology has the potential to provide a more engaging reminiscence experience (Lazar et al. 2014). Technology based reminiscence activities can be rapidly accessed and ready for use or quickly personalised to the individual and family. However, a review of technology-based interventions has suggested that, although using technology for reminiscence is an area of significant interest, there remains a need to explore the media most suitable to individuals at different stages of dementia (Lazar et al. 2014).

The authors concluded that there are benefits to using ICT for reminiscence interventions which include; access to rich and engaging multimedia reminiscence materials (Elfrink et al. 2017), opportunities for people with dementia to participate in social interactions and take ownership of conversations (Hamel et al. 2016) and a reduction in travel and time commitments for carers (Lazar et al. 2014). Despite developments in technology facilitated

remembrance, there is limited research on the role of technology in supporting home-based, personalised remembrance and the importance of remembrance and information technology (IT) training for people living with dementia and their carers. This novel study, with its focus on technology facilitated, home-based, personalised remembrance sought to address these issues and in doing so contribute to the international debate on the use of remembrance in dementia care.

Aims and Objectives

The overall aim of this feasibility study was to investigate the outcomes of a home based, individual specific remembrance intervention through the use of a co-created iPad app for people living with dementia and their family carers. The objectives were:

- To identify the needs and capabilities of participants living with dementia and their family carers when using the InspiredD app (Phase 1)
- To examine the impact of individual specific remembrance on the person living with dementia and their family carers using a range of outcomes measures(Phase 2);
- To calculate preliminary costings to inform a potential cost effectiveness analysis of this intervention (Phase 2).
- To explore participants views on the intervention (Phase 3);
- To enhance relationships and quality of life;

Methods

The study had three phases, collecting different types of data to inform our understanding.

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 developed app was tested with a paired sample of 30 people living with mild to moderate dementia and their family carers. A remembrance trainer from the Remembrance Network Northern Ireland guided participants in gathering personal memorabilia. An IT assistant then provided training in the use of the remembrance app. Participants used the system for 12 weeks at home. Questionnaires which examined the impact of remembrance on mutuality, wellbeing, quality of life and quality of the relationship

between participants living with dementia and their family carers were collected at 3 points throughout the study. Health economics data were also collected to understand how cost effective this intervention would be in future work. The app was designed to capture data relating to patterns of usage by the 30 participating dyads. The aim of incorporating this kind of user data into the InspireD app was to understand the behavioural and usage patterns of how a person living with dementia and their family carers actually reminisced when presented with video, audio and images which were either personal or general material. In so doing, improve our understanding of the usage behaviour of those living with dementia and their carers when engaging with the InspireD app.

Phase 3: Individual interviews were conducted with a sample of participants (n=32) to explore their experience of the intervention.

Findings

Phase 1- Developing and testing the InspireD app for persons living with dementia and their carers

The InspireD app was designed and developed with input from a Lead User Dyad and a User Development Group. Phase 1 results indicated that the InspireD app was usable for some participants living with dementia. Carers found the app easy to use and could support their relative living with dementia to use it to reminisce. Our results revealed that standard usability testing may not be suitable for evaluating apps designed for people living with dementia. Phase 1 has demonstrated the importance of working with those living with dementia 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 personal memorabilia are key factors which encourage usage of the InspireD app. Our results suggested that participants viewed the InspireD app as potentially offering another side to the condition facilitating connections with those around them and, crucially, within their relationship.

Phase 2 –Participants interaction with the InspireD app

The IT training provided appears to have been effective as participants living with dementia and their carers were able to use the InspireD app for reminiscing. Moreover, the participants

living with dementia mostly used the app for reminiscing sessions, which is of no surprise given that this was its main purpose. Our results confirmed that reminiscence of personalised memorabilia was preferred over general material and that carers played a crucial role in adding personalised memories to the app. The recording of app usage in our study provided insights into each paired sample behaviours. This information indicated relatively strong engagement, most positively, the main users were those living with dementia and their preferred use was to reminisce using personal photographs. Overall, over the 12 weeks, on average, a participant living with dementia used the InspireD app for around one session of reminiscing per week and usage peaked at 11am, 3pm and 8pm. This 'once per week' reminiscence session may seem relatively low, but our results show the participants living with dementia used the app independently of their carer consistently over the 12-week period.

Phase 2- Primary and Secondary Outcome Measures

Carers in our study were predominately female (80%), while 66.7 % of those living with dementia were male. As might be expected, carers were younger and had more experience with computers. Our findings indicated increases in mutuality, quality of the caring relationship and wellbeing from the beginning to the end of the study for participants living with dementia. However, we observed no significant differences in mutuality, quality of the caring relationship and wellbeing throughout the study for carers. Our sample size was small and unlikely to generate statistically significant results but it is interesting to note that participants who had a higher mutuality score at the beginning of the study were linked with better outcomes. The health economic component of this study aimed to estimate the cost-effectiveness of the reminiscence intervention with the overall aim of informing a future research design. The study found a decrease in community health and social care costs, and increase in hospital costs and family care costs and no change in medication costs. The results suggest a moderate improvement in health related quality of life for those living with dementia. Given the small number of participants involved these results are more descriptive but raise some important issues for discussion for the development of a full cost-effectiveness study in the future.

Phase 3 - Interviews

The analysis of 31 interviews with participants explored two key aspects of this study relating to process (how the study was delivered) and outcome (what we have learned). Five core 'process' themes emerged which highlighted how positively participants found reminiscence and IT training and the compatibility of the app with their daily life, while also identifying the need for carer support and involvement. The questionnaires 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 some questions did not capture the many challenges within a caring relationships following a dementia diagnosis. The positive impact of the intervention on relationships and as a confidence building measure, particularly for participants living with dementia were also key themes.

The second aspect of this study explored *outcomes*, with five core themes identified. The devastation of the diagnosis and perceptions of a lack of support from external services, provided an emotional backdrop for this phase of the study. As a result of sharing personalised and significant memories, participants reflected that they felt closer to their loved one. Carers highlighted that having an aid for communication and a stimulus to share memories was a significant factor in this. The main theme focused on the impact of the intervention on relationships and on a new perspective that recognised abilities and gains rather than losses and disabilities, ("There is still so much inside"). The significance of personal memories ("Memories that are important to me") was a core theme although this was not without its challenges, particularly in situations where such memories were painful. A further theme revealed the intervention had a significant impact on the caring relationship ("It's become very close") and was viewed as an enjoyable way to care for themselves and their loved one. Personal achievements through study involvement were highlighted but were different for those living with dementia and their carer. Carers' achievements tended to be more relationship focused, whereas the participants living with dementia felt app usage and their ongoing skills development as a significant achievement.

"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"

Conclusion

Reminiscence has been promoted internationally as a way of enhancing standards of care and quality of life for people living with dementia. Our study developed a new intervention of home-based and personalised reminiscence, using an iPad app (InspireD) which was co-created by people living with dementia and their family carers. The findings of this study indicate increases in mutuality, emotional well-being and quality of care-giving relationship for the participants living with dementia, and non-significant differences for carers in mutuality, emotional wellbeing, and quality of care-giving relationship from the beginning to the end of the study. This suggests that a more individualised relationship-centred approach to reminiscence, facilitated through the design of the InspireD app, has the potential to generate a positive impact on people living with dementia without negative consequences for family caregivers. These findings support emerging global evidence that suggests individual specific psychosocial interventions are effective in dementia care. It is important to highlight that our study is not without limitations and that pre-existing factors in the participants lives or relationships may have influenced the results. Nonetheless, our intervention, which involved a programme of training and use of an iPad app, has a significant contribution to make to ongoing development of technology-facilitated reminiscence.

Personal and Public Involvement (PPI)

The principle 'Nothing About Us Without Us' is embedded in the global movement towards involving persons with disabilities in the planning of strategies and policies that affect their lives. As the use of computer based 'apps' are fast becoming an important part of everyday life, the design of programmes which can be used by all, regardless of mental or physical impairments, in the design and testing of devices is vital (Carroll and Rosson, 2007; Span et al. 2013; O Connor et al. 2016). As a result, researchers have proposed standard instruments for measuring the 'usability' of a developed app (Sauro, 2016; Gibson et al. 2016). However, where there are diminished mental abilities and perhaps also physical challenges, issues can arise that pose problems when using these standard methods for usability testing (Astell et al. 2009; Riley et al. 2009). It is widely accepted that developers must take into account the needs, abilities and desires of those who will be using the app 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 devices and apps, should involve those who will be using it, regardless of the challenges, and that their contribution should be recorded by usability measurements (Brankaert and Ouden, 2015).

Findings from our study reinforce the immeasurable benefit of working collaboratively with the person living with dementia 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 person living with dementia and their carer. Valuable insights have been gained about the suitability (or otherwise) of standardised usability protocols for participants living with dementia. 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 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.

User Development Group

The InspireD app was designed and developed with input from a Lead User Dyad and the creation of a User Development Group. The 6 paired participants that formed our User Development Group were recruited through the Alzheimer's Society Home Support Network from the study area. At the beginning of the research study 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. This app, created to facilitate the process of reminiscence, was tested using standard usability measures and methods by individuals living with dementia and their family carers. 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. In addition to the workshops, the dyads used the app over a period of 1-2 weeks at home. All participants remained in Phase 1 until the end. All questionnaires used to test the impact of the intervention in phase 2 were also pilot tested with participants living with dementia and

their carers to ensure they were suitable and sensitive. A steering group was established to guide the study. Membership of the steering group was derived from the Alzheimer's Society Home Support Network, Dementia Together NI, Reminiscence Network NI, WHSCT and a dementia specialist nurse. This ensured that the interest of the public and those living with dementia was at the forefront of all aspects of the study.

User Engagement throughout the Study

In Phase 2 a total of 60 individuals, i.e. 30 dyads (person living with dementia and their carer) were recruited through the Trust's Community Mental Health Team for older people and in particular through the Trust's Cognitive Rehabilitation Team. Phase 3 involved 31 semi-structured interviews with participants living with dementia and/or their family carer. The interview questions chosen for this phase were informed by the findings from Phase 1, Workshop 4 and from learning gained as the study progressed. Our study findings, therefore, illustrate the immeasurable benefit of working collaboratively with those living with dementia to co-create and test the InspireD app. 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.

Practice, Policy and Research Implications/Recommendations

Practice and Policy Recommendations

- 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.
- The research team propose to actively engage with, and disseminate research findings to, service user organisations and advocacy groups such Dementia NI, Alzheimer's Society and AgeNI to ensure our pathway to impact leads us to those who would benefit most.
- It is proposed that health and social care practitioners (for example, specialist and community nurses) receive appropriate training on the importance of shared memories when engaging in this type of activity.

- ☐ 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 at home 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.
- ☐ 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 caring relationship.
- We recommend a large randomised controlled trial (RCT) of home-based individual specific reminiscence to test our findings further.
- Future research should consider 1) our calculations of an appropriate sample size of participants 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 of the app on a more frequent basis.
- ☐ It is further recommended that research is conducted to develop appropriate usability measures to facilitate the full engagement of those living with dementia in technology design and refinement.

- Consideration should be given to follow up study with InspireD participants to assess the impact of the intervention over time, exploring facilitating factors and potential barriers to on-going engagement since the end of the original study.
- ☐ This reminiscence intervention relied on the involvement of family members, larger studies are warranted to explore the outcomes on their health and wellbeing.
- Given the use of the app in everyday situations, the emphasis on creativity could be further developed in future research. A follow-up study with a focus on ‘everyday creativity’ could help 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.
- ☐ Future research should consider the suitability of instruments used to measure outcomes in dementia research.
- 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 and consider the costs and family caregivers resource usage specific to dementia, for the development of a future cost-effectiveness study.

Pathway to Impact

We have a communications strategy, which incorporates dissemination and publication activities, targeting a breadth and depth of journals, conferences and web-based media to maximise policy and societal impact.

Publications

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.

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,

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).

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).

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)

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). *Assessing 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 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/inspiredapproj>.

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). Professor Ryan delivered the opening address at a conference which showcased the achievements of Dementia Together NI on 30th November 2017. As the promotion of evidence-led policy and law-making within Northern Ireland is the underlying aim of the Knowledge Exchange Seminar Series (KESS), we will further maximise the impact of our research by presenting our findings at KESS in Stormont at the earliest available opportunity.

Pathway to Societal Impact

As a direct result of this study, we now have six fully trained reminiscence facilitators in the WHSCT area. This is a significant capacity building achievement. It is also impactful for future research and practice development initiatives as the personalised and relationship-centred reminiscence modelled by these facilitators was significant in maintaining participants' engagement with our study and the development of "*an enjoyable way to care*". The InspiredD team 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 play is due to be staged in Donegal and Derry/Londonderry in 2018 and we are currently trying to source additional funding to extend the run to other parts of Ireland, North and South.

Acknowledgements/Relevant Logos

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 letters 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 The 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.

References

- AgeNI (2017) *Dementia*. Available from: <http://www.ageuk.org.uk/northernireland/health--wellbeing/dementia/> (Accessed 7 October 2017).
- 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 Society (2017) *United against dementia*. What is Dementia. Fact sheet 400 London: Alzheimer's Society.
- 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.
- 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.
- Carroll JM, Rosson MB (2007) Participatory design in community informatics. *Design Studies* 28(3): 243-261.
- Cotelli M, Manenti R, Zanetti O (2012) Reminiscence therapy in dementia: A review. *Journal of Maturitas*. 72 (1) , 203-205.
- 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), 23-25.
- 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.
- 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>
- 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.
- 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.
- 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

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.

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.

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.

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)

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, 75-89.

Smith. G (2016) *Dementia Care. A Practical Approach*. London: CRC Press.

Span M, Hettinga M, Vernooij-Dassen M, Eefstinghe 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

Subramaniam P & Woods B (2012) The impact of individual reminiscence therapy for people with dementia: systematic review. *Expert Rev. Neurother*, 12(5), 545-555.

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.

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, Hounsborne 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), 1-116.