

# Dementia Care Research: Sharing Knowledge for Policy and Practice



## Background

- It is estimated that at present in Northern Ireland 23,735 people live with dementia, 1,269 of whom have early-onset dementia. In common with other parts of the developed world, as the local population ages, dementia is increasingly becoming a major public health and social issue, with numbers of people with dementia projected to rise to around 57,500 by 2051.<sup>1</sup> If it is considered that each of these people will have a network of lay and professional carers then it can be estimated that, by 2051, upwards of 500,000 people could be coping with the impact of dementia in their everyday lives in Northern Ireland.
- This programme of work was commissioned by HSC R&D Division, Public Health Agency (PHA), in collaboration with The Atlantic Philanthropies (AP), and sought to address the increasing prevalence of dementia in NI and the burden it places, and will place, on health and social care staff and resources, and on the quality of life and wellbeing of service users and their wider network of carers. Its development follows from the launch of the NI Dementia Strategy, *Improving Dementia Services in Northern Ireland*, in 2011 and sought to complement and align with the work of the Dementia Strategy Implementation Group (DSIG), chaired by the PHA and Health and Social Care (HSC) Board (Commissioners of HSC Services) and charged with delivering the strategy's accompanying action plan.
- The Strategy aims to: promote a greater public understanding of how dementia impacts people's lives; encourage the sharing of information to allow individuals with dementia to live well as valued members of society through safe, effective and patient centred care; and respond to the voice of people with dementia in the way services are planned and delivered. It advocates the need for further research in dementia care through initiatives aimed at building inter-disciplinary and inter-professional research in health and or social care. These initiatives should have a strong element of personal and public involvement as well as involvement from the HSC Trusts and organisations which support them. Though the Strategy recommended research in three main areas - cause, cure and care, this programme of work focussed on the care aspect.
- To develop the priority areas for research, consultation with key stakeholders including service users, health professionals and commissioners utilized initial topics identified by national priority setting exercises in the UK led by the James Lind Alliance (part of the National Institute for Health Research, NIHR) and the Alzheimer's Society to derive a locally agreed priority list of topics on which robust evidence was currently unavailable. This programme sought to fill these evidence gaps.
- Applications were expected to address one of the 6 prioritised topics within a Northern Ireland context in the field of dementia care. Staff and Staff Training; Quality of Care; Co-ordination of Care; Information and Communication; Management of Behaviours; Management of Symptoms.
- Following a 2 phased call and evaluation by an international panel including a person living with dementia and a carer, 7 projects were funded for a period of up to 3 years.
- This booklet provides a summary of the projects, their key findings and recommendations for policy and practice.
- The full reports and executive summaries can be found at [www.research.hscni.net](http://www.research.hscni.net)

<sup>1</sup> Alzheimer's Research UK Dementia Statistics Hub

Photo on front cover kindly donated by TESA project.

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#RDdementia19

## Foreword by Chief Medical Officer

I am pleased to introduce a summary of the projects which were funded as part of the HSC R&D Division Dementia Care Research Programme, in collaboration with The Atlantic Philanthropies.

The programme was commissioned in response to the research recommendations of the NI Dementia Strategy- Improving Dementia Services in Northern Ireland. The research questions were based on topics informed by a local priority setting exercise with key stakeholders in dementia including staff, commissioners and service users.

The priority areas addressed by the studies were the quality of care, the co-ordination of care, staff and staff training, information and communication, the management of symptoms and the management of behaviours.

Each project was conducted by a team of experts in academia, clinical services and care and included members from a range of disciplines, organisations and sectors as well as people with dementia and their carers. The studies took place across different sites including Trusts, nursing homes, hospice, the community and voluntary sector. The quality of each study has been evaluated through input from experts in dementia who are based in other parts of the UK or internationally.

Each project has a list of practice and policy recommendations contained in this booklet and we are relying on our commissioners and health and social care staff at the frontline to help to implement these through the future development of services and training and the research community to build on these findings through future proposals and collaborations.

My final acknowledgement is for the contributions made by local people with dementia and their carers who assisted in the selection of the priority areas, helped evaluate the proposals for funding, contributed to the design of the studies as research partners and took part in the research as participants. This programme would not have been possible without them.

Dr Michael Bride  
Chief Medical Officer  
Dept of Health, Northern Ireland

<i>Dementia Care Research: Sharing Knowledge for Policy and Practice</i> 29 March 2019 from 9.30am to 2.00pm Linen Suite, Mossley Mill		
9.30am	Registration	
10.00am	Welcome and Opening Remarks	<b>Professor Ian Young</b> , Director, HSC R&D Division and Chief Scientific Officer, Department of Health
10.10am	Setting the Context: Implementing the NI Dementia Strategy	<b>Mr Seamus McErlan</b> , Co-Chair of the NI Dementia Strategy Implementation Group
10.20am	The Dementia Care Research Programme	<b>Ms Angela Hodkinson</b> , The Atlantic Philanthropies
10.30am	<b>Presentation of Research Findings</b>	
	Promoting informed decision making and effective communication through advance care planning for people with dementia and their family carers	<b>Professor Kevin Brazil</b> , Professor of Palliative Care, Queen's University Belfast
	Pain assessment and management for patients with advanced dementia nearing the end of life	<b>Dr Carole Parsons</b> , Lecturer in Pharmacy Practice, Queen's University Belfast
	Evaluation of a healthcare passport to improve quality of care and communication for people with dementia (EquiP)	<b>Professor Gerry Leavey</b> , Professor & Director of The Bamford Centre, Ulster University
11.15am	<b>Coffee Break</b>	
11.45am	<b>Presentation of Research Findings (con't)</b>	
	A feasibility study of facilitated reminiscence for people living with dementia	<b>Professor Assumpta Ryan</b> , Professor of Ageing and Health, Ulster University
	The development of a comprehensive medicines management approach for persons with dementia in primary care	<b>Dr Heather Barry</b> , Lecturer in Pharmacy Practice, Queen's University Belfast
	TESA: Technology enriched supported accommodation for people living with dementia, and their caregivers	<b>Professor Suzanne Martin</b> , Professor of Occupational Therapy, Ulster University
	Risk Communication in Dementia Care - ( <b>Poster Display</b> )	<b>Professor Brian Taylor</b> , Professor of Social Work, Ulster University
12.30pm	<b>Q&amp;A Session</b>	
1.00pm	<b>Closing Responses</b>	<b>Ms Corinna Hammond</b> , Carer Representative  <b>Dr Michael McBride</b> , Chief Medical Officer, Department of Health, NI
1.30pm	<b>Lunch and Close</b>	

### **Dr Michael McBride, Chief Medical Officer, Department of Health NI**



Michael McBride was appointed to the post of Chief Medical Officer for the Department of Health, in September 2006.

Prior to joining the department he had been Medical Director at the Royal Group of Hospitals

from August 2002.

Dr McBride graduated with Distinction from Queen's University Belfast in 1986 and completed his undergraduate and postgraduate training in Northern Ireland. In 1991 he attained a Research Fellowship at St Mary's Medical School and Imperial College London, where he carried out research into new drug treatments for HIV.

Dr McBride has been a Consultant in the Health Service since 1994 when he was appointed Consultant Physician in HIV medicine at the Royal Group of Hospitals and has more than 10 years health service management experience.

He has a longstanding interest in continuing medical education and was Postgraduate Clinical Tutor in the Royal Group of Hospitals between 1996 and 2000 and Director of Education in the Royal Hospitals from 2000.

As Medical Director at the Royal Hospitals, he contributed to strategic change at trust, regional and national level. As the Trust lead for clinical and social care governance, he had responsibilities for all aspects of clinical quality and patient safety.

Dr McBride took up the post of Chief Medical Officer during a time of significant change for Health and Social Care in Northern Ireland with responsibilities for Policy and Strategy in relation to Public Health, Quality and Safety and Research and Development. He also provides strategic advice to Minister and other Government departments on health related matters. He has been closely involved in the development of the new Health and Social Care structures, post Review of Public Administration, including the establishment of the Public Health Agency. Dr McBride currently leads in the work to transform health and social services in Northern Ireland in line with Health and Wellbeing 2026 – Delivering Together.

At the request of the Health Minister Dr McBride took up the post of Chief Executive of Belfast Health and Social Care Trust from

December 2014 to February 2017. He combined this role with Chief Medical Officer. As Chief Executive Dr McBride was head of an integrated health and social care Trust which provided hospital-based and social care services to the population of Belfast, as well as most of Northern Ireland's regional specialist services. He had responsibility for key Ministerial priorities, corporate responsibility for the Trust's 20,000 employees, and overseen the Trust's annual budget of almost £1.3bn.

### **Professor Ian Young, Chief Scientific Advisor, Department of Health & Director of Research & Development for Health and Social Care**

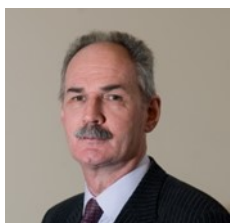


Ian Young is currently Chief Scientific Advisor to the Department of Health and Director of Research and Development for Health and Social Care. In addition, he is Professor of Medicine at Queen's University Belfast, where

he was also Director of the Centre for Public Health from 2008-2014, and Deputy Medical Director and Consultant Chemical Pathologist at Belfast Health and Social Care Trust. Professor Young's main clinical and research interests are in biochemical aspects of nutrition, particularly in relation to disease prevention.

He is an author of over 350 published research papers and has obtained over £30 million in research income. He is Chair of the Scientific Division of the International Federation for Clinical Chemistry and Laboratory Medicine, the world's leading laboratory medicine organisation, and Associate Editor of Clinical Chemistry, the journal of the American Association for Clinical Chemistry. He is a member of the UK Scientific Advisory Committee on Nutrition, and the Scientific Advisory Board of the National Institute of Biological Standards and Controls.

### **Mr Seamus McErlean, Social Care Commissioning Lead, HSCB**



Seamus McErlean qualified as a Social Worker from Ulster Polytechnic (1981) and completed an MSc in Advanced Social Work at QUB (2000).

He is employed as a Social Care Commissioning Lead with the regional HSCB and provides social work advice on commissioning decisions about services for older people and adults to the Western Local Commissioning Group.

Seamus is co-chair of the multi-agency regional Dementia Strategy Implementation Group.

He has extensive experience of working in the residential care sector as practitioner and manager and has also had senior managerial experience within a HSC Trust where he had responsibility for services to older people and people with sensory impairment. He has also worked in regulation.

He has a particular interest in services to older people including residential, domiciliary and Dementia care services and has published research on the needs and experiences of younger people with dementia.

### **Angela Hodkinson, Programme Executive, Atlantic Philanthropies**



The Atlantic Philanthropies is a global philanthropic foundation that aims to challenge destructive and discriminatory practices and tackle the root causes of inequity, especially where systemic barriers hold

people back unfairly. Atlantic made grants in Northern Ireland for 23 years, making its final funding commitments in 2014. Angela Hodkinson was Programme Executive for Atlantic's Ageing Programme, which from 2012 was focused on grantmaking to improve the lives of people with dementia. This included representing Atlantic on its partnerships with PHA (on the Dementia Care research programme) and the NI Executive (on a programme to transform dementia care and support, comprising Dementia Together NI and the Dementia E-health and Data Analytics Pathfinder Programme). As part of its winding

up process in 2015, Atlantic formally delegated its on-going local grant management responsibilities to a newly formed NGO – the Social Change Initiative (SCI). Now working on behalf of SCI, Angela continues to represent Atlantic's interests in dementia in Northern Ireland, and has a particular focus on capturing and sharing the strategic learning from the partnership between Atlantic and the NI Executive.

### **Professor Kevin Brazil PhD, Professor of Palliative Care, Queen's University Belfast**



Kevin Brazil holds the appointment of Professor of Palliative Care in the School of Nursing and Midwifery, Queen's University Belfast. He is also a Fellow in the Centre of Social Innovation and Evidence, Queen's University Belfast, where he

is the Lead for the Chronic Illness and Palliative Care Research Programme. He holds an honorary appointment in the Department of Health Research Methods, Evidence, and Impact, Faculty of Health Sciences, McMaster University, Hamilton, Ontario Canada.

Professor Brazil's research focuses on the structure, process, and outcomes in service delivery of quality care for family carers and patients as they near the end-of-life. As part of this work, he examines how personal, social, and environmental factors affect care. This work is designed to assist in the development, evaluation and translation of new and innovative interventions to improve access, quality and outcomes in this population. He has over 300 publications including 190 peer review journal publications related to these interests. He has taught undergraduate and post graduate learners in palliative care and health services research. He has been active on numerous working and advisory groups at the international, national, and regional levels and has served on several grant review boards in both Canada and Europe.

## **Dr Carole Parsons, Lecturer in Pharmacy Practice, Queen's University Belfast**



Carole Parsons graduated from Queen's University Belfast in 2002 with a First Class Honours degree in Pharmacy, and completed her pre-registration training in both hospital and community pharmacy practice. In 2003 she returned to the School to undertake a PhD in Pharmaceutics and was appointed to a Lectureship in Pharmacy Practice in January 2009.

Carole's research interests focus on prescribing and use of medicines in advanced stages of malignant and non-malignant terminal disease as patients approach the end of life. She has been involved in work examining pain recognition, assessment and management in people with advanced dementia who are nearing the end of life, and is interested in the ways in which medications are discussed, decided upon, managed and administered to these patients, from the perspectives of healthcare professionals, carers and families. Carole is also interested in how prescribers make decisions and communicate with the families of people with advanced dementia regarding withdrawal or continuation of drug treatments. She has recently started to examine medication management issues for people with advanced cancer, and medication appropriateness and deprescribing for frail older people and those with limited life expectancy.

Carole has authored 80 peer-reviewed publications to date. She is a member of the Executive Committee of the Northern Ireland Palliative Care Research Forum and the Clinical Management Group of the Northern Ireland Clinical Research Network for Dementia. She serves on the editorial board of the International Journal of Gerontology and Geriatric Medicine.

## **Professor Gerard Leavey, Director of the Bamford Centre for Mental Health & Wellbeing, Ulster University**



Gerard Leavey is Director of the Bamford Centre for Mental Health & Wellbeing, Ulster University and Clinical Lead for the Northern Ireland Clinical Research Network. Prior to this, he was Director of Research at

Barnet, Enfield Haringey Mental Health NHS Trust in North London. He has undertaken a considerable body of research in psychiatry and health services research and played various key roles in the psychiatric research community in London and the UK.

Much of his work relates to health inequalities, help-seeking, and the improvement of mental health services for disadvantaged groups. He has written extensively on the mental health of refugee and migrant communities. Current research in Northern Ireland includes the Northern Ireland Schools and wellbeing study (NSAW) a large survey of help-seeking attitudes and behaviours among adolescents. Studies funded by the R&D Division of the PHA are the IMPACT study on young service users' transition from Child & Adolescent Mental Health Services to Adult Mental Health Services, and the EQuIP study, evaluating the acceptability and use of healthcare passport for people living with dementia. Gerry has a long-standing collaborative relationship with the Department of Mental Health Sciences at University College London and current studies include NIHR and ESRC funded research programmes on housing provision for people with severe mental illness; managing agitation in dementia and an RCT of an intervention for older victims of violence.

## **Corinna Hammond, Carer Representative**



Corinna Hammond was a carer for her dad who had a diagnosis of early onset Alzheimer's dementia; he has since passed away.

She was involved in the Dementia Strategy for N.I. as a Carer Representative and some of the work streams and initiatives that followed. Since then she has trained as a Social Worker and works with people with a diagnosis of dementia, their families and carers.



## **Professor Assumpta Ryan, Professor of Ageing and Health, Ulster University**



Assumpta Ryan's research is focused on ageing and the care of older people. Specific interests include the needs and experiences of family carers, caregiving in dementia and quality of life in nursing and residential homes. Assumpta is the Northern Ireland Lead for the UK wide

'My Home Life' Leadership Support and Community Development Programme for care home managers.

She has published extensively in a range of academic journals and has presented at a broad range of national and international research conferences. Assumpta is Editor of the 'Journal of the All-Ireland Gerontological Nurses Association' and is on the Editorial Board of 'Dementia: The International Journal of Social Research and Practice' and 'The International Journal of Older People Nursing'. Assumpta is currently President of the All-Ireland Gerontological Nurses' Association.

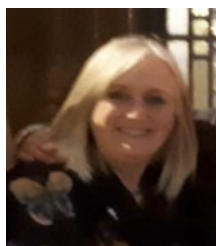
## **Dr Heather Barry, Lecturer in Pharmacy Practice, Queen's University Belfast**



Heather Barry completed her PhD at QUB, and held a postdoctoral research position at the University of Exeter. Most recently, she was a Visiting Researcher at McMaster University in Canada.

Her work focuses on service delivery and organisation of care within the primary care setting, older people (particularly those with dementia and frailty), prescribing and medicines management. Heather maintains close links with community pharmacy, and is a member of the Pharmaceutical Society of Northern Ireland and the Royal Pharmaceutical Society of Great Britain.

## **Professor Suzanne Martin PhD, Professor of Occupational Therapy and Head of School Health Sciences, Ulster University**



Suzanne Martin (PhD) is Professor of Occupational Therapy and Head of School Health Sciences at Ulster University. She is a Fellow of the College of Occupational Therapists UK and a panel member for the National

Institute for Health Research. She is a trainer and contributor to the Cochrane library.

Her research focus is on new and emerging technologies within Health and Social Care. Suzanne has successfully led a range of EU and Nationally funded research projects to develop and explore new devices and services to support people living with a disability at home.

## **Professor Brian Taylor, Professor of Social Work Ulster University**



Brian Taylor is Professor of Social Work at Ulster University where he leads the research cluster on *Decision, Assessment, Risk and Evidence Studies in Social Work*.

He joined the University after ten years of varied experience in practice and management, and fifteen years in training and organisation development in health and social care. Brian is a Fellow of the Academy of Social Sciences; a founder member of the Board of the European Social Work Research Association; a Senior Fellow of the School for Social Care Research at the National Institute for Health Research, London; and an Associate of the Harding Centre for Risk Literacy at the Max Planck Institute for Human Development, Berlin.

## Pain Assessment and Management for Patients with Advanced Dementia Nearing the End of Life

**Principal Investigator:** Carole Parsons, Queen's University, Belfast

**Researcher Fellow:** Bannin De Witt Jansen

**Co-Investigators:** Kevin Brazil; Hilary Buchanan; Doreen Maxwell; Sonja McIlpatrick Sharon Morgan; Peter Passmore; Max Watson

### Why did we start?

Pain assessment and management for people with advanced dementia nearing the end of life is highly challenging and complex. Patient self-report is often unavailable or unreliable. Debate regarding the reliability, validity and clinical utility of observational pain assessment tools is ongoing. Evaluation and exploration of whether and how health professionals use these tools and their impact on patient outcomes remains a critical gap in current evidence. No studies have been conducted to date which examine health professionals' or carers' experiences and perspectives of pain assessment and management in patients with advanced dementia approaching the end of life.

### What did we do?

We conducted qualitative interviews to determine the issues in pain assessment and management in people with advanced dementia nearing the end of life in primary, secondary, nursing home and palliative care settings. We interviewed 3 bereaved carers, 23 doctors, 24 nurses and 14 healthcare assistants (HCAs). Analysis of these interviews identified a need for healthcare professional training and professional development in pain assessment and management in advanced dementia. Participants expressed a strong desire for case-based learning led by a health professional with clinical experience and specialist expertise. This provided the evidence for adoption of the Project ECHO® Model for this intervention. A series of five TEAM Pain AD teleECHO clinics were developed, delivered and evaluated.

### What answer did we get?

The interview data highlighted, and the teleECHO clinic evaluations reinforced, the importance of developing networks for knowledge exchange across specialties and care settings, and between physicians, nurses and healthcare assistants. Healthcare assistants were frustrated at their perceived exclusion from multidisciplinary care teams. Evaluations demonstrated the value of the teleECHO clinics in enhancing healthcare professional knowledge and self-efficacy in assessing and managing pain for people with advanced dementia, and the potential for this type of educational intervention in other clinical areas.

### What should be done now?

Policy and practice initiatives should cross specialisms and care settings, involving all members of the multidisciplinary healthcare team, patients' families and other key health and social care staff. Training should be needs-driven, available on a regular basis, and involve those who require the training in co-design of the curriculum. Policy and practice initiatives should also make provision for an expanded role for healthcare assistants. The ECHO® Model should be adopted for healthcare professional training and education in pain in dementia, and is translatable to other clinical areas. Further work is required to evaluate its impact on service delivery and patient outcomes, in addition to healthcare professional knowledge and self-efficacy.

## Implications for Policy and Practice

- To enhance engagement and increase the likelihood of delivering sustained practice change, future education and training programmes in pain assessment and management for people with advanced dementia must be needs-driven, available on a regular basis, and should involve service users (i.e. those individuals who require the training) in the co-design of the curriculum and the scheduling of the training sessions/clinics. This should include all health and allied health professionals (doctors, nurses, HCAs, speech and language therapists, occupational therapists, pharmacists) who have responsibility for the treatment, management and/or care of patients in advanced and end-stages of dementia.
- The Project ECHO© model, which crosses specialisms and care settings, and involves all members of the multidisciplinary healthcare team, patients' families and other key health and social care staff, should be utilised for education and training. It also has significant potential for patient care management. This applies to pain assessment and management in advanced and end stage dementia, but will also translate to other patient populations and clinical areas, and could be integrated into the Northern Ireland End of Life Care Operational System (ELCOS), the aim of which is to prompt practitioners in the development of an individualised care plan.
- The Project ECHO© model should continue to be developed and evaluated in terms of its impact, not only on healthcare professional knowledge and self-efficacy, but also on service delivery and patient outcomes.
- The role of HCAs should be expanded to include monitoring for and reporting on treatment response, side and adverse effects, and use of basic pain assessment tools such as the Abbey Pain Scale. However, it must be recognised that a number of factors require significant consideration when exploring the possibility of an expanded role for HCAs in pain assessment and management. These include the way in which training is delivered, and by whom, and the process of selecting staff for this enhanced role, given the variation in knowledge, skills and competence of HCAs.
- Observational pain tools may have a role in pain assessment, however, further evaluation of the reliability and validity of these tools and their ability to discriminate between pain and non-pain related distress is required.

## Risk Communication in Dementia Care

**Principal Investigator:** Brian Taylor, Ulster University

**Research Assistant:** Mabel Stevenson

**Co-investigators:** Michelle McDowell; Beverley Savage; Joanne Knox

### Why did we start?

Supporting people with dementia in line with community care policies requires increasing attention to assessing, communicating and managing risks for people living in their own home. There is a challenge in supporting client choices that include risk-taking whilst demonstrating professional accountability. Risk communication is increasingly important as we seek to engage clients and families in shared decision making. This presents particular challenges in dementia services.

### What did we do?

We conducted:

- a rigorous review of research on risk concepts and risk communication in dementia;
- a qualitative study with people with mild-moderate dementia;
- analysis of this data involving people with mild-moderate dementia;
- a qualitative study with family carers of a person with dementia;
- a qualitative study with professionals in community dementia services; and
- a survey of professionals in community dementia services.

### What answer did we get?

- Risk is often conceptualised as seriousness of possible harm rather than as likelihood.

- Background and emotion may influence the conceptualisation and communication of risk.
- Family carers are often involved in managing complex risks.
- Common risks were identified, and have been codified into a framework to aid understanding.
- Health and social care professionals make extensive use of numeric information in practice, although they more often communicate risk information with words.
- Professionals frequently overestimate how often risks with severe outcomes occur.
- Verbal descriptors for numeric likelihoods of possible harm are widely interpreted.
- There was strong interest in the possibilities for visual modes of communicating risk.

### What should be done now?

- The public leaflet produced with the Public Health Agency (PHA) and Health and Social Care (HSC) Board should be widely distributed.
- The leaflet for professionals hosted on the University website should be widely advertised.
- Models of co-research should continue to be developed.
- The materials on domains of risk and risk communication should be included in appropriate training resources and similar guidance material for staff.

- A database of risk factors should be developed to support staff in managing risks.
- Visual methods of communicating risk should be studied for their potential application.
- Focus on solutions rather than problems e.g. 'have you thought about trying...'
- Use positive language in communications for example words such as 'safety' or 'independence.'

### Implications for Policy and Practice

- Be aware of the individual's personal history and how this may make them think about risks – for example their job history, hobbies, personality and experiences. "We might go into a house and think 'gosh that's wild risky' [but] they might have been doing it all of their life" (professional).
- People with dementia should be supported wherever possible to think about risks for themselves rather than being told what to do. This could involve sensitively bringing the risk to their attention e.g. 'how are you managing with...' or 'the traffic was very bad today, do you also find that?' "I don't like to be treated like a child. I am quite happy to be independent, but sensible" (person with a dementia) "Instead of telling the person the risk, it's trying to get them to think about and identify the risks themselves" (professional).
- Choose the right time to talk about the risk with the person with dementia. Some individuals find that there are certain times of the day when they feel more confident making choices.
- Give the person with dementia time to think before making a decision. "You see I am trying to make a decision but there's millions of things going through my head too" (person with a dementia).
- If you are worried about a person with dementia, sensitively talk through the reasons why you think it may not be safe for that person to continue with a particular activity. "If it makes sense to me then that's fine" (person with a dementia).
- Write down any important points for the individual as a visual reminder of the conversation.
- Practical information for family carers should include advice on dealing with risk in everyday life. This could include general guidance in the form of group information sessions, written materials or personalised advice.
- Translate important professional concepts such as positive risk taking and proportionality into everyday language for families and people with dementia.
- Consider using visual aids to communicate risks to people with dementia and families.
- Assemble data on frequency of risk outcomes as a reference point for staff. Overestimations of risk might be expected to lead to risk averse practice. Communicating more accurate likelihoods to service users may encourage people with dementia and families to worry less about risks that are actually very unlikely to occur.

## Promoting informed decision making and effective communication through advance care planning for people with dementia and their family carers

**Principal Investigator:** Kevin Brazil, Queen's University Belfast

**Research Fellows:** Gillian Carter; David Scott

**Co-Investigators:** Chris Cardwell; Mike Clarke; Peter Hudson; Katherine Froggatt; Dorry McLaughlin; Peter Passmore; W George Kernohan.

### Why did we start?

Advance Care Planning (ACP) is a process of discussion between patients, health care providers and, those closest to them. ACP aims to clarify a patient's preferences for their future care in the event that they lose capacity to make decisions for themselves. If a patient has not clarified their wishes in advance, often, family members are asked to make difficult and emotive choices about whether or not to proceed with life sustaining treatments. Although guidelines suggest that ACP should commence as early as possible, evidence shows that most nursing home residents with dementia do not have an advance care plan. Hence, this study sought to identify the key components of an ACP intervention, develop an evidence-based family focused intervention, and evaluate its impact on the families of nursing home residents with dementia.

### What did we do?

We developed and tested an ACP intervention that comprised the following 'key' components: a trained ACP facilitator; family education; family meetings; documentation of ACP decisions; and, orientation of GPs and nursing home staff to the intervention. This study employed both quantitative and qualitative methodologies. The quantitative component comprised a paired cluster randomised controlled trial. Outcomes of interest included: family carer uncertainty in decision making; family carer satisfaction with nursing home care; psychological distress among family members; quality of death; and, administrative outcomes. The qualitative component of the study examined the experience of family members as a best interest decision maker and their experience of participating in the ACP process.

In addition, we also interviewed nursing home managers and the ACP facilitator in order to assess their experiences and perceptions of implementing the intervention.

### What answer did we get?

There was evidence of a reduction in decisional conflict among carers who received the intervention when compared to the usual care group. There was also evidence of a statistically significant improvement in family carer satisfaction with nursing home care. No statistically significant differences were noted between the two groups on measure of psychological distress. Although we found an increase in Do Not Resuscitate (DNR) orders and a reduction in both hospital admissions and deaths in the intervention group, this difference was not statistically significant.

Qualitative findings revealed the feelings of burden experienced by family carers and the sense of premature loss they felt as a direct consequence of their relative's dementia. Many carers reported having a limited understanding of dementia and had mixed experiences of using healthcare services. Nursing home managers recognised that a major barrier to implementing ACP was the lack of dementia knowledge demonstrated by both family members and nursing home staff as well as time and resource constraints.

## What should be done now?

Education is essential to allow family carers to contribute to or make informed best interest decisions on their relative's behalf. Our study demonstrated that it is feasible to implement an ACP intervention in dementia care nursing homes with effective outcomes. ACP should be integrated into 'usual care' within nursing homes and should be supported by other healthcare providers such as GPs. Overall, we identified a need to increase dementia knowledge among both family carers and nursing home staff.

## Implications for Policy and Practice

This study identified a range of recommendations for policy and practice. Some of the key recommendations are summarized here:

- Dementia should be recognized as a terminal illness. This should inform the development of all policies relating to dementia care.
- In order to facilitate the timely completion of end-of-life care plans we need to increase awareness about ACP among the general population.
- There is a pressing need to improve knowledge about ACP among health care professionals who work outside acute hospitals and palliative care.
- There is a need for policies which will help to facilitate the development of effective partnerships between staff based in the community, primary care, palliative care and the nursing home sector.
- Nursing homes should have an explicit policy to guide the provision of end-of-life care for residents with dementia.
- Where possible, nursing home residents with a diagnosis of dementia should not be moved at a crucial point in their care.
- A range of education programmes and tools have been developed to help nursing homes deliver improved end-of-life care. However, these programmes need to be evaluated, particularly in relation to people with dementia and their families.

## The Development of a Comprehensive Medicines Management Approach for persons with dementia in primary care

**Principal Investigator:** Carmel Hughes, Queen's University Belfast

**Research Fellows:** Heather E Barry; Laura E Bedford; Mairead McGrattan

**Co-Investigators:** Cristin Ryan; A. Peter Passmore; A. Louise Robinson; Gerard J Molloy; Carmel M Darcy; Hilary Buchanan

### Why did we start?

People with dementia (PwD) experience unique challenges when managing their medicines, due to the difficulties they have with their memory and not being able to communicate as well with others. This may affect the way in which doctors and other healthcare professionals prescribe and care for these patients. There has been limited research on how medicines are managed in PwD, particularly for those living in their own homes and being cared for by general practitioners (GPs) and other members of the primary care team. The aim of this project was to develop an approach (intervention) to improve medicines management for PwD, with help from patients, carers and healthcare professionals.

### What did we do?

The project comprised three phases of work. **Phase 1:** Using a large prescribing database we looked at what medicines were being prescribed for PwD by their GP, and we used a tool that helped us to assess the quality of prescribing. **Phase 2:** We interviewed PwD, their carers, GPs and community pharmacists to discuss medicines management from each individual's perspective. We analysed these interviews and from the results, we developed an intervention in which GPs, community pharmacists, PwD and carers could work together to improve medicines management. **Phase 3:** We tested this intervention in a small number of community pharmacies to see how it worked in reality.

### What answer did we get?

From the database study, we found that PwD were receiving many medications, and that patients were receiving drugs or combinations of drugs that were not always considered to be clinically appropriate. Whilst GPs were mindful about prescribing appropriately for PwD, they sometimes lacked confidence prescribing certain drugs. Community pharmacists were concerned about how well PwD took their medicines. Both GPs and pharmacists felt it was important to review PwDs' medication, but struggled to find time to do this thoroughly. PwD and carers did not report any problems with medicines management at the time of the interviews. An approach was devised for community pharmacists to undertake a face-to-face medication review with PwD and their carers, and to communicate any suggested medication changes to the patient's GP. Whilst we attempted to try this out in three community pharmacies, none of the pharmacists was able to recruit PwD or carers to the study, which in part was due to a lengthy screening and recruitment process. Therefore, the approach was unable to be tested.

### What should be done now?

Further work is needed to test and evaluate the developed approach to see how well it can be implemented in clinical practice and if it can have a positive impact on patient outcomes. Consideration will have to be given as to how best to screen, recruit and



consent PwD in a future study. The project has provided useful information about the appropriateness of prescribing for PwD, and this should be considered by healthcare professionals involved in prescribing and/or dispensing medications for PwD in the future. It may also help inform future work in this area by helping researchers to focus their attention on potentially inappropriate classes of drugs found to be commonly prescribed for PwD.

### Implications for Policy and Practice

- We suggest that a collaborative partnership between GPs and community pharmacists may be required in order to streamline the process, and consideration should also be given to the changes that are happening within primary care currently, with the possibility of involving other primary healthcare professionals (such as GP Practice Pharmacists) in the future.
- Due to the exploratory nature of the research conducted during this project, there are limited implications for practice at the current time.
- However, the work conducted in Phase 1 highlighted the need for appropriate and sensible prescribing for PwD. Conducting regular and thorough reviews of patients' medication will ensure that medicines-related issues are addressed for these patients.
- The qualitative work undertaken in Phase 2 highlighted the importance of carer involvement in any future interventions developed for PwD.
- The issue of prescribing appropriately for PwD should be explored further in future work, for example similar work could be conducted using larger and more detailed databases, and there needs to be further investigation into why certain classes of drugs continue to be prescribed inappropriately for PwD, particularly anticholinergic drugs.
- Clearly, given the difficulties that were experienced during the third and final phase of work, we recommend that further work will need to be done to refine the intervention before further feasibility testing can happen. In particular, the way in which we screen and recruit PwD and carers should be reviewed with the aim of making this as straightforward as possible, both for participating healthcare professionals as well as potential patient participants.

### **Evaluation of a Healthcare Passport to improve Quality of Care and Communication for People with Dementia (EQUIP)**

**Principal Investigator:** Gerard Leavey, Ulster University

**Research Associates:** Dagmar Corry; Emma Curran; Bethany Waterhouse-Bradley

**Co-Investigators:** Stephen Todd; Aine Abbott; Vivien Coates; Max Watson; Sonja McIlpatrick; Brendan McCormack; Bernadine McCrory.

#### **Why did we start?**

How to better support people living with dementia and multiple comorbidities is a major challenge to the individual and their families. It is also an increasing problem for health and social services, particularly so when demand is high and resources are shrinking. There is a need for interventions that assist people living with dementia to navigate treatment and support in ways that are 'joined-up' and enhance their autonomy and dignity. Healthcare passports (HPs) are available for different patient groups but their acceptability and usefulness in dementia care has not been assessed.

#### **What did we do?**

As a component of a feasibility assessment of a dementia healthcare passport, we undertook a realist review of the evidence. This approach seeks to provide a more explanatory analysis of the evidence on what works, for whom, in what circumstances and why. We then undertook a qualitative longitudinal study to examine the experiences of a purposive sample of people living with dementia and their family carers and their use of the healthcare passport at different time points. We explored barriers and facilitators of the use of the passport with other service user groups and with healthcare professionals. We also examined General Practitioners' views on the passport.

#### **What answer did we get?**

The passport, at a very general level is considered as potentially worthwhile. However, there are various barriers that deter more effective and widespread usage. Thus, the passport requires more clarity about 'ownership' – we found that it is predominantly held and used by the family caregivers. Passport use is often determined by how recently a diagnosis of dementia was provided and/or the severity of the symptom. At early stages, the passport is deemed unnecessary, at later stages where the carer assumes greater control, it is sometimes regarded as an additional burden. The negative or 'lukewarm' response by clinicians dampened or quashed further use by families.

#### **What should be done now?**

While it does not constitute a stand-alone solution to current problems in dementia care, with some alterations, and with health and social care professionals' knowledge and understanding of the passport and its purpose, it has the potential to improve quality of life for the patients and carers. Retaining personhood, improving communication and promoting self-management require the commitment and dedication of all health and social care professionals, in collaboration with family carers and patients.

## Implications for Policy and Practice

- Some families will require much more in-depth consultation on the use of the passport and over a longer period of time than the resources permitted in the current evaluation. Thus, the passport should not be issued to families soon after diagnosis or at the early stages of dementia. Indeed, it may be that the criterion for issuing a healthcare passport is the presence of complex or multiple needs alongside a dementia diagnosis. It must be made clear that it is a “health passport” rather than a “dementia passport”. People living with dementia need to know that it is widely used by all patients, so that they do not feel stigmatised by its use.
- Implementation will require a concerted policy drive to have the passports more widely recognised and accepted by health and social care professionals and this will necessitate time and resources to explain its purpose and level and type of professional contribution. Nevertheless, family use of the passport is strongly predicated on the passport’s acceptance by professionals. Moreover, families need to know that the passport is in common use.
- Widespread implementation will require a publicity campaign, perhaps using leaflets and posters in GP surgeries and other clinical settings. GPs may take the lead in introducing and explaining the passport to patients and carers in the first instance to avoid negative associations. Importantly too, it must be made explicit that the passport belongs to, and is for the benefit of, the person with dementia and their family.
- The degree and exact nature of GP resistance may require further understanding about how, if at all, it may be overcome. Alternatively, future design and implementation may have to consider which service should take responsibility for the dissemination and oversight of the passport. While it is important that GPs are committed to the aims of the passport, sustainability will be underpinned by Health and Social Care Professionals (HSCPs) and long-term engagement with families.
- Successful use of the passport relies on the commitment and capacity of family and other informal caregivers, including the use of the passport, and communication with all HSCPs. This commitment and capacity is determined to a large extent by the perceived quality of life, including their own health, but also by the extent to which they believe that the passport will actually help them. The implementation of the passport must accommodate the needs and values of families and the involvement of carers could be made more explicit.
- Contextual factors such as organisational culture, the learning environment and the care environment itself, are acknowledged as posing the most significant challenges to person centred care and the development of cultures that can sustain person centred care (McCormack et al., 2011). The implementation and effectiveness of the passport is more likely to succeed when these wider determinants are also appreciated.
- An electronic version (on an internet platform or a smart phone app) may assist communication as it could facilitate instant access to HSCPs, while being password protected and not in breach of data protection (access could be provided or restricted as required).
- To ensure accuracy and consistency, any entries pertaining to medical treatment and therapies or interventions should be made and updated by the relevant HSCPs in their relevant sections. The “medical sections” of the passport ought to be standardised in order to ensure that all relevant details are provided for all patients.
- Personal narratives also varied considerably, so some guidance would be helpful to ensure that basic information is provided.
- A space for name and photograph of the patient should be on the front cover of HPs.

## A Feasibility Study of Facilitated Reminiscence for People living with Dementia

**Principal Investigator:** Assumpta Ryan, Ulster University

**Research Fellows:** Claire McCauley; Aideen Gibson

**Co-Investigators:** Liz Laird; Maurice Mulvenna; Brendan Bunting; Finola Ferry; Raymond Bond; Kevin Curran

### 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.

## Implications for Policy and Practice

- 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 as 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.
- Information and Technology (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 InspiredD app to travel with dyads throughout their dementia journey.
- On a broader strategic level, the use of Information and Communications Technology (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 People Living with Dementia (PLWD) and their families.
- The InspiredD 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.

## **TESA: Technology enriched supported housing – a study into the lived experience of elders with dementia and their carers**

**Principal Investigator:** Suzanne Martin, Ulster University

**Research Fellows:** Jean Daly Lynn; Janeet Rondon-Sulbaran

**Co-Investigators:** Assumpta Ryan; Brendan McCormack; Eamon Quinn; Margy Washbrooke

### **Why did we start?**

As the number of older people increases, a rise in the number of people living with dementia has emerged, it is therefore timely to consider housing options that aim to provide real home environments, where people living with dementia (PLWD) can grow older with dignity, autonomy and support. Technology enriched supported housing has been available in Northern Ireland for over fifteen years. The aim of this study was to explore the perspectives of PLWD who live in person-centred, technology enriched housing schemes, as well as their family and paid employees at the facilities.

### **What did we do?**

The study adopted a qualitative approach to get an in-depth understanding of all the stakeholders engaged in each scheme. Descriptive demographic information was obtained from each of the nine participating housing schemes, along with an environmental and technology audit. One to one interviews were completed with a sample of stakeholders which included PLWD, family carers, and formal paid carers. Peer researchers conducted the interviews with the tenants who were PLWD. PLWD were also invited to participate in art-based focus groups to express feelings about the housing schemes. In addition, all caregivers were invited to complete a survey to gather attitudes towards technology. The research was underpinned by McCormack and McCance's Person-centred Practice Framework (McCormack & McCance, 2017).

### **What answer did we get?**

The nine schemes were operating at 91% of capacity at the time of the research. The technology enriched support accommodation (TESA) facilities were home like, individual, custom environments for tenants to live in. Person-centred practice was at the core of care provision, tenants could thrive, flourish and maintain meaningful relationships with people and places. Not all tenants were aware of the technology provision. Those persons who were aware of it felt it gave them reassurance and feelings of security. A major theme from informal caregiver interviews was the shift from care provider modality to care manager. Technology in the facilities did not appear to impact on decision-making by informal carers during transition, however, it was valued once the PLWD lived in the TESA facilities. Technology supported the formal caregiver to provide high quality, person-centred care, providing reassurance and feelings of safety for both tenants and their next of kin. Both types of caregivers held similar views around the benefits of technology, however, views on issues such as privacy and consent varied. Safety was considered more important than right to privacy by family caregivers.

## What should be done now

A number of recommendations emerged from the research. Organisations involved in the design and delivery of TESA housing should be encouraged to collaborate and share learning. An audit of facilities to ensure that General Data Protection Regulation (GDPR) and safeguards are in place to protect tenants' data would be useful. Economic modelling of TESA and testing against more traditional care would be beneficial. Debate and guidance on designing, developing and delivering TESA and the ethical use of technology for PLWD is required. It is important to ensure the voice of PLWD continues to be heard within research.

- Debate and guidance on the ethical use of technologies for PLWD would be helpful.
- All research with a focus on PLWD should have their voice within it.

## Implications for Policy and Practice

- Advanced care planning post diagnosis of dementia should include information and discussion on these types of accommodation options so people can have explicit consent in place and triggers identified to support transition from home to these facilities.
- Shared learning across these facilities should be promoted to inform the ongoing operational delivery of care particularly on topics like GDPR, and embedding data in notes and records and evidencing how pervasive technologies inform care.
- An audit should be completed to ensure all sites are adhering to the GDPR outlining what technical and organisational safeguards are in place to protect tenants' data.
- A move away from bespoke technologies and systems might be a positive progression enhancing the opportunity to standardise and understand implementation within services.
- Expertise and knowledge of designing, developing and delivering TESA schemes could be migrated into practice guidelines.
- Economic modelling on the TESA and testing against more traditional care would be useful.

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