

Health and Social Care R&D Division

Evaluation of the Research Programme in Dementia Care

Final report / Year 4

June 2019

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EXECUTIVE SUMMARY

Introduction

RSM UK Consulting LLP (RSM) were commissioned in 2015 by the HSC Research and Development Division to conduct a longitudinal evaluation of the Research Programme in Dementia Care over a four year period. This report is the final report covering April 2018 to March 2019 but draws together an overall summation of the programme.

HSC R&D Division in partnership with The Atlantic Philanthropies jointly commissioned a programme of research to develop knowledge of how best to deliver evidence-based care in Northern Ireland (NI) to people living with dementia, in an evidence-informed policy context, and to enhance the local capacity to undertake high quality research relevant to dementia care. The aim of the Research Programme in Dementia Care was to ultimately lead to direct improvements in patient care and systemic changes in the way services are commissioned and delivered.

An open call for proposals for the Research Programme in Dementia Care was first issued in June 2013 and then again in February 2014. Seven projects were successful and awarded a total funding of £2,205,307. Three projects started in 2014 and the remaining four began in 2015

The overall aim of the RSM work, as set out in the Terms of Reference, was to 'evaluate the Research Programme in Dementia Care.' Table 1 below provides an overview of the Terms of Reference and the relevant sections where these are addressed within this report:

Table 1 Terms of reference

Terms of reference	Report section
Inter-disciplinary and inter-sectoral relationships developed as a result of joint research projects	4.2.1 Relationships
Capacity built to continue applied dementia care research in NI and attract alternative funding	4.2.3 Capacity
Perceived quality and breadth of dissemination activity	4.1 Increasing knowledge
Degree to which the findings of research projects have influenced dementia care and support services delivered by Government and have the potential for future influence	4.3 Influences on service delivery, policy and health & wellbeing

Methodology

The methodology for this, the final year report, involved the following stages:

- A desk top analysis of key documentation relating to the Research Programme.
- Telephone and face to face consultations with the Principal Investigators (7) and research team members (7).
- Telephone and face to face consultations with strategic stakeholders (14) and staff from HSC R&D Division (2).
- Post launch event survey (38 responses).

Previous Report Findings

The initial report was completed in 2015 and included consultations with stakeholder and surveys with applicants. The key findings for this report included:

- In general, both stakeholders and applicants believed that the call for proposals was very well organised.
- It was also suggested that it would be useful to have an online submission system.
- The processes used to evaluate the applications were highly regarded by key stakeholders and the evaluation panel and were believed to be in line with best practice.

This first interim report was completed in 2016 and included consultations with stakeholder and surveys with Principal Investigators (PIs) and research teams. The key findings for this report included:

- Feedback from PIs that inter-disciplinary and inter-sectoral relationships had continued to develop as a result of joint research projects with PIs indicating they had collaborated with other researchers outside their main discipline.

The second interim report was completed in early 2018 and included surveys with PIs and research teams. The key findings of this report included:

- PIs had established working relationships across sectors and were implementing Personal and Public Involvement (PPI) to a positive effect.
- PIs had established partnerships and had participated in research activities which have increased the awareness in public sector of the research and developed the partnership within Health and Social Care.

Final Report Key Findings

The key findings of this project have been mapped against the Terms of Reference:

- **Relationships:** The programme and research funding were viewed as helpful in promoting the development of interdisciplinary relationships within and between institutions, deepening these relationships to a greater extent than would have been possible without funding.
- **Capacity:** Overall capacity was felt to have been built in applied dementia research in NI, particularly considering the low baseline position at outset.
- The funding has been used to support over 60 researchers across seven projects, with several successes in career development with junior researchers moving into substantive positions within universities in NI or beyond.
- Capacity was also developed in undergraduate and postgraduate teaching, through Research Team members using the research projects as case studies within lectures for undergraduate and post-graduate students.
- **Dissemination:** Dissemination appears to have been strong in academic terms, with 28 high-quality publications produced so far. However, some stakeholders suggested that further dissemination would be useful, such as through a process for dissemination and knowledge transfer (e.g. a Dissemination Officer).
- **Impacts on Policy:** Views on the impact of the research studies on policy were mixed. Some projects indicated improved practices and education/ training, whereas others indicated that more could be done to translate findings into practice.
- Three projects indicated that research showed that, if scaled and spread more widely, their studies/ innovations would have potential for health and wellbeing benefits in future. However, there are no current plans for scaling, so we cannot comment further on the extent to which this might be achievable.
- Whilst all indicated that there is scope for research projects to influence policy, there is pressure in academia to focus on further research rather than translation of findings into practice on the ground, and the absence of devolved government in NI has made influencing policy difficult to achieve.
- Two of the projects (so far) have successfully secured further research grant funding from a range of sources (£1.5m has been secured, with partners), which would not have happened in absence of programme. This suggests capacity, relationships and opportunities have been built and have potential to be sustained as a result of this programme.

Recommendations

Based on this summative review we have developed six recommendations which are geared towards further enhancing the impact of this programme, and also replicating its successes in other research calls in the future. These recommendations are shown in the figure below.

1	Relationships developed	<i>We recommend that the HSC R&D Division continue to nurture and support relationships which have developed through this programme of work. This may include agreeing methods for keeping in touch, e.g. newsletters and groups, and circulating updates on ongoing or new research and opportunities in dementia care.</i>
2	Capacity built	<i>We recommend that the HSC R&D Division develop a plan to maintain and build upon the capacity which has developed through this programme. Outputs from the research projects should be disseminated widely within universities and HSC Trusts to encourage their use in training and education, to encourage further capacity building in the sector.</i>
3	Quality & breadth of dissemination activity	<i>We recommend that dissemination activities should continue as planned, including updating ResearchFish as appropriate. The HSC R&D Division should develop a plan to promote knowledge transfer and translation of findings into the HSC system, so that impact is enhanced on the ground. This may include consideration of further funding for dissemination activities, particularly those which will encourage knowledge transfer and will make an impact on HSC staff, service users and their families.</i>
4	Influencing dementia care & support services	<i>We recommend that the HSC R&D Division, along with PIs, should seek to identify opportunities for further funding to take successful research projects forward, including trialling these at a larger scale. All PI's should set up meetings with commissioners and policy representatives to explain the findings from their studies and discuss how these might influence the delivery of care in the future.</i>
5	Involvement of people living with dementia	<i>The HSC R&D Division, along with the wider Health and Social Care System, should seek to facilitate the involvement of people living with dementia in all stages of the research process, both as participants and as partners. This should include working with Ethics and Research Governance Committees to ensure that research aims and objectives are understood and supported as far as possible.</i>
6	Other	<i>We recommend that the HSC R&D Division should consider replicating many of the positive aspects of this programme in future research calls. This should include: a supportive application process, multi-disciplinary research teams, PPI and a flexible approach to delivery where possible.</i>



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1 INTRODUCTION AND BACKGROUND

Introduction

RSM UK Consulting LLP (RSM) (formally PACEC Ltd) was commissioned by the Health and Social Care Research and Development Division (HSC R&D Division) to conduct a longitudinal evaluation of the Research Programme in Dementia Care (2015 – 2018). This is the final report from the four-year formative and summative evaluation. This report is final and summative but should be read in conjunction with reports from years one, two, and three.

Background to the Research Programme in Dementia Care

1.1.1 HSC R&D Division's collaboration with The Atlantic Philanthropies

The Research Programme in Dementia Care was developed in response to the NI Dementia Strategy, 'Improving Dementia Services in Northern Ireland' (2011) and complements and aligns with the work of the Dementia Strategy Implementation Group (DSIG), chaired by the Public Health Agency (PHA) and HSC Board (Commissioners of HSC Services). It was charged with delivering the strategy's accompanying action plan. The HSC R&D Division was invited by Atlantic Philanthropies to submit a bid for partnership funding for dementia research in October 2012. The HSC R&D Division proposed a programme of research to enhance knowledge of how best to deliver evidence-based care in Northern Ireland (NI) to people living with dementia, in an evidence-informed policy context, and to enhance the local capacity to undertake high quality research relevant to dementia care. The successful bid led to the allocation of £2million to the programme in 2013, under the Atlantic Philanthropies Older People's Programme¹. A key focus of this programme is to improve the quality of health care for those with dementia in NI by providing evidence-based approaches to inform policies and practices both in NI and on a global scale. The aim of the Research Programme in Dementia Care is to ultimately lead to direct improvements in patient care and systemic changes in the way services are commissioned and delivered.

1.1.2 Identification of research priorities

To identify the most salient research priorities in dementia care in NI, the HSC R&D Division conducted a consultation with key stakeholders including service users, health professionals and commissioners in liaison with the DSIG in May 2013. This consultation exercise used initial topics identified by a national priority setting exercise led by the James Lind Alliance and the Alzheimer's Society (refer to Appendix 1 for James Lind Alliance priorities). This list was used by the HSC R&D Division to derive a locally agreed priority list of topics on which robust evidence was currently unavailable (refer to Appendix 1 for topics). Via an electronic priority setting list, key stakeholders were asked to prioritise five topics in order of importance which they thought were most salient to the care of patients with dementia and their carers in NI. In total, 30 responses were received. The most frequently mentioned topics were then used to inform the research call. The Programme focused on six research priorities within a NI context in the field of dementia care as highlighted below:

- Staff and staff training;
- Quality of care;
- Co-ordination of care;
- Information and communication;
- Management of behaviours; and
- Management of symptoms

¹ Atlantic Philanthropies, Ageing <http://www.atlanticphilanthropies.org/ageing-northern-ireland>

The programme sought to fill these evidence gaps by commissioning substantive research projects using methodologies proposed by teams of local researchers, policy makers and clinical and academic experts to make direct improvements in patient care and systemic changes in the way services are commissioned and delivered. Two calls were issued for proposals, the first in June 2013 in which eight applications were submitted, three of which were awarded funding (£987,228.52 awarded in total). The second call was issued in February 2014, again eight applications were received and four were awarded funding (£1,282,651 awarded in total).

Terms of Reference

The overall aim of the project, as set out in the Terms of Reference, was to 'evaluate the Research Programme in Dementia Care.' Table 1.1 below provides an overview of the Terms of Reference and the relevant sections where these are addressed within this report:

Table 1.1 Terms of Reference

Terms of Reference	Report section
Inter-disciplinary and inter-sectoral relationships developed as a result of joint research projects	4.2.1 Relationships
Capacity built to continue applied dementia care research in NI and attract alternative funding	4.2.3 Capacity
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Degree to which the findings of research projects have influenced dementia care and support services delivered by Government and have the potential for future influence	4.3 Influences on service delivery, policy and health & wellbeing

The requirements for RSM were to evaluate the Programme across a four-year period and to produce reports for each year. This document represents the Final Report.

Methodology

The methodology for the final report involved the following stages:

- A desk top analysis of key documentation relating to the Research Programme;
- Telephone and face to face consultations with the Principal Investigators (7) and members of the research teams (7);
- Telephone and face to face consultations with strategic stakeholders (14) and key staff from HSC R&D Division (2); and
- Post launch event survey (38 responses).

In February and March 2019 RSM conducted interviews with research team members and wider stakeholders. Participants were asked questions on a number of aspects of the Research Programme including any outcomes and impacts which may have been demonstrated. Not all questions were asked to all participants. (see Appendix 2 for discussion document)

Responses have been aggregated to preserve the anonymity of the respondents. In order to distinguish between participants who were actively involved in the research, and those who were part of the wider stakeholder group, the following terms will be attributed to comments

- **Research team** – (Principal Investigators, co-investigators, research assistants and the wider research team)
- **Wider stakeholders** – (PPI representatives, external partners, commissioners and Trust representatives)

1.1.3 Hanney Payback Framework

The model used for the evaluation over the four-year period was based on the Hanney Payback Framework. This is a tool designed to measure the impact of health R&D funding and has been used extensively in a number of Health and Social Care research projects. It assesses the impact of research against five categories:

- Knowledge;
- Benefits to future research and research use;
- Benefits from informing policy and product development;
- Health and health sector benefits; and
- Broader economic benefits.

The Hanney framework can be found in Appendix 4

1.1.4 Northern Ireland Strategy and policy documents

A key factor in the development of all aspects of HSC services and Department of Health, Social Services and Public Safety (DHSSPS) policies is R&D. There are a wide range of regional, national and international policy and strategic documents which are relevant to the Research Programme in Dementia Care.

The documents reviewed highlight the need for more research into dementia and the need to build dementia research capacity in NI. Table 1.2 shows the documents reviewed, a more complete overview can be found in appendix 5.

Table 1.2 Northern Ireland Strategy and policy

NI Policy / Strategy	Relevance to Research Programme in Dementia Care
DHSSPSNI (2016) Health and Wellbeing 2026 - Delivering Together ²	The Delivering Together report notes that the current structures to deliver health and social care services in Northern Ireland are unsustainable to continue delivering a world class health system, with an ageing population noted as one of the challenges This report notes that to realise a new model of person-centered care it essential to make better use of technology and data, and highlights that a programme of work to improve the use of health analytics, focused on dementia patients will start in 2017. The report lists 18 actions that should be implemented, including the development of a patient portal for dementia patients.
DHSSPSNI (2011) 'Improving Dementia Services in Northern Ireland: A Regional Strategy' ³	This strategy made a number of key recommendations regarding the promotion of dementia research. It concluded that research is needed in three main areas: cause, cure and care and that there is a need for a coordinated approach to research, pooling talents and resources.
DHPSSNI (2011) 'Transforming Your Care': A Review of Health and Social Care in Northern Ireland ⁴	This report made reference to number of key areas to address in regard to dementia care: <ul style="list-style-type: none"> • Improve regional standards of care, especially for dementia

² DHSSPS (2016) Health and Wellbeing 2026 – Delivering Together [online] <https://www.health-ni.gov.uk/sites/default/files/publications/health/health-and-wellbeing-2026-delivering-together.pdf>

³DHSSPS (2011) Improving Dementia Services in Northern Ireland: A Regional Strategy <https://www.health-ni.gov.uk/publications/improving-dementia-services-northern-ireland-regional-strategy>

⁴ DHSSPS (2011) Transforming Your Care: A Review of Health and Social Care in Northern Ireland [online] <http://www.transformingyourcare.hscni.net/wp-content/uploads/2012/10/Transforming-Your-Care-Review-of-HSC-in-NI.pdf>

NI Policy / Strategy	Relevance to Research Programme in Dementia Care
	<ul style="list-style-type: none"> • Need for greater provision of services for older people at home and in the community - the decline in the number of nursing homes is not matched with the growth in cases of dementia <p>More support in the community is needed, and an effective model of care needed to speed up hospital admission time.</p>
DHSPSSNI (2013) Service Framework for Older People ⁵	This framework aims to improve the health and social well-being of older people in Northern Ireland, to promote evidence-based practice, to safeguard vulnerable individuals and groups and to enhance multidisciplinary working
Ministerial advisory group on dementia (2011) ⁶	<p>This advisory group identified areas in which dementia research needs improved/how it should be focused:</p> <ul style="list-style-type: none"> • Collaboration is needed between the public and commercial research sectors with greater mutual transparency • The established aim to embed the delivery of research across the full care pathway and in all service sectors • Opportunities for quality scientists from contiguous fields and a strengthened research leadership is needed • To increase the success of the dementia research community in competitive funding contexts and improve the coordination between funders on priorities for dementia research • To extend public engagement in dementia research
DHSSPSNI (2016) Research for Better Health and Social Care Strategy (2016-25) ⁷	This strategy aims to improve the health, wellbeing and prosperity of the Northern Ireland population through excellent, world-renowned R&D in health and social care that is led from NI.
The Northern Ireland Dementia Learning and Development Framework (2016) ⁸	The Northern Ireland Dementia Learning and Development Framework 2016, outlines the knowledge and skills health and social care staff need to respond to the needs of people living with dementia. The framework aims to standardise education in dementia care to ensure consistency in standards and approach for all health and social care staff.
DHSSPSNI (2015) Personal and Public Involvement (PPI) Guidelines ⁹	Since this guidance was issued, the legislation for the Health and Social Care (Reform) Act (Northern Ireland) 2009 ('the Reform Act') was enabled. The Reform Act places a statutory duty of public involvement and consultation on Health and Social Care organisations. Therefore, organisations have a statutory duty to involve service users, carers and the public in the commissioning, planning and delivery of all Health and Social Care (HSC).

⁵ DHSPSS (2013) Service Framework for Older People [online] <https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/service-framework-for-older-people-full-document.pdf>

⁶ Department of Health (2017) Ministerial advisory group on dementia research [online] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215558/dh_127904.pdf

⁷ DHSSPS (February 2016) Research for Better Health and Social Care: A Strategy for Health and Social Care Research and Development in Northern Ireland (2016-2025) [online] <https://www.health-ni.gov.uk/publications/research-better-health-and-social-care-strategy-2016-25>

⁸ NI Executive / Dementia Together NI / HSC Board (2016) The Dementia Learning and Development Framework [online] http://www.hscboard.hscni.net/download/PUBLICATIONS/dementia/26092016_Learning_Development_Framework.pdf

⁹ DHSSPSNI (2015) Personal and Public Involvement Guidelines [online] <https://www.health-ni.gov.uk/publications/personal-and-public-involvement-pi-dhssps-guidance-hsc>

NI Policy / Strategy	Relevance to Research Programme in Dementia Care
Alzheimer's Society (2016) Assessing cognition in older people: a practical toolkit for health professionals ¹⁰	The Alzheimer's Society have produced a toolkit – developed by an expert writing group and supported by Department of Health. It is aimed to help health professionals determine the most appropriate cognitive assessment tool for use with patients in their setting. Measuring someone's cognitive function is an important assessment clinicians make, particularly those in old age psychiatry and geriatric medicine, and is key to detecting dementia and delirium. Cognitive assessments cover a very broad range of activities
Public Health Agency (2014) Strategy for Personal and Public Involvement in HSC Research ¹¹	Local and national policy increasingly emphasises the central role of service users and the public in shaping Health and Social Care (HSC) Organisations now have a statutory duty to involve users and the public then they are commissioning, planning and delivering HSC services, this is known as Personal and Public Involvement (PPI). This allows individuals to be included in decisions about their specific care or treatment. The public and wider community can also be consulted on the design, delivery and location of local services. Effective PPI is central to the delivery of safe, high quality services and, as such, is a key element of clinical and social care governance.

Table 1.3: Other relevant policy, strategies and research (national/ international)

Other relevant policy, strategies and research	Relevance to Research Programme in Dementia Care
UN (1991) Principles for Older Persons ¹²	These principles should be considered by all organisations and regarded as a framework for policy. The United Nations Principles for Older Persons were adopted by the UN General Assembly (Resolution 46/91) in December 1991
NICE Guidelines (2018) Dementia: Assessment, Management and Support for people living with dementia and their carers ¹³	This document identified key areas for implementation in areas including non-discrimination, valid consent, rights of carers, coordination and integration of health and social care managers and treatments and services provided.
Alzheimer's Research UK (2012) Defeating Dementia Building Capacity to Capitalise on the UK's Research Strengths ¹⁴	Research was conducted to identify the quality and quantity of time spent on dementia research. It identified that capacity in terms of the number of researchers is low, particularly when compared to other major disease areas. It was estimated the ratio of researchers working on dementia to those working, for example, on cancer is roughly 1:6.
Mental Capacity Act (Northern Ireland) (2016)	This Act (2016) has yet to be enacted. The Act will be a significant step forward for promoting the dignity, autonomy and human rights of citizens, to combine both mental health and mental capacity law. The Act will ensure that if a person has capacity, they can make decisions about their medical treatment even if they have a mental health condition. In addition, the Act provides a framework for making decisions on behalf of people who lack capacity and uses the principle of best interests to guide this.

¹⁰ Alzheimer's Society (2015) Assessing cognition in older people: a practical toolkit for health professionals [online] https://www.alzheimers.org.uk/download/downloads/id/3475/alzheimers_society_cognitive_assessment_toolkit.pdf

¹¹ PHA (2014) Strategy for Personal and Public Involvement in HSC Research [online] <https://www.publichealth.hscni.net/directorate-nursing-and-allied-health-professions/allied-health-professions-and-personal-and-public-5>

¹² UN (1991) Principles for Older Persons [online] <http://www.un.org/documents/qa/res/46/a46r091.htm>

¹³ NICE Guidelines (2018) Dementia: assessment, management and support for people living with dementia and their carers [online] <https://www.nice.org.uk/guidance/ng97>

¹⁴ Alzheimer's Research UK Defeating dementia, building capacity to capitalise on the UK's research strengths http://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/ARUK_Defeating_Dementia_-_Building_capacity_to_capitalise_on_the_UKs_research_strengths.pdf

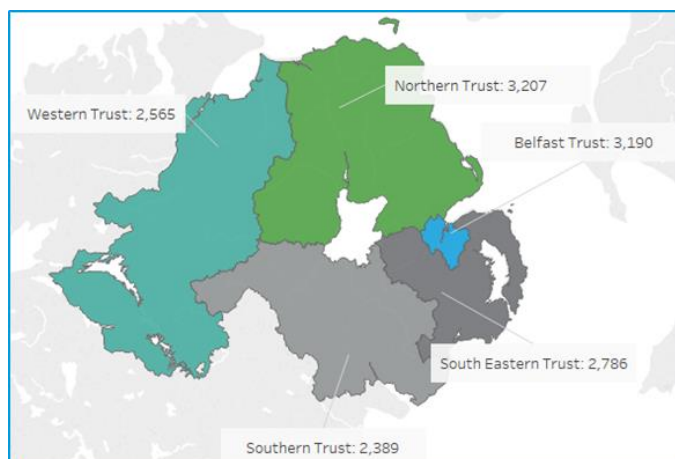
Since the last report, the documents referenced in Table 1.2 have not been updated (with the exception of the Research for Better Health and Social Care Strategy and the publication of Delivering Together). This is due to a lack of Government in NI meaning that no new policies or legislation have been enacted, in particular the Mental Capacity Act.

However, there have been updates to the palliative care guidelines. A second phase of work has begun, focusing on e-health on data analytics, which has been funded by Atlantic Philanthropies. This phase started approximately 18 months ago and involves working with HSC Trusts and researchers to build databases with accessible, clean data so that staff and researchers can access them, use them to inform service delivery and identify research gaps.

1.1.5 Statistical Indicators of Dementia in Northern Ireland

To contextualise the need for research in dementia care, the following section provides an overview of the key, macro level statistics. The number of patients registered with dementia across all HSC Trusts has increased every year in NI from 2010 to 2018 from 10,637 to 14,137, an increase of 33%.

Figure 1.1 Number of patients registered with Dementia in Northern Ireland in 2018



The Western HSC Trust had the largest increase of patients registered with dementia with an increase of 56% from 2010.

Source: Northern Ireland: Department of Health; 2017/2018 raw disease prevalence trend data for Northern Ireland

Figure 1.2 Number of patients registered with Dementia by GP practice in Northern Ireland in 2018



In 2018, the lowest number of dementia patients registered per practice was four, and the largest number was 177. This has increased since 2017 when the lowest number of patients registered was two and the largest was 162. The East of Northern Ireland, which encompasses the Northern HSC Trust and Belfast HSC Trust has the largest number of patients.

Source: Quality and Outcomes Framework General Practice Northern Ireland 2018

Table 1.3 Estimated current and projected number of people living with dementia and/or a diagnosis by Health and Social Care Trust

Estimated current and projected dementia diagnoses	Belfast Trust	Northern Trust	South Eastern Trust	Southern Trust	Western Trust	Total
Number of people with a dementia diagnosis in 2018	3,190	3,207	2,786	2,389	2,565	14,137
Estimated total number of people living with dementia in 2021 (with & without diagnosis)	4,315	6,848	5,335	4,677	3,805	24,980
Number who will have a diagnosis in 2021	2,969	3,531	3,051	2,834	2,473	14,858
Number of people without a diagnosis in 2021	1,346	3,317	2,285	1,843	1,332	10,123
% of diagnosis in 2021	69%	52%	57%	61%	65%	59%

Sources: Alzheimer's Research UK Northern Ireland Diagnosis Rates¹⁵ & Northern Ireland: Department of Health; 2017/2018 raw disease prevalence trend data for Northern Ireland.

The Alzheimer's Society estimates that by 2021 there will be almost 25,000 people living with dementia in NI, compared to 14,858 people who are expected to have a diagnosis in 2021, representing a dementia diagnosis rate of 60%. The projected number of people living with dementia is set to increase in the coming years and Table 1.3 illustrates the disparity between individuals with dementia who receive a diagnosis and those with dementia who are not diagnosed. The variation in local diagnosis rates has been well documented and suggested reasons for variation have included waiting times for diagnostic tests, lack of awareness and attitudes towards dementia.¹⁶

Structure of the report

The report is structured as follows

- Section 2: Overview of the Research Projects
- Section 3: Effectiveness of the Research Programme processes
- Section 4: Impacts from the Research Programme
- Section 5: Other findings
- Section 6 Conclusions and recommendations

Acknowledgments

The evaluation team would like to thank the staff in the HSC R&D Division for providing the necessary information to complete the research, Dr Brendan Murtagh and the Consultees who took the time to complete the interviews and survey over the course of the four years.

¹⁵ <https://www.dementiastatistics.org/statistics/diagnoses-in-the-uk/>

¹⁶ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/april-2015/living-dying-dementia-ni-full.pdf>

2 OVERVIEW OF RESEARCH PROJECTS

Introduction

This chapter looks at the projects which were successful in securing funding from the Research Programme, with information on dissemination activities and project costs. For further details on the application process please see chapter 3.

Successful Projects

Overall, seven projects were awarded funding under this programme of research following evaluation by an external panel of international experts. Table 2.1 provides an overview of the seven successful projects and the research priorities the projects relate to.

Table 2.1 Successful projects

	Project	Aim	Research Priority
1	Pain assessment and management for patients with advanced dementia nearing the end of life	The study aims to examine the main issues in pain assessment and management of patients in NI. The research will be used to identify model(s) for the assessment and management of pain nearing the end of life tailored to the setting of care (patient's home; nursing home).	Management of symptoms
2	Risk Communication in Dementia Care	The overall aim of this project is to develop better ways to support families in managing risks to help people living with dementia stay in the community for longer.	Information and communication
3	Promoting informed decision making and effective communication through advance care planning for people with dementia and their family carers	The overall aim of this project is to evaluate the application of a best practice Advance Care Planning model for individuals living with dementia in nursing homes and to ultimately move towards the development of practice in nursing homes that will support family carers in decisions and promote person-centred care for individuals living with dementia	Information and communication
4	The development of a comprehensive medicines management approach for persons with dementia	The ultimate aim of this project is to develop an approach in which GPs; community pharmacists, people living with dementia and their carers can work together to improve medicines management	Management of symptoms
5	A feasibility study of facilitated reminiscence for people with dementia	This study aims to assess whether reminiscence is a satisfactory criterion that can help alter behaviour, ultimately improving quality of life and care for people living with dementia and their carers.	Staff training Quality of care Co-ordination of care Information and communication Management of behaviours Management of symptoms

	Project	Aim	Research Priority
6	Technology enriched supported housing – a study into the lived experience of older people with dementia and their carers	The aim of this project is to examine supported housing schemes for people with dementia, looking at what can be improved and what can be changed so individuals are better informed about supported housing as an alternative arrangement for living in the community.	Quality of care
7	The evaluation of a Healthcare Passport to improve quality of care and communication for people living with dementia (EQuIP)	The aim of this project is to examine the effectiveness of a healthcare passport as a communication tool for people living with dementia.	Information and communication Co-ordination of care

It should be noted that from desk review and interviews, it was identified that only one of the seven projects did not reach its intended research goals due to factors/ difficulties at an early stage of the project. However, the research team were able to publish their early findings and have drawn learnings from the study to influence potential future research.

2.2.1 Monitoring of projects

HSC R&D Division monitored the projects on an ongoing basis and required PIs to submit an annual progress report. Details required in the annual progress report include:

- Summary of research for lay audience;
- Description of progress to date in achieving research objectives;
- Description of outputs related to the Award, including publications, presentations, training opportunities; other awards/grants obtained, indicators of prestige awarded to members of research team;
- Personal and Public Involvement in the project;
- Proposed work plan; and
- Impact on practice.

A final report was also required by HSC R&D Division on completion of the project. HSC R&D Division received details of all reports or publications stemming from the research supported by this grant and the support of HSC R&D Division was acknowledged in all publications. Budget monitoring occurred on a quarterly basis and Table 2.2 shows the total expenditure for each project.

Overall, projects were delivered on time and within budget. Interviews found that some extensions to both budgets and timeframes had been negotiated by PIs with the HSC R&D Division, for example to cover maternity leave or extensions pertaining to the ethical approval process. Overall these were well managed, allowing the Programme to remain within its grant limits.

Table 2.2 Project expenditure

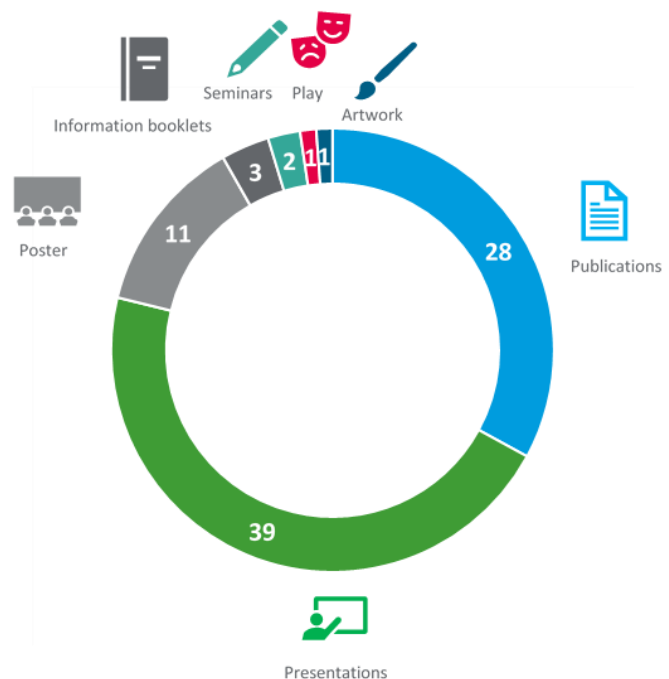
	Project	Grant Awarded	Grant used	Variance (%)
1	Pain assessment and management for patients with advanced dementia nearing the end of life	£320,550	£291,396	£29,154 (9%)
2	Risk Communication in Dementia Care	£251,781	£252,891	-£1,110 (-0.4%)

	Project	Grant Awarded	Grant used	Variance (%)
3	Promoting informed decision making and effective communication through advance care planning for people with dementia and their family carers	£341,215	£321,339	£19,876 (6%)
4	The development of a comprehensive medicines management approach for persons with dementia	£292,922	£322,639	-£29,717 (-10%)
5	A feasibility study of facilitated reminiscence for people with dementia	£278,604	£323,321	£44,717 ¹⁷ (16%)
6	Technology enriched supported housing – a study into the lived experience of older people with dementia and their carers	£385,581	£373,356	£12,225 (3%)
7	The evaluation of a Healthcare Passport to improve quality of care and communication for people living with dementia (EQuIP)	£334,654	£320,598	£14,056 (4%)
	Totals	£2,205,307	£2,205,540	-£233

Programme dissemination activities

Dissemination activities were a requirement for research projects, these activities have been collated from the annual reports, final reports and interviews. Figure 2.1 shows the breadth of activities which have taken place within the Programme. Whilst there have been a number of traditional methods used such as publications, presentations and posters, innovative approaches have also been employed including displays of artwork, a play and seminars with non-professional/ lay audiences. These methods were employed to reach wider audiences and increase inclusion (for a full list of the dissemination activities per project see Appendix 7).

Figure 2.1 Dissemination activities ¹⁸



¹⁷Additional funding was awarded to this project following a recommendation from the panel that the project involve the Clinical Trials Unit and a health economics element. Following their input, the data collection was increased and extended, which was not possible within the original budget

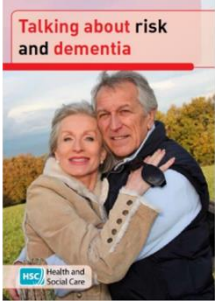

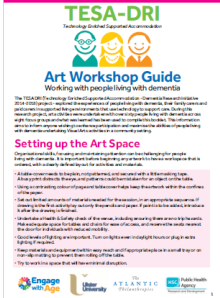
¹⁸ Source: Interviews in Year 4

Programme Impacts

The evaluation assessed impacts of the projects and Programme as a whole through surveys and interviews. A common theme which emerged throughout the Programme was the development in capacity and experience of dementia research in NI through (table 2.3);

- the support of research posts;
- the completion of academic qualifications and promotions;
- the integration of research findings into university course curriculums; and
- the added knowledge and understanding of dementia care in NI
- One of the projects also played an important role in increasing the number of reminiscence facilitators within the Trust

Table 2.3 Some examples of project outputs

Impacts	Examples
<p>Public information leaflets designed to provide practical advice for people living with dementia and their families on making decisions about risk in everyday life.</p>	
<p>Further funding has been secured from the Joint Programme - Neurodegenerative Diseases (JPND) and the Alzheimer's society: Scaling up the Family Carer Decision Support Intervention: A transnational effectiveness-implementation evaluation. Teams across Northern Ireland, England, Canada, Netherlands, Republic of Ireland and Czech Republic will work together to adapt and test the FCDS intervention, so it can be widely put into practice</p>	<p>https://www.alzheimers.org.uk/research/our-research/JPND</p>
<p>Conference Presentations e.g. on Advance Care Planning at the International Conference on Palliative Dementia Care in May 2019</p>	
<p>Successful collaborations with healthcare and charitable organisations established</p>	

Due to the suspension of the NI Executive, there have not been any Departmental Ministers since March 2017. The lack of Ministers means that it has not been possible to implement any new policies or funding initiatives without ministerial sign-off. Whilst some PIs have met with senior civil servants to discuss their research findings this has limited the impact which can be achieved.

Summary

- All seven projects which were awarded funding successfully undertook their research studies. Whilst there was some variance in the level of grant used vs awarded (both positive and negative variances), overall the Programme was delivered on budget.
- Six of the seven studies reached their intended research outcomes, whilst the remaining study was able to partially deliver on outcomes and publications.
- A total of 85 dissemination activities were undertaken, ranging from more traditional publications, posters and presentations through to innovative approaches such as artwork and a play.
- Most projects were able to demonstrate impact in a range of ways, either by supporting research activities, producing resources for patients, carers and families, introducing study findings into training or through new collaborations.

3 EFFECTIVENESS OF THE RESEARCH PROGRAMME PROCESSES

Introduction

This section of the report will look at the successful applications to the Research Programme and will cover;

- The application process;
- The applicant's views on the process; and
- The assessment criteria.

Responses have been aggregated to preserve the anonymity of the respondents. In order to distinguish between participants who were actively involved in the research, and those who were part of the wider stakeholder group the following terms will be attributed to comments

- **Research team** – (Principal Investigators, co-investigators, research assistants and the wider research team).
- **Wider Stakeholders** – (PPI representatives, external partners, commissioners and Trust representatives).

Applications process

An open call for proposals for the Research Programme in Dementia Care was first issued in June 2013. The call was issued through HSC R&D Division's distribution list and through the website. The call closed in September 2013. Eight applications were submitted, three of which were awarded funding (£987,228.52 awarded in total).

To allocate the remaining funding, it was decided that a second call should be issued. This ran from February 2014 and closed in May 2014. It was also advertised through the HSC R&D Division's distribution list and a consultation event was held on 6th March 2014 to provide potential applicants with more detail in relation to the Programme and feedback from stage 1 of the call. Eight people from a range of backgrounds attended. Initially eight applications were received, four of which were awarded funding (£1,282,651 awarded in total). Three of these applications were from applicants who had applied in the initial first stage and were successful in the second stage (one applicant with the same research title and two with a different research title) (Table 3.1).

Table 3.1 Application timeline

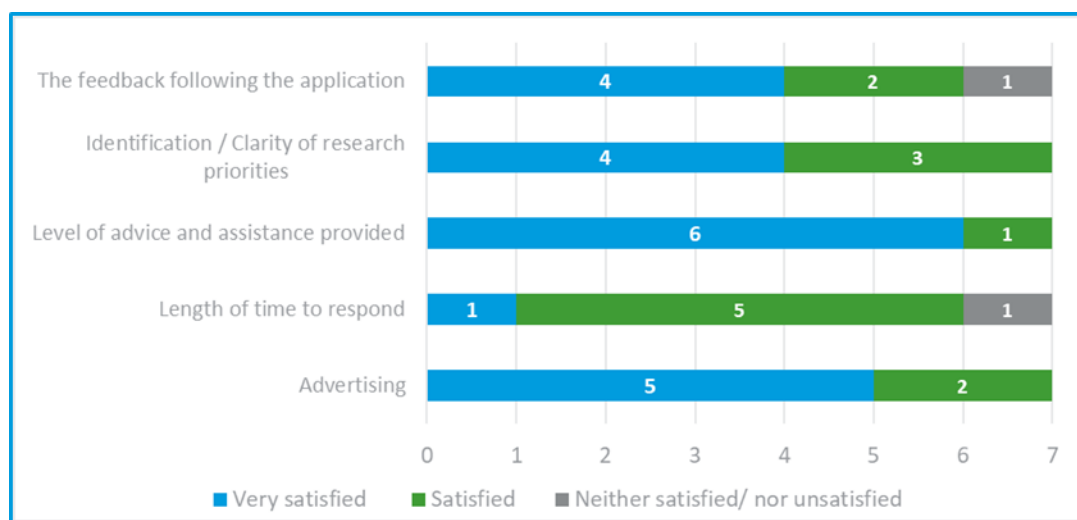
Date	Activity	Outcome
June 2013	Open Call advertised	
September 2013	Call closes	Eight applicants; Three successful. Award amount: £987,228.52
Award amount: £987,228.52		
February 2014	2nd call launched	
6th March 2014	Consultation event held	Eight attendees
May 2014	2nd call closes	Eight applicants; Four successful. Award amount: £1,282,651

The consultation was attended by three (43%) of the Principal Investigators (PIs). Of those who attended the consultation event, all PIs felt it was very well organised and very useful in providing a clearer understanding of the research priorities.

3.1.1 Levels of satisfaction with application process

The majority of the PIs (n=5) believed the call for research proposals was very well organised, whilst a few (n=2) of PIs indicated that they felt the call was somewhat organised¹⁹. Figure 3.1 below provides an overview of the PIs' level of satisfaction with aspects of the call for proposals from year 1

Figure 3.1 PI satisfaction with the application process- Year 1



Prior to submitting their application, the majority of PIs (n=6) submitted queries. Of those who submitted queries, all indicated that they were very satisfied with the response provided and the timescale the response was delivered in. A number of PIs highlighted that the support from the HSC R&D Division was excellent and helped significantly during the application process.

Assessment of the applications

All valid applications were subject to peer review by referees selected from those nominated by the applicants and by additional referees allocated by HSC R&D Division. Applicants recommended two peer reviewers and HSC R&D Division chose an additional two. All peer reviewers were external, independent experts who reside outside NI. Following peer review, applications for this programme were evaluated by an external panel of international experts in the field of dementia care, members of the Dementia Strategy Implementation Group (DSIG) and PPI representatives. Rigorous evaluation criteria were used in order to ensure that the funding was allocated for high quality research projects that were likely to deliver outputs. Members of the external assessment panel are set out in Appendix 6.

Though the PPI representatives were involved in the review process, one did not feel that they had been encouraged to provide opinions on all aspects of the proposal, which they felt would have been beneficial:

'[There was] no opportunity to provide an opinion on a topic – as we work on the ground level and also the panel may have an opinion on it. There has been feedback on the PPI component but not on the proposals.... I struggled only to comment on the PPI aspects of the proposal – I could have given an opinion on the actual research topics being proposed, e.g. the relevance of pain management to life as a carer for someone with dementia' (PPI rep)

Applicants were advised in the specification that their proposals would be evaluated against the criteria highlighted in Table 3.2 below.

¹⁹ Source: Year one report

Table 3.2 Assessment criteria for applications

Area	Criteria
Policy relevance	<ul style="list-style-type: none"> Does the proposed research study address one or more of the research topics within the NI context?
Innovation and novelty of research proposal	<ul style="list-style-type: none"> Does the proposed research study make a relevant contribution to the existing knowledge-base?
Knowledge of area and understanding of key issues	<ul style="list-style-type: none"> Does the applicant(s) demonstrate adequate knowledge of their chosen area? Does the applicant(s) demonstrate an understanding of the key issues?
Quality of the proposal	<ul style="list-style-type: none"> Are the aims and objectives/research questions clearly stated? Is the proposed methodology adequate and appropriate? Is the project planning adequate? Is the envisaged outcome likely to be achieved? Have the dissemination and implementation of results been addressed? Has a suitable plan for knowledge transfer been developed?
Track record/experience of research team and suitability of environment	<ul style="list-style-type: none"> Do the applicant(s) have relevant experience in the chosen area? Do the applicant(s) have a suitable track record? Is the environment suitable to support the proposed research? Does the application demonstrate adequate collaboration between sectors and organisations?
Value for money	<ul style="list-style-type: none"> Does the proposed research represent value for money?
Personal Public Involvement	<ul style="list-style-type: none"> Have the applicants demonstrated that they have sought to include service users and the public, including from appropriate groups, in a partnership role in the research process rather than solely as research participants? Is the level of PPI appropriate and justified? Does the proposal demonstrate an understanding of the benefits of PPI? Does the applicant aim to incorporate PPI in the reporting/dissemination of the study?
Dissemination / Knowledge Transfer	<ul style="list-style-type: none"> Does the protocol include satisfactory plans for dissemination and Knowledge Transfer?

Evaluation panel members were asked to score the application per the scale outlined below:

- 1-2: Well below required standard;
- 3-4: Fair, but below required standard;
- 5-6: Meets required standard;
- 7-8: Above required standard; and
- 9-10: Well above required standard

Patient and Public Involvement

As part of the application for funding, all PIs were required to demonstrate how their research would include Personal and Public Involvement (PPI)²⁰. The purpose of the PPI was to include people living with dementia (including their carers) as partners in the research, to ensure that they were involved in the design of studies and the outcomes being measured.

The PIs provided information on how people living with dementia and their carers were involved in the design, implementation and dissemination of the research. In addition, the PIs have highlighted that the PPI activities have had a positive impact upon the delivery of, and outcomes from, the research. Areas where people living with dementia inputted to research included:

- Development of data collection tools;
- Peer researchers assisting with the collection of data;
- Assisting with recruitment of other representatives – one PPI contact provided close contacts with carers groups and partner organisations to gain support;
- Providing insights from the carer's perspective; and
- Assisting with understanding the potential value of a healthcare passport.

Specific benefits of including PPI in the research reported by the PIs included:

- Ability to work directly with people living with dementia;
- People living with dementia were recruited to review data collection tools, their feedback helped to keep the tools grounded, user-friendly and meaningful;
- Personal experience and insight given by PPI representative; and
- Development of a more user-centered experience addressing literature gaps with regards dementia patient involvement in research analysis.

Recruitment of people living with dementia

As part of the studies, all PIs recruited people living with dementia to look at the impact of their interventions on the lives of those with dementia and their families and carers as research participants.

Some of the research teams did not experience any issues with recruitment or involvement. Teams appeared to find the recruitment process more straight forward when they were associated with an organisation who had already had groups available.

'Due to the Alzheimer's Society it was very easy to join the meeting of carers and make contact.' (research team)

'Alzheimer's Society were key and did their best to facilitate with PPI.' (research team)

'The main facilitator of PPI activity was Dementia NI as a promoter of this.' (wider stakeholder)

Other teams had challenges with recruitment of participants;

'It was difficult to set up meetings with elderly people as they were sometimes in and out of the hospital or just unable to attend.' (research team)

²⁰ Personal and Public Involvement (PPI) is the active and meaningful involvement of service users, carers and the public in Health and Social Care (HSC) services. See reference to Strategy.

‘There were also ethical issues as this population is vulnerable due to their cognitive impairment, it is challenging to know what they are able to give their consent to and commit to.’ (wider stakeholder)

Some expressed that the process of consent could be challenging, and the nature of dementia meant that the participant’s condition could rapidly change. Table 3.3 provides an overview of the study populations within each of the projects.

As shown in the table below, nearly 1,000 patients, members of public staff or other stakeholders were involved across the seven projects as subjects in the studies. The prescribing data of a further 6,826 patients were also reviewed for one of the studies.

Table 3.3 Study populations for each Research Project

Project Title	Study Participants
Risk Communication in Dementia Care	17 people living with dementia, 22 carers, 160 community professionals
Pain Assessment and Management for Patients with Advanced Dementia Nearing the End of Life	Patient and public involvement representative Dr Hilary Buchanan. 3 bereaved carers, 23 doctors, 24 nurses and 14 healthcare assistants. 5 TeleECHO clinics and pre-clinic=119 staff
Promoting Informed Decision Making and Effective Communication through Advanced Care Planning for People Living with Dementia, and their Family Carers	197 family carers across 24 nursing home sites, 10 nursing home managers and 1 ACP facilitator
Evaluation of a Healthcare Passport for people living with dementia	26 patients and 25 carers followed longitudinally and 5 GPs +2 service user engagement groups
A feasibility study of facilitated reminiscence for people with dementia	60 patients and carers (30 dyads)
The development of a comprehensive medicine’s management approach for persons with dementia in primary care	Prescribing data reviewed for 6 826 persons identified on EPD. Interviews with 18 patients, 5 carers, 15 GPs and 15 community pharmacists
Technology enriched supported housing – a study into the lived experience of older people with dementia and their carers	Records of 243 tenants in 9 TESA facilities were reviewed. Interviews with 25 tenants, 25 informal carers and 21 formal carers. 64 tenants took part in focus groups across 8 facilities
Total involved	926 participants were substantively involved and a further 6,826 participants were involved via the prescribing database

Obtaining ethical and research governance approval for the research

Research governance and ethical approval were required for all the research projects to be able to conduct research with people living with dementia to ensure the quality of the research and to protect the rights, dignity, safety and wellbeing of those involved. The Office for Research Ethics Committees Northern Ireland (ORECNI) provided ethical approval for many of these projects and in some instances, projects also sought ethical approval from their university ethics committee. Research governance approval was also required by the individual HSC Trusts in which they were conducting their research.

There were a number of research teams who found the ethical and research governance approval processes challenging and time-consuming. It was apparent that while there was some confusion about the difference between the two approval processes, both had led to difficulties for some of the research teams due to perceived gatekeeping. Three projects indicated that the approval processes led to delays in their project timelines;

'Ethics was very challenging to put into place, it really delayed the start of the project and at one point put the project at risk.' (research team)

'[there was a] lack of understanding from ethics committees that people living with dementia have the right to make decisions and have their voice heard.' (research team)

There was the perception that the ethical approval processes were not appropriately set up to deal with research of this nature which led to issues in gaining approval;

'[Ethics] was challenging and very time consuming...by definition, we are dealing with vulnerable people whilst the ethics committee is largely dealing with non-vulnerable groups...I'm getting used to the caution, challenge and questions, but what would help is if the ethics committee ensured that there was a professional Social Worker on each committee.' (research team)

'People hold on to traditional view that people living with dementia cannot take part. Ethics doesn't help, it is very paternalistic and starts off from the view point that research will do harm and they are the protectors. Ethics really needs to be reviewed as it has become so process driven the default position it to say no.' (research team)

'If there is going to be continued funding of this type research then the ethics frameworks really need to be addressed, otherwise there is the danger of wasting a lot of money.' (research team)

Some of the interviewees felt that the approval processes needed to be reviewed and research commissioners need to be made aware of the challenges that researchers face.

Summary

- Overall the application process ran smoothly - two calls were required to generate the necessary level of responses and quality of submissions. Feedback has been very positive, and the HSC R&D Division was found to be helpful in addressing queries.
- All projects involved patients and public, including people living with dementia who were involved in a range of ways. Most involvement has been fairly traditional (e.g. providing insights from PPI perspective) however, there has also been some co-production activities e.g. helping with data collection and analysis. In total the seven research projects involved nearly 1,000 patients, members of the public, staff or wider stakeholders and over 6,000 were also involved via the prescribing database.
- Getting ethical and research governance approval was a challenge for many of the research teams and some viewed that enhancing understanding of the subject area amongst ethics and research governance committees would be helpful.

4 IMPACTS FROM THE RESEARCH PROGRAMME

Introduction

This section of the report will look at the impacts from the Research Programme and will cover;

- the dissemination activities of the projects;
- the launch event;
- the benefits to future research; and
- the influences on policy, service delivery and health and wellbeing.

Increasing Knowledge

4.1.1 Approaches to dissemination

There have been a number of approaches to disseminate the research and any emerging findings. The most commonly used method to disseminate information was via presentations at conferences and papers published in journals. The number of publications per project so far are highlighted in table 4.1, with some example papers.

Table 4.1 Publications

Project Title	Number of Publications	Journals
Risk Communication in Dementia Care	7	The International Journal of Social Research and Practice ²¹ - 2016, 2017 & 2017 Health, Risk and Society ²² - 2016, Journal of Risk Research-2016 British Journal of Social Work- 2016 Health and Social Care in the Community- 2017
Pain Assessment and Management for Patients with Advanced Dementia Nearing the End of Life	5	Palliative Medicine ²³ -2016 & 2018 Journal of Clinical Nursing 2-017 BMC Palliative Care- 2017 BMC Health Services Research 2018
Promoting Informed Decision Making and Effective Communication through Advanced Care Planning for People Living	6	The Journal of Nursing Home Research ²⁴ - 2015,2016 Journal of Advanced Nursing ²⁵ -2017 Palliative medicine- 2016,2016 & 2018

²¹ Stevenson, M., McDowell, M. E., and Taylor, B. J. (2016). Concepts for communication about risk in dementia care: A review of the literature. *Dementia: The International Journal of Social Research and Practice*. Advance Online Publication. doi: 10.1177/1471301216647542

²² Stevenson, M., Taylor, B. J. and Knox, J. (2016). Risk in dementia care: searching for the evidence. *Health, Risk and Society*, 18(1-2), 4-20. doi: 10.1080/13698575.2015.1119256

²³ De Witt Jansen, B, Brazil, K, Passmore, P, Buchanan, H, Maxwell, D, McIlfatrick, SJ, Morgan, SM, Watson, M & Parsons, C 2017, "There's a Catch-22". *The complexities of pain management for people with advanced dementia nearing the end of life: a qualitative exploration of physicians' perspectives' Palliative Medicine*, vol 31, no. 8, pp. 734-742. DOI: 10.1177/0269216316673549

²⁴ Carter, Gillian, McLaughlin, Dorry, Kernohan, WG, Hudson, Peter, Clarke, Mike, Froggatt, Katherine, Passmore, Peter and Brazil, Kevin (2016) *Transitions Experienced by Carers on the 'Living-Dying' Journey of a Relative with Dementia*. *Palliative Medicine*, 30 (6).

²⁵ Carter, G., McLaughlin, D., Kernohan, G., Hudson, P., Clarke, M., Froggatt, K., Passmore, P., Brazil, K. (2017). The experiences and preparedness of family carers for best interest decision-making of a relative living with advanced dementia: A qualitative study. *Journal of Advanced Nursing*.

Project Title	Number of Publications	Journals
with Dementia, and their Family Carers		
Evaluation of a Healthcare Passport for people living with dementia	1 1- awaiting publication	BMC.Health Services Research-2016 ²⁶
A feasibility study of facilitated reminiscence for people with dementia	6	Dementia ²⁷ - 2018, 2018 &2017 JMIR mental health-2018 ²⁸ International Journal of Older People Nursing-2017
The development of a comprehensive medicine's management approach for persons with dementia in primary care	2 2- awaiting publication	The Journal of Alzheimer's Disease- 2016 ²⁹ Age and Aging- 2018
Technology enriched supported housing – a study into the lived experience of older people with dementia and their carers	1 1- under review 1- awaiting publication.	Dementia- 2017 ³⁰
Total	28 + 5 pending	

Information on publications was gathered from the publications listed in the final reports, QUB & UU Research portal pages³¹ and Research Gate.

Over the period from grant award until March 2019, the conferences, presentations, discussions and meetings given by the PIs had taken a variety of locations at the international, national and regional level which included;

- **Regional / national level:** Dementia NI; Dementia Together NI; The Alzheimer's Society; The Reminiscence Network Northern Ireland; Ulster University; Queen's University Belfast; Dementia Strategy Implementation Group; The Dementia Innovation Lab, which is organised by the Department of Finance and Personnel; HSC NI Dementia Navigators Trust wide meeting; and Western Health & Social Care Trust
- **International level:** The Integrated Care in Dementia symposium; Max Planck Institute (MPI) for Human Development; World Research congress of the European Association for Palliative Care; and Social Work & Social Care Research in Practice conference

²⁶ Leavey, Gerard et al. "The Evaluation of a Healthcare Passport to Improve Quality of Care and Communication for People Living with Dementia (EQuIP): A Protocol Paper for a Qualitative, Longitudinal Study." *BMC Health Services Research* 16 (2016): 363. *PMC*.

²⁷ Ryan, Assumpta A., et al. "There is still so much inside": The impact of personalised reminiscence, facilitated by a tablet device, on people living with mild to moderate dementia and their family carers." *Dementia* (2018): 1471301218795242.

²⁸ Laird, Elizabeth A., et al. "Using Mobile Technology to Provide Personalized Reminiscence for People Living With Dementia and Their Carers: Appraisal of Outcomes From a Quasi-Experimental Study." *JMIR mental health* 5.3 (2018): e57.

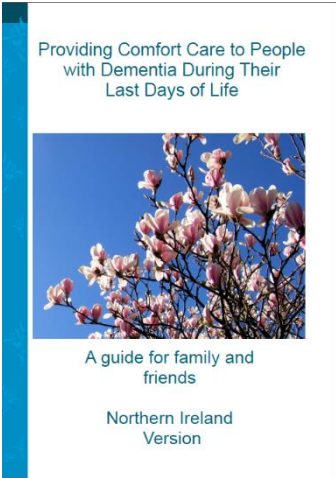
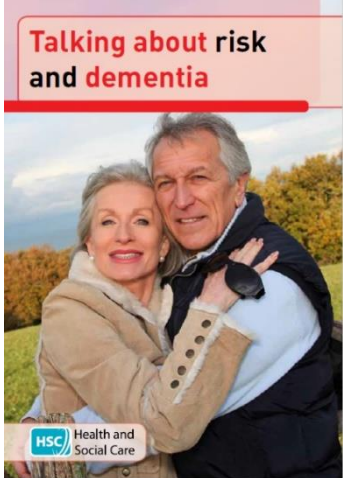

²⁹ Barry HE, Cooper JA, Ryan C, Passmore AP, Robinson AL, Molloy GJ, Darcy CM, Buchanan H, Hughes CM. Potentially inappropriate prescribing among people with dementia in primary care: a retrospective cross-sectional study using the Enhanced Prescribing Database. *Journal of Alzheimer's Disease* 2016; 52(4): 1503-1513.

³⁰ Daly Lynn, Jean, et al. "A systematic review of electronic assistive technology within supporting living environments for people with dementia." *Dementia* (2017): 1471301217733649.

³¹ <https://pure.ulster.ac.uk/en/> , <https://pure.qub.ac.uk/portal/>

Several PIs reported how they used other methods of dissemination than the formal methods described above. These included;

- A podcast on the issue of palliative care and dementia to raise awareness and understanding to aid families and carers.
- Involvement in a number of inter-disciplinary activities which included:
 - Contributing to the research of risks in pharmacy regulators and health communications, to provide a focal point on Dementia, to provide pharmacy technicians with an overview and better understanding of this area of practice.
 - Cochrane database of Systematic Reviews - Palliative care interventions in advanced dementia³².
- Collaboration with a playwright to create a play using the views of people living with dementia and carers. There are plans to stage a play in May and September 2019.
- The production of materials from carers and professionals;
 - The Comfort Care booklet, which has been identified by the World Health Organisation (WHO) as a best practice instrument ³³ (Figure 4.1).
 - The risk communication public leaflet was produced for the public to facilitate discussions between carers and people living with dementia on making choices about risk (Figure 4.2).
- Partnering with an artist who worked with people living with dementia to create pieces of art which explored the perspectives of people living in technology enriched housing (Figure 4.3).

Figure 4.1 Comfort care booklet	Figure 4.2 Risk communication booklet	Figure 4.3 Artwork from group of people living with dementia
		 <p data-bbox="935 1384 1399 1637"><i>In this piece of work the faces were created in the likeness of the tenants. It's representative of how they see themselves and how they would like others to see them. The text flowing around the portraits are quotes taken from the residents when replying to the questions 'What aspects of life are important to you, what makes you happy and feel at home?'</i></p>

³² Froggatt, K., Connolly, S., O'Shea, E., Sampson, E.L., Casey, D., Devane, D. and Murphy, E., 2016. Palliative care interventions in advanced dementia. *The Cochrane Database of Systematic Reviews*, 2016(12).

³³ World Health Organisation, 2011. Palliative care for older people: better practices. Copenhagen: WHO.

4.1.2 Impact of Dissemination activities

From the interviews there were mixed views on the impacts achieved from dissemination activities. Some respondents indicated that the dissemination activity was very impactful and study outputs were of a high quality;

'I take my hat off and have a lot of respect for [PI] in terms of the routine and number of publications and academic outputs from [their] project. This was very strong and there was a real breadth to the dissemination activities.' (research team)

'The activities have met and, in some cases, exceeded the expectations of their impact. The artwork project with people who had dementia in each of the sites, the engagement was excellent.' (research team)

Some of the wider stakeholders expressed that they were unsure of the impacts of the activities and felt that more co-ordination of these activities was required;

'I'm not sure what impact these dissemination activities had.' (wider stakeholder)

'If [the Programme] was being run again they would recommend [having] one person who is an impact officer/dissemination officer.' (wider stakeholder)

Interviewees were asked about their knowledge and awareness of the activities that had been undertaken to disseminate the findings from the Programme/project(s) and any planned events that they were aware of. Some participants found that the funding was not sufficient to cover all the dissemination activities they would have like to partake in;

'It would be really useful to have funding for conferences and papers as conferences are major networking opportunities and where you can begin a collaboration that can help get a big grant.' (research team)

4.1.3 Dissemination via the Programme Launch event

In March 2019 the HSC R&D Division organised a Programme launch event entitled 'Dementia Care Research: Sharing Knowledge for Policy and Practice'. This was an event to showcase the Research Programme and its findings.

There were speakers from a range of backgrounds including; the Chief Medical Officer (CMO) for NI (Dr Michael McBride), the Director of HSC R&D Division (Professor Ian Young), the Social Care Commissioner at the HSCB (Seamus McErlean), Angela Hodgkinson from The Atlantic Philanthropies, Corinna Hammond (PPI Representative) and Principal Investigators from the projects and members of the research teams. The speakers provided strategic context to the programme of research whilst the project PIs or research team members provided an overview of each of the project's aims, methods, results and the outcomes and impacts that their research may have. A summary of the research projects with key recommendations for policy and practice was also disseminated³⁴.

³⁴ HSC R&D Division / The Atlantic Philanthropies (2019) Dementia Care Research: Sharing Knowledge for Policy and Practice [online]
https://research.hscni.net/sites/default/files/Dementia%20Launch%20PROOF%202_1.pdf



Left to right: Dr Gillian Carter (QUB), Ms Corrina Hammond (PPI representative), Dr Gail Johnston (PHA), Ms Angela Hodkinson (AP), Dr Carole Parsons (QUB), Dr Heather Barry (QUB), Professor Gerard Leavey (UU), Dr Janice Bailie (PHA), Professor Suzanne Martin (UU), Professor Assumpta Ryan (UU), Ms Jean Daly-Lynn (Engage with Age) and Dr Michael McBride (CMO).

4.1.4 Post-Event Survey- Dementia Care Research: Sharing Knowledge for Policy and Practice

As part of the wider evaluation, delegates at the event were asked to complete an anonymous survey to gather feedback on the impacts of the Programme. The survey received a total of 38 responses. The most common background for delegates completing the survey were Researchers (37%, n=14) and Commissioners/ Managers (13%, n=5). Figure 4.4 below provides an overview of feedback on each of the Pls' presentations and delegates were asked; to what extent would you agree or disagree with the following statements. The majority of delegates agreed and strongly agreed (74%, n=28) that the Q&A session was useful and informative. There was a very positive response from delegates agreeing and strongly agreeing that the nine presentations were useful and informative, the feedback for agreeing and strongly agreeing ranged from (55% - 89%, n=21-33).

Figure 4.4 survey response: To what extent would you agree or disagree with the following statements on the presentations

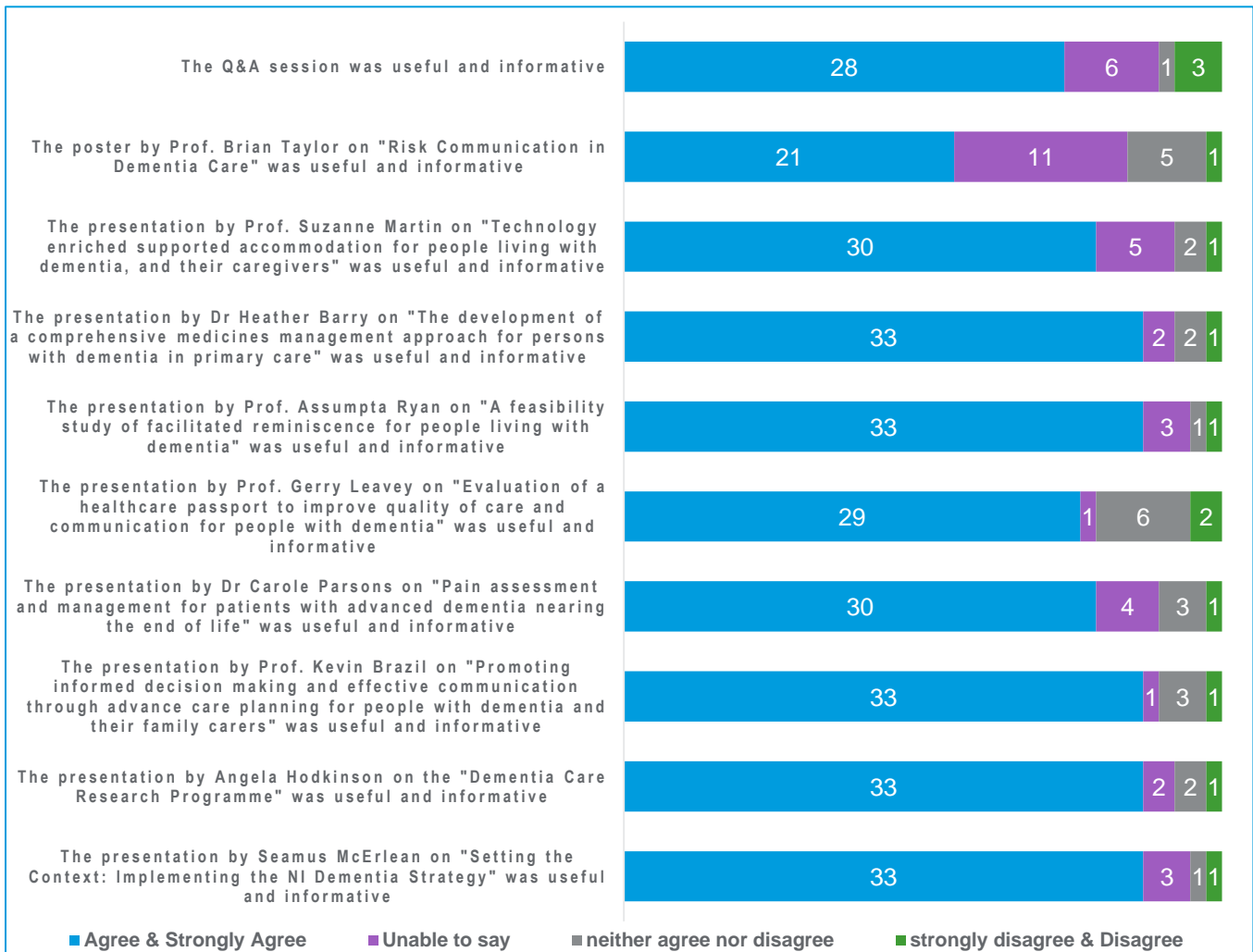
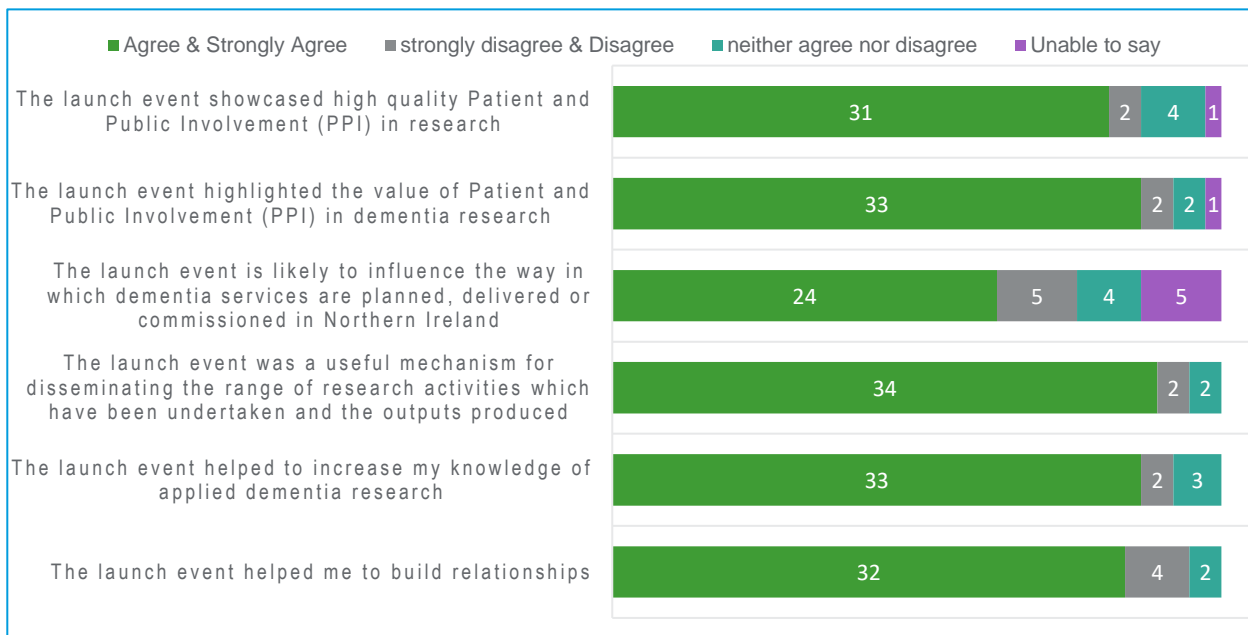


Figure 4.5 provides an overview of the delegates' perceptions on the impact the launch event had on the sharing, dissemination and understanding of dementia care research. There was a very positive response from delegates agreeing and strongly agreeing; (90%, n=34) agreed and strongly agreed that "The launch event was a useful mechanism for disseminating the range of research activities which have been undertaken and the outputs produced".

Figure 4.5 survey response: To what extent would you agree or disagree with the following statements on the impacts of the launch event



4.1.5 Survey final comments

The majority of the comments left by the delegates were positive (n=17) about the event and the programme of research as a whole. Delegates found the opportunities to network and learn more about the project valuable;

'Great to see outcome of important stream of work'

'I thought the launch went very well. It would be great to see some of the technologies progressed and launched. For example, the reminiscence app this is something I think would be beneficial within Dementia care.'

'Well organised and informative event, well done to all involved. Really enjoyed the day and networking collaboration opportunities will be very useful in the future.'

There were some less positive comments, with some expressing that they were not sure how this could be translated into practice;

'It is not very clear what are the research priorities going forward. It is not very clear what opportunities exists to fund further work in the area.'

'I was not convinced that the research will lead to change in health practices'

4.1.6 Future use of the research findings

Interviewees were asked if there were any other ways in which the findings of the research or from the Programme as a whole could be used in the future and what would need to be in place to make this happen.

The themes that emerged were in relation to further development of the research and further funding;

'Findings need to be part of knowledge transfer activities to make an impact – though this would need specific funding.' (research team)

'There are a lot of questions raised which can be explored.' (research team)

'The Passport should be more digitally based. In their experience dementia patients were operating technology and not using paper-based platforms.' (research team)

For some projects, further questions were raised which had not previously been considered. While for others there was the need for further funding to fully explore the findings of the current research.

A further theme which emerged was the need for research to align with the strategic outlook of dementia care and have integration with policy makers

'There should be closer links between what happens in academia and what is happening on strategy, so that the research efforts are recognised and brought into practice.' (wider stakeholder)

Whilst a policy brief was circulated at the launch event and shared on the website, one stakeholder commented that:

'...each research project should produce a policy briefing paper, rather than a big report, which would be more suitable for this intended audience. Each project should identify key targets within the policy sphere.' (wider stakeholder)

From these comments it is clear that there is sometimes a disconnect, real or perceived, between the academic research and the evidence needed to support policy.

Benefits to future research

4.1.7 Relationships

Interviewees were asked to identify if they were aware of the Programme/ project(s) influencing the development of **inter-disciplinary relationships** over the lifespan of the project. Most felt that the research projects and funding has helped to develop relationships further by offering a focused piece of work;

'There has been more cross institute [QUB and UU] working and cross disciplinary [working.]' (research team)

'These [relationships] may have occurred without the project, but the funding allows for something very specific to work on and that means there is a greater chance of these relationships developing. That is the benefit of these types of projects, it gives a very clear focus and some very tangible activities to work on and funding to actually do it, it's this combination that makes it work.' (research team)

Interviewees were also asked if these relationships would have come about without the funding awarded by AP and HSC R&D Division. Some interviewees felt that the funding had played an important role in the development of these relationships;

'[We] would not have had the opportunity to meet these people. Researchers are always somebody you saw the papers from, the end products.' (wider stakeholder)

'[We] needed to have the Programme for these relationships to have taken place.' (research team)

Interviewees were also asked to identify if they were aware of any **Inter-sectoral relationships** developing as a result of the Programme/ project(s). For some, they felt that the project acted as a catalyst for the development of new relationships;

'We would not have got in touch with the [NI] Trust without the project and we would not have created links with the Reminiscence Network.' (research team)

While for others, the funding provided the opportunity to develop pre-existing relationships through a focused piece of work;

'There was existing knowledge, relationships and networks. The added value of the grant was that it provided a platform for a sustained and focused piece of work.' (research team)

'The project certainly strengthened and cemented these relationships.' (wider stakeholder)

Some interviewees felt that due to NI's relatively small size and there only being two main universities, there was already a lot of crossover of research team members and partnership with organisations:

'NI is a small place and some of the teams had people in common. There was an increase in relationships particularly in the voluntary sector, such as the Reminiscence Network.' (wider stakeholder)

'There was definitely a burden on the voluntary sector with seven projects all trying to recruit in a small area such as NI.' (wider stakeholder)

Some of the Organisations involved as partners or collaborators in the programme are shown in the graphic below:



Case study- Max Planck Institute (MPI) for Human Development

How did this relationship come about?

There was a pre-existing relationship with this prestigious Institute, however there had not been collaboration prior to this project.

What happened as a result of this relationship?

The Institute has expertise in words and numbers for risk communication and since this project collaboration has continued

Would this relationship have come about without this funding?

While there was a pre-existing relationship, the funding allowed 3 years of solid partnership working which has strengthened and enhanced the relationship considerably

Case study- UU Computer Science faculty

How did this relationship come about?

Assistance was needed to develop the app used in this project, the computer science faculty could help to build it.

What has happened as a result of this relationship?

The app is being refined and developed further and there is continued work with members of computer science faculty.

Would this relationship have come about without this funding?

Unsure as to whether this relationship would have developed without the funding

4.1.8 Capacity

Interviewees were asked if capacity in dementia care research had been developed in applied dementia research as a result of the funding, particularly considering the relatively low baseline position at the outset of this Programme. The areas in which capacity was thought to have been developed included:

- Training of research team / members of the project team;
- Promotion with research team / full time position;
- Impacts on partners involved; and
- Integration of findings into course curriculum.

There was general agreement from the interviewees that capacity had been built in dementia research;

'The capacity in NI has definitely developed very well through the grant – you can see a lot of it.' (wider stakeholder)

For some of the partner organisations, the Programme encouraged more engagement with this group;

'It has encouraged me to do more with this client group as a result.' (wider stakeholder)

Within the research teams, the funding had also created training opportunities for researchers and had assisted some in the securing of permanent posts;

‘Capacity has been built in dementia research with lectureships awarded to some researchers, enabling them to carry on research in this area.’ (wider stakeholders)

‘There has been development, nurturing and mentoring of the research team, and many have continued with research in this area.’ (research team)

‘...people brought in to work on the project have developed their research skills.’ (research team)

Capacity had also been built in the education of university students. Some research teams have been able to translate their research findings into content for the curriculum of their undergraduate and postgraduate courses;

‘The findings have already been integrated into the teaching of the undergraduate and postgraduate [allied health professional] courses.’ (research team)

Table 4.2 illustrates the number of researchers involved in each project, not all were involved for the full project. Over 60 researchers were involved across the seven projects. We are aware that in a number of instances, that PIs and research team members have continued and further developed their research interest in the area of dementia or related to their original research study. For example, one research team member secured a lectureship, and another is working for an NI Public Sector organisation in the research arena.

Table 4.2 Researchers involved

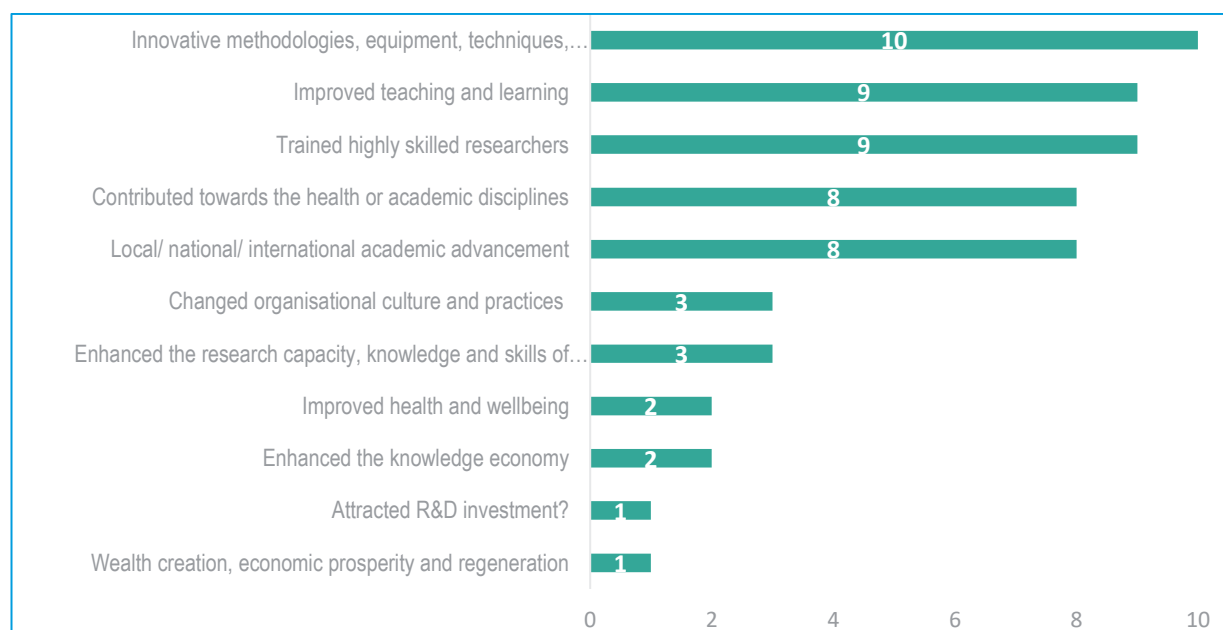
Project Title	Researchers involved	
Risk Communication in Dementia Care	Brian Taylor (PI) Mabel Stevenson Joanne Knox	Michelle McDowell (<i>Max Planck Institute for Human Development</i>) Beverly Savage
Pain Assessment and Management for Patients with Advanced Dementia Nearing the End of Life	Bannin De Witt Jansen Kevin Brazil (<i>PI during CP's Mat leave</i>) Hilary Buchanan Doreen Maxwell	Sonja McIlfratrick Sharon Morgan Peter Passmore Max Watson Carole Parsons (PI)
Promoting Informed Decision Making and Effective Communication through Advanced Care Planning for People Living with Dementia, and their Family Carers	Kevin Brazil (PI) Chris Cardwell Mike Clarke Peter Hudson Katherine Froggart	Dorry McLaughlin Peter Passmore W George Kernohan Gillian Carter David Scott
Evaluation of a Healthcare Passport for people living with dementia	Gerard Leavey (PI) Dagmar Corry (<i>involved for 1 year</i>) Brendan McCormack (<i>involved with design stage only</i>) Bernadine McCrory Sonja McIlfratrick	Stephen Todd Aine Abbot Vivien Coates Max Watson Emma Curran Bethany Waterhouse-Bradley

Project Title	Researchers involved	
A feasibility study of facilitated reminiscence for people with dementia	Assumpta Ryan (PI) Clare McCauley Liz Laird Aideen Gibson Maurice Mulvenna	Raymond Bond Brendan Bunting Kevin Curran Finola Ferry
The development of a comprehensive medicine's management approach for persons with dementia in primary care	Heather E Barry Carmel M Hughes (PI) Cristin Ryan Gerard J Molloy Hilary Buchanan	Peter Passmore Mairead McGratten Louise Robinson Carmel Darcy Laura Bedford
Technology enriched supported housing – a study into the lived experience of older people with dementia and their carers	Janeet Rondon-Sulbaran Suzanne Martin (PI) Assumpta Ryan Margy Washbrooke	Jean Daly Lynn Brendan McCormack Eamon Quinn (<i>Engage with Age</i>)

RCUK Pathways to impact

Interviewees were asked to review the RCUK Pathways to Impact diagram (Appendix 3) and identify which areas they felt this project/ Programme has achieved with regards to academic impacts. Figure 4.6 below shows the frequency with which each area is selected.

Figure 4.6 RCUK pathways to impact



Interviewees were also asked to articulate why they had made these selections. Only some provided comments.

Within the section on 'Innovative methodologies, equipment, techniques, technologies or cross-disciplinary approaches' interviewees felt this had been achieved in a variety of ways;

'Peer researchers were very innovative and the artwork as a sense of home with people who don't have verbal language – very innovative.' (research team)

'...their innovative methodologies allowed them to engage with people with dementia in a very meaningful way. It breaks down what might be quite turgid processes.' (research team)

Within the section on 'improving teaching and learning' several interviewees identified that the research had already been embedded into courses;

'Already embedding the learning in the curriculum' (research team)

'...teaching has been informed by the research being undertaken within the school. This helps to inform students about their future practice.' (research team)

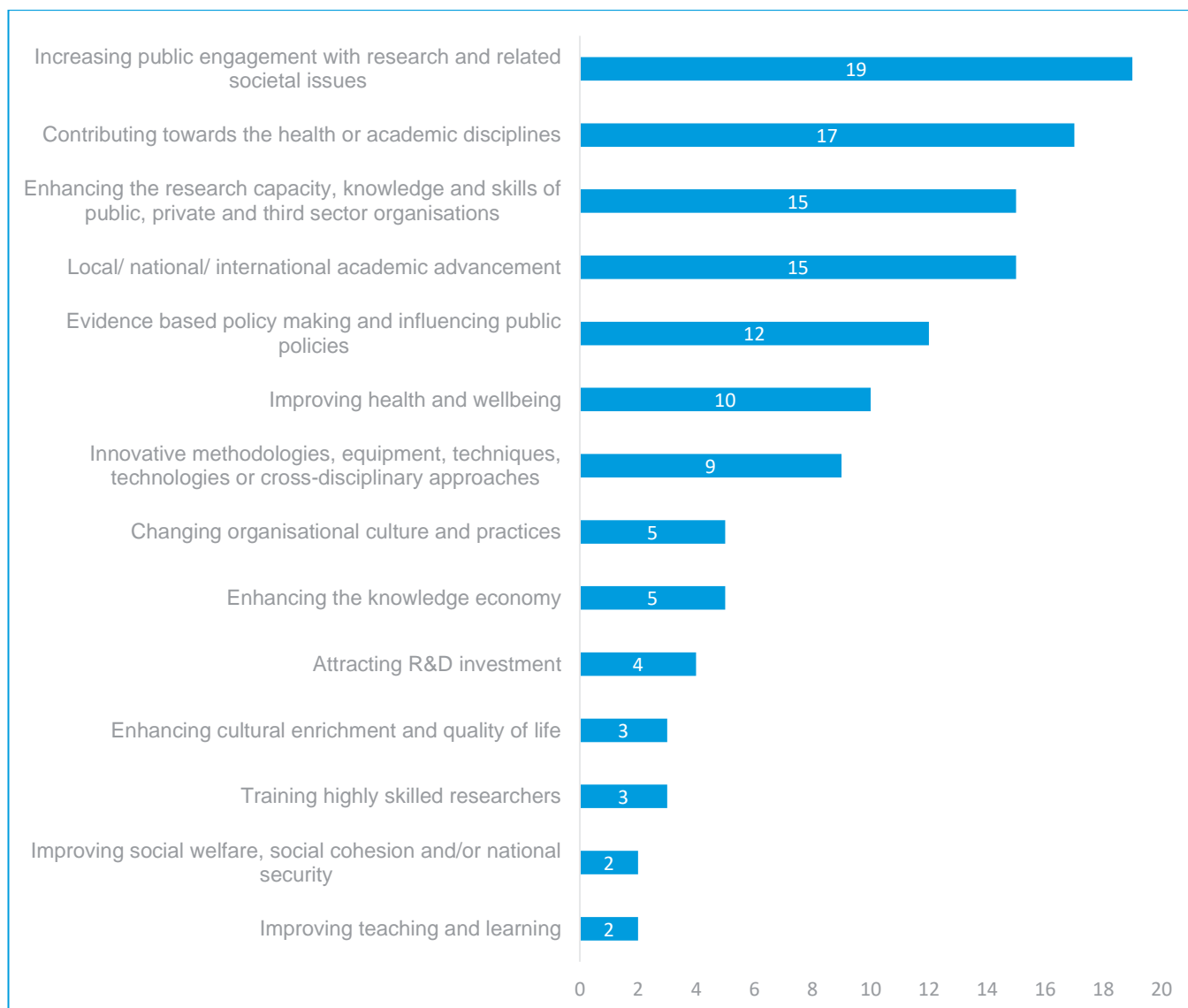
Within the section on 'Training highly skilled researchers' interviewees identified that there was training across the team;

'[The research assistant] had an excellent training programme and made use of training available to [them]. I stretched myself as well.' (research team)

'...capacity was built, particularly for early career researchers.' (research team)

Based on the Research Council UK's Pathways to Impact framework, delegates were asked to indicate three areas where they felt the Research Programme in Dementia Care in NI has achieved the most in terms of economic and societal impacts. Figure 4.7 provides an overview of the survey responses for the main impacts of the Research Programme in Dementia Care in NI. The highest response reported by the survey feedback was; "Increasing public engagement with research and related societal issues" (50%, n=19). This was followed by; "Contributing towards the health or academic disciplines" (45%, n=17).

Figure 4.7 survey response



Influences on service delivery, policy and health & wellbeing

Interviewees were asked a number of questions on the potential impacts and influences of the research/ the overall Programme.

4.1.9 Influence on dementia services

Interviewees were asked if the findings were likely to influence the way in which dementia services are planned, delivered or commissioned. From some of the responses provided, there was the indication that there was already an observable impact;

‘Yes, improved practices – can identify the need and source the appropriate referral. There is more training of staff, with increased awareness and increased pathways as a result. Behaviours have changed on the ground as people have greater knowledge from their training...’ (wider stakeholder)

‘I know that the research projects are informing education and training – nurses know about the projects and findings are brought into their training.’ (research team)

Others indicated that there was the potential for impact (particularly those working on the ground in the health and social care system), though more work in the area would be required in order to bring about changes;

'There is the potential for the research to influence health and social care at an array of levels. There has not been much work in this area before.' (research team)

'The current findings can be translated into policy, but this can be strengthened if they reflect the current operational policies and tools in use.' (wider stakeholder)

Whilst the programme of research was based on a priority setting exercise with key stakeholders, one respondent felt that the way in which research was commissioned should be altered to better address the service needs;

'Clinicians on the ground are better at identifying gaps in service provision. Research should really be funded based on needs from the ground, rather than the interests within academia.' (wider stakeholder)

4.1.10 Influence on health and wellbeing

In previous consultations, all PIs expected that the findings of their research would lead to a number of health and well-being benefits. Examples of previously anticipated health and well-being impacts included:

- One PI confirmed that their research which piloted reminiscence therapy using an app on an iPad provided a positive experience which focused on gains in the context of memory retention and learning new skills, which therefore had a positive impact on the health and well-being. The research findings indicated that:

"There were statistically significant increases in mutuality, quality of caregiving relationships and emotional well-being from baseline to endpoint for people living with dementia. Among the carers, there were non-significant increases in mutuality and quality of caregiving relationships, and a non-significant decrease in emotional wellbeing".

- One PI reported that there was evidence of emerging health and well-being impacts. Over the course of their research they visited participants, approximately on four-to-five occasions, for which these participants appeared to become more likely to access services that in the past, they were unwilling to consider. These included an increased uptake of voluntary and statutory services such as day centres.
- One PI detailed that the booklet for family carer education was designed and purposely reviewed by an expert panel including service users, before being pilot tested to assure that the contents would have an impact on the health and well-being of users in NI.

4.1.11 Influence on Policy

In previous reports two PIs were aiming for their research to influence government policy, while the others were not intending for this to be a key aim (it would be reasonably expected that impacts on policy would be evidenced later, i.e. beyond the timing of this final evaluation).

From the interviewees who felt able to comment on the Programme's influence in policy, there was general agreement that there was scope to influence policy but that this required more work;

'The current findings can be translated into policy, but this can be strengthened if they reflect the current operational policies and tools in use. The different projects have different potential impacts. Some of the projects had more translatable findings.' (wider stakeholder)

'In terms of policy there is a need to dig deeper, there is an interest and an appetite but often there is also the need to move on to the next grant. The translation of research to policy takes time and hard measures of research are grants' (research team)

'Once the papers have been published and the PhD complete, then start lobbying senior policy makers and hope to be making an impact in the next 3-5 years.' (research team)

As previously mentioned there have been complexities surrounding the Government in NI, with no devolved government in power since January 2016 and this has led to challenges within the policy environment. There may also be a disconnect between the priority of academics to publish while the funders want to demonstrate tangible outputs for practice and policy. This is one of the main challenges of Knowledge Exchange/Implementation Science.

Economic benefits

4.1.12 Employment

The funding provided employment within the research teams through the creation of 12.5 posts since 2015 (Table 4.3).

Table 4.3 Research jobs created

Project	Number of posts	Length of posts
Pain assessment and management for patients with advanced dementia care nearing the end of life	2 posts	Research Fellow – 3 years PHD Student – 2-3 years
Risk Communication in Dementia Care	1 post	Full time, 3 years
Promoting informed decision making and effective communication through advance care planning for people with dementia and their family carers	2 posts	1 Research post – 30 months 1 Research post – 12 months
The development of a comprehensive medicines management approach for persons with dementia	1 post	36 months
A feasibility study of facilitated reminiscence for people with dementia	3 posts	IT Research Assistant – 1 year Research Assistant – 18 months Trainer – 4 months
Technology enriched supported housing	1.5 posts	1 full time post – 24 months 1 part time post – 24 months
The evaluation of a Healthcare Passport to improve quality of care and communication for people living with dementia (EQuIP)	2 posts	1 post – 3 years 1 post – 1.5 years

Within the posts which were fixed- term, the individuals have been very successful in gaining further, relevant employment, with most still in the field of dementia.

4.1.13 Funding attracted

A number of PIs reported that they had secured additional research funding. Both for existing projects and for new opportunities (Table 4.4)

Table 4.4 Additional funding

Project	Funding body	Amount
Promoting Informed Decision Making and Effective Communication through Advanced Care Planning for People Living with Dementia, and their Family Carers	Alzheimer's Society	approximately £290,000
	Joint Programme - Neurodegenerative Diseases (JPND)	£1.2 million (combined amount from all 5 partner countries)
A feasibility study of facilitated reminiscence for people with dementia	HSC R&D Division	£41,760 ³⁵
	Local funder	approximately £12,000

One PI secured a funding increase through the HSC R&D Division of £41,760 to meet the increased data collection demands as a result of revision to the Health Economics component of the original proposal which was a requirement of the Panel. This PI has also had discussions with the Reminiscence Network Northern Ireland through Age NI and expects to secure funding (approximately £12,000) to further develop the app used in the project.

Another PI secured funding from the Alzheimer's Society (approximately £290,000) and from the Joint Programme - Neurodegenerative Diseases (JPND) to expand transnationally with a combined fund of £1.2 million from all the partners involved.

Participants were asked if they were aware of the research attracting any further funding from other funding bodies. There was a mixed response with some having secured funding and others not yet applying;

'Since the project was completed they have received two research grants... Without the funding and the call for dementia research, this would not have come about.' (research team)

'They have received funding [from a local funder], this puts them in a better position to apply for a bigger grant further down the line.' (research team)

'One application is still ongoing. Looking for other funding opportunities internationally.' (research team)

As there were two calls for proposals held, around a year apart, this has led to variation in the progress of the projects in attracting new funding. In general, those projects which started earlier, and which were completed less recently (during 2017 or 2018) were more likely to have a known outcome from further applications.

³⁵ Additional funding was awarded to this project following a recommendation from the panel that the project involve the Clinical Trials Unit and a health economics element. Following their input, the data collection was increased and extended, which was not possible within the original budget

Summary

- Over the course of the research, the seven funded projects have produced 28 publications so far, and a further five publications are pending. There have also been a range of presentations, discussions and meetings held at national (NI & UK) and international level.
- **Dissemination** appears to have been strong in academic terms, with many high-quality publications produced. However, some suggested that further dissemination would be useful both in an academic sense (further papers and conferences) but also to support translation of research findings into policy or practice.
- A Programme launch event was held to facilitate further dissemination – overall 34 of the 38 respondents (89%) indicated that the event was a useful mechanism for dissemination the range of research activities which were undertaken, and the outputs produced. However, respondents were less certain of how the event will influence planning, delivery and commission of the services in future (only 24 of 38 / 63% thought the event would have an influence).
- **Relationships:** overall the project and research funding were viewed as helpful in promoting the development of interdisciplinary relationships within and between institutions, and also deepening these relationships to a greater extent than would have been possible without funding. There has also been some inter-sectoral relationship development with other organisations in the voluntary and statutory sector, as well as with global organisations.
- **Capacity:** overall capacity was felt to have been built in applied dementia research in NI, particularly considering the low baseline position at outset. The projects have involved over 60 researchers across seven projects, with a number of successes in terms of progressing the development of more junior researchers into substantive positions within universities in NI or beyond, or into related roles. Research team members were also able to build capacity in under graduate and post graduate teaching, using the research projects as case studies.
- In terms of the RCUK Pathways to Impact, the Programme as a whole was felt to have achieved most in terms of improving teaching & learning and training highly skilled researchers, based on views from PIs and research teams in interviews. There was also strong support for the extent to which the Programme had contributed to health and academic disciplines and to local, national and international academic advancement.
- **Influence on dementia care and support, and potential for future influence:** views on the impact of the research studies were more mixed in this area. Some projects indicated improved practices and education/training, whereas others indicated that more could be done to translate findings into practice.
- Three projects indicated that research showed that, if scaled and spread more widely, their studies/innovations would have potential for health and wellbeing benefits in future. However, there are no current plans for scaling, so we cannot comment further on the extent to which this might be achievable.
- Whilst all indicated that there is scope for research projects to influence policy, there is pressure in academia to focus on further research rather than translation of findings into practice on the ground, and the absence of devolved government in NI has made influencing policy difficult to achieve.
- In total, the Programme has created 12.5 FTE research posts since 2015. There have been a number (at least three) of successful examples of individual transitioning from fixed terms posts to related further and higher employment opportunities.
- There have been some successes amongst two of the projects (so far) in securing further research grant funding from a range of sources, which would not have happened in absence of the Programme. To date, over £1.5m has been secured (with partners) as a result, whilst research teams continue to submit and await outcomes of further grant applications. This suggests capacity, relationships and opportunities have been built and have potential to be sustained as a result of this Programme.

5 OTHER FINDINGS

Fulfilling objectives

Participants were asked what extent they would say that the Research Programme/ project(s) had met the original aims and objectives. Most participants felt that the programme and projects had met their original aims.

Some felt that the original aims had been exceeded, with developments that they had not foreseen;

'[We] had not envisaged the educational resources and have achieved engagement outside the conventional audiences.' (research team)

'Yes, it has probably even exceeded the expectations, with the richness of the information coming through.' (research team)

For one project the challenges early in the project led to delays which caused them to scale back on their original plans.

'The project didn't meet its original aims. The main challenge was around ethics.' (research team)

While there was general agreement that the project aims had been met, there was the sense from some participants that there is still work to be done, especially with regards to integrating the findings into policies and bringing about organisational change;

'It can take a long time to filter down and sometimes this just doesn't happen. Everyone needs to take a certain level of responsibility.' (wider stakeholder)

'...as a clinician working on the ground, I haven't seen any impact.' (wider stakeholder)

'The next stage would be to make the most out of the funding, creating another funding call with the R&D Division and other charities that will result not just in academia but actual policy. We should not draw a line under these studies.' (wider stakeholder)

Some participants had limited involvement in the projects so did not feel that that they could comment on the extent to which the aims were met.

Final Comments

Participants were given the opportunity to give final comments at the end of the interview. For some members of the research teams, they were keen to highlight that the support from the R&D office was mentioned as being very beneficial;

'HSC R&D [Division] have been a very supportive and sympathetic partner.' (research team)

'The HSC R&D Division were accommodating and helpful – they were supportive when dealing with delays, and other funders are not as flexible.' (research team)

'...there were some unforeseen delays but the R&D office were warm, relaxed and supportive.' (research team)

From the perspective of the wider stakeholders, some commented that more collaboration would have been helpful in the research design;

'Co -production with policy makers at the beginning would really add value.' (wider stakeholder)

'If there was more collaboration from the outset it would make these projects more transferable into practice.'
(wider stakeholder)

'With any research going forward, conversation with carers and patients from the outset would make a difference and get a real-life picture early on. Earlier conversations could potentially have helped with this Programme.' (wider stakeholder)

Unanticipated consequences

Interviewees were asked if there were any unanticipated consequences which arose from the research projects.

These included the relationships formed through this research;

'Connecting with the Max Planck Institute was quite innovative for us. Social Work is not well connected – internationally the definition for Social Work is not agreed and regulation of profession is not consistent. Good to use expertise at this level.' (research team)

Within some projects the benefits of the intervention had a wider reach than originally anticipated;

'The nurses gaining valuable communication training from the booklet. They felt more comfortable talking to the patients. It increased the awareness of advanced care plans and took the pressure off.' (research team)

There was also the perception that this programme of research had raised the profile of dementia;

'It has raised the topic and the profile of dementia research which is always positive. This research has highlighted the opportunities for the regional palliative care programme to work with the research community which has also been beneficial.' (wider stakeholder)

Summary

- Most stakeholders felt that the Programme and research projects had met or exceeded original aims from a research perspective. Whilst one project did not meet its intended aims, it would be reasonably expected that in a group of seven projects that not all would complete and indeed having six projects complete as planned appears to be a relative success.
- There was broad agreement that more work could be done to translate research into practice to enhance impact and bring about change for people living with dementia and their families.
- Overall the support throughout the Programme from the HSC R&D Division was viewed as very beneficial and helpful to its overall success.
- In terms of unanticipated consequences, a number of positive effects were realised including: new/ wider relationships developing, wider impacts than planned and raising profile of dementia.

6 CONCLUSIONS AND RECOMMENDATIONS

The overall aim of the project, as set out in the Terms of Reference, was to ‘evaluate the Research Programme in Dementia Care.’ Table 6.1 below provides an overview of the Terms of Reference and the relevant sections where these are addressed within this report:

Table 6.1 Terms of reference

Terms of reference	Report section
Inter-disciplinary and inter-sectoral relationships developed as a result of joint research projects	4.2.1 Relationships
Capacity built to continue applied dementia care research in NI and attract alternative funding	4.2.3 Capacity
Perceived quality and breadth of dissemination activity	4.1 Increasing knowledge
Degree to which the findings of research projects have influenced dementia care and support services delivered by Government and have the potential for future influence	4.3 Influences on service delivery, policy and health & wellbeing

The following sections provide conclusions and recommendations based on each of the Terms of Reference for year four of the evaluation, and for the Programme as a whole over its duration.

Inter-disciplinary and inter-sectoral relationships developed as a result of joint research projects

The Programme and research funding were viewed as helpful in promoting the development of interdisciplinary relationships within and between institutions, and also deepening these relationships to a greater extent than would have been possible without funding. There has also been some inter-sectoral relationship development with other organisations in the voluntary and statutory sector, as well as with global organisations.

Capacity built to continue applied dementia care research in NI and attract alternative funding

Overall capacity was felt to have been built in applied dementia research in NI, particularly considering the low baseline position at outset. The projects have involved 60 researchers across seven projects, with a number of successes in terms of progressing the development of more junior researchers into substantive positions within universities in NI or beyond, or into related roles. Research team members were also able to build capacity in undergraduate and postgraduate teaching, using the research projects as case studies.

In terms of the RCUK Pathways to Impact, the Programme as a whole was felt to have achieved most in terms of improving teaching & learning and training highly skilled researchers, based on views from PIs and research teams in interviews. There was also strong support for the extent to which the Programme had contributed to health and academic disciplines and to local, national and international academic advancement.

Perceived quality and breadth of dissemination activity

Dissemination appears to have been strong in academic terms, with many high-quality publications produced. However, some suggested that further dissemination would be useful both in an academic sense (further papers and conferences) but also to support translation of research findings into policy or practice.

A Programme launch event was held to facilitate further dissemination – overall 34 of the 38 respondents (89%) indicated that the event was a useful mechanism for disseminating the range of research activities which were undertaken, and the outputs produced. However, respondents were less certain of how the event will influence planning, delivery and commission of the services in future (only 24 of 38 / 63% thought the event would have an influence).

Degree to which the findings of research projects have influenced dementia care and support services delivered by Government and have the potential for future influence

Views on the impact of the research studies were more mixed in this area. Some projects indicated improved practices and education/ training, whereas others indicated that more could be done to translate findings into practice. Since some projects had recently finished this may still happen with time.

Three projects indicated that research showed that, if scaled and spread more widely, their studies/ innovations would have potential for health and wellbeing benefits in future. However, there are no current plans for scaling, so we cannot comment further on the extent to which this might be achievable.

Whilst all indicated that there is scope for research projects to influence policy, there is pressure in academia to focus on further research rather than translation of findings into practice on the ground, and the absence of devolved government in NI has made influencing policy difficult to achieve. It would be reasonably expected that further impacts on policy from the projects would be evidenced later, i.e. beyond the timing of this final evaluation.

Other issues

In total, the Programme has created 12.5 FTE research posts since 2015. There have been a number (at least three) of successful examples of individuals transitioning from fixed term posts to related further and higher employment opportunities.

There have been some successes amongst two of the projects (so far) in securing further research grant funding from a range of sources, which would not have happened in absence of the Programme. To date, over £1.5m has been secured (with partners), whilst research teams continue to submit and await outcomes of further grant applications. This suggests capacity, relationships and opportunities have been built and have potential to be sustained as a result of this Programme.

Recommendations

Given that this is the final report on this Programme of research, we have developed six recommendations which are geared towards further enhancing the impact of this Programme, and also replicating its successes in other research calls in the future. These recommendations are shown in the figure 6.1 below.

Figure 6.1 Recommendations

1	Relationships developed	<i>We recommend that the HSC R&D Division continue to nurture and support relationships which have developed through this programme of work. This may include agreeing methods for keeping in touch, e.g. newsletters and groups, and circulating updates on ongoing or new research and opportunities in dementia care.</i>
2	Capacity built	<i>We recommend that the HSC R&D Division develop a plan to maintain and build upon the capacity which has developed through this programme. Outputs from the research projects should be disseminated widely within universities and HSC Trusts to encourage their use in training and education, to encourage further capacity building in the sector.</i>
3	Quality & breadth of dissemination activity	<i>We recommend that dissemination activities should continue as planned, including updating ResearchFish as appropriate. The HSC R&D Division should develop a plan to promote knowledge transfer and translation of findings into the HSC system, so that impact is enhanced on the ground. This may include consideration of further funding for dissemination activities, particularly those which will encourage knowledge transfer and will make an impact on HSC staff, service users and their families.</i>
4	Influencing dementia care & support services	<i>We recommend that the HSC R&D Division, along with PIs, should seek to identify opportunities for further funding to take successful research projects forward, including trialling these at a larger scale. All PI's should set up meetings with commissioners and policy representatives to explain the findings from their studies and discuss how these might influence the delivery of care in the future.</i>
5	Involvement of people living with dementia	<i>The HSC R&D Division, along with the wider Health and Social Care System, should seek to facilitate the involvement of people living with dementia in all stages of the research process, both as participants and as partners. This should include working with Ethics and Research Governance Committees to ensure that research aims and objectives are understood and supported as far as possible.</i>
6	Other	<i>We recommend that the HSC R&D Division should consider replicating many of the positive aspects of this programme in future research calls. This should include: a supportive application process, multi-disciplinary research teams, PPI and a flexible approach to delivery where possible.</i>



APPENDICES

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Appendix 1 James Lind Alliance Dementia Research Priorities

The James Lind Alliance³⁶ outlines the top ten dementia research priorities as highlighted in Table 7.1 below. The following questions were prioritised by people living with dementia, carers, and health and social care professionals to inform the future of dementia research. The priorities were launched at Alzheimer's Society's Research conference on 27th June 2013.

Table 7.1 James Lind Alliance Dementia Research Priorities

No.	Priority
1	What are the most effective components of care that keep a person with dementia as independent as they can be at all stages of the disease in all care settings?
2	How can the best ways to care for people living with dementia, including results from research findings, be effectively disseminated and implemented into care practice?
3	What is the impact of an early diagnosis of dementia and how can primary care support a more effective route to diagnosis?
4	What non-pharmacological and/or pharmacological (drug) interventions are most effective for managing challenging behaviour in people living with dementia?
5	What is the best way to care for people living with dementia in a hospital setting when they have acute health care needs?
6	What are the most effective ways to encourage people living with dementia to eat, drink and maintain nutritional intake?
7	What are the most effective ways of supporting carers of people living with dementia living at home?
8	What is the best way to care for people with advanced dementia (with or without other illnesses) at the end of life?
9	When is the optimal time to move a person with dementia into a care home setting and how can the standard of care be improved?
10	What are the most effective design features for producing dementia friendly environments at both the housing and neighbourhood levels?

³⁶ <http://www.lindalliance.org/top-tens.asp>

Appendix 2 Discussion guide

HSC R&D Division - Evaluation of the Research Programme in Dementia Care Stage 4: Summative Assessment / Final Report Year 4

Discussion guide for stakeholder consultations (FINAL) (For use with PIs & Research teams and strategic stakeholders)

RSM has been commissioned by the HSC R&D Division to conduct an evaluation of the Research Programme in Dementia Care. As part of this, we are undertaking consultations with Principal Investigators and their research teams across the seven funded projects, strategic stakeholders and Patient/ Public Involvement representatives to inform our final (Year 4) report.

My name is [Laura Brownlee/ Helen Mitchell/ David Fleming], and I am an evaluator from the RSM team. Thank you for agreeing to participate in this interview. Is now still a good time to complete the interview?
[Proceed if yes]

The purpose of today's discussion is to understand your views on the following:

- The relationships developed as a result of the joint research projects;
- The capacity built to continue applied dementia care research in NI and attract alternative funding;
- The perceived quality and breadth of dissemination activity; and
- The degree to which the findings of research projects have influenced dementia care and support services delivered by Government and have the potential for future influence.
- Any other areas which you may like to discuss, or suggestions which you would like to make, in relation to the Research Programme.

It should take around [1 hour 30 minutes (for PIs/ research teams / 45 minutes (for strategic stakeholders)] for our discussion. Your comments will be completely anonymous and confidential, will be stored securely by RSM, and will not be attributed to you in our final report. During our conversation, we would like to take some written notes as a record of the key themes emerging, are you happy for us to make some written notes?

- [If yes] Thank you – I will write some notes as we talk.
- [If no] Thank you – we will not make any records from our conversation.

Introductory questions

1. Tell me about your level of awareness/ involvement in the Research Programme in Dementia Care, and how you became involved in the programme of work/ specific project(s)?
2. Over the last year, how have you been involved in the programme/ project? Has your level of involvement changed over the last 4-5 years since the programme began?

Project progress [note: this section will only apply to discussions with PIs & Research teams]

3. Note: in this section, we will work through the responses which each PI/ research team provided to the online Questionnaire for Principal Investigators in November/ December 2017 (previous responses will be printed out). We will ask them for any further updates to account for activities which took place during 2018 in the following areas:

It should be noted that for projects which had finished by the time of the Year 3 report (February 2018), we would expect minimal updates to the previous survey, but would expect that those projects which have been ongoing during 2018 may have more to add.

- Project start and end date (for those which had not already finished by the time of the Year 3 report)
- Knowledge sharing and dissemination activities during 2018

- Influence on government policy during 2018
 - Influence on dementia services during 2018
 - Any new partnerships which have been formed during 2018
 - Any challenges during 2018
 - PPI involvement during 2018
 - Pathways to Impact Plan – whether this was developed and implemented during 2018
 - Developments relating to health and wellbeing impacts in 2018
 - Developments relating to economic impacts in 2018
 - Research capacity built during 2018
4. Looking back on the achievements as outlined in the Year 3 evaluation report (February 2018), for your project, could you update us on any changes or progress made over the last year in terms of:
- a. Actual research outcomes vs proposed outcomes (page 2)
 - b. Project status (page 31)
 - c. Grant awarded, spend and difference (pages 32 and 33)
 - d. Progress (pages 37 to 40, specifically for projects which were ongoing throughout 2018)

Relationships developed [note: this section, and all following sections, will apply to discussions with PIs & Research teams and all strategic stakeholders]

5. Over the last four years, how has your project/ the programme influenced **inter-disciplinary** relationships?
- a. Can you provide an example?
 - b. What has the outcome/ impact of these relationships been?
 - c. Might this have happened anyway in the absence of the project(s)?
 - d. Are there any ways in which the programme and dementia research more broadly could better develop these relationships?
6. Over the last four years, how has your project/ the programme influenced **inter-sectoral** relationships?
- a. Can you provide an example?
 - b. What has the outcome/ impact of these relationships been?
 - c. Might this have happened anyway in the absence of the project(s)?
 - d. Are there any ways in which the programme and dementia research more broadly could better develop these relationships?
7. With regards to Patient and Public Involvement (PPI), how would you describe the level of activity over the last four years?
- a. Were there any specific challenges or facilitators?
 - b. Similarly thinking about ethics/ research ethics, did you experience any challenges over the four years? (e.g. involving/ accessing people living with dementia)
 - c. Are there any other ways in which the programme (and dementia research more broadly) could involve patients, carers and the public to a greater degree?

Capacity building and funding attracted

8. Over the last four years, has capacity been developed in applied dementia research as a result of the funding?
- a. If yes, describe the capacity which has been developed, e.g. research assistants gaining qualifications, research fellows developing more experience?
 - b. If no, why do you think this is has been the case? Might any additional actions have helped to further build capacity?

9. Over the last four years, has the research attracted any further funding from other funding bodies (e.g. follow-on studies)?
 - a. If yes, was the funding to extend current research or to address new research questions which emerged from the primary study? Further to this, please describe: the funder, project title and aims, amount and period of funding received, the team working on this, and any other details available?
 - b. If no, are there any potential opportunities to attract funding at this stage? Who/ which organisations might this project/ projects look to for such opportunities?
 - c.

Quality and breadth of dissemination activity

10. What activities are planned / have been undertaken to disseminate the findings from this project/ all seven projects? e.g. publications in peer-reviewed journals, conference posters/ presentations, events, other knowledge sharing activities, etc. [note: this might also include discussion of the event on 29th March]
11. Over the last four years, how effective have the dissemination activities been for this project/ the programme, using the following scale: very effective, quite effective, neither/nor, quite ineffective, very ineffective?
 - a. Why do you say that?
 - b. If neither/nor or lower, what might the research team(s) have done differently to disseminate their findings?
 - c. Are there any further dissemination activities which could be undertaken?
12. From the dissemination activities undertaken over the last four years, what impact has there been on the following:
 - a. Policy (in health and social care or more broadly)?
 - b. Service delivery?
 - c. Future research?
13. If the impacts of your research/ the programme are yet to emerge, what plans do you have in place to achieve an impact from these?

Influencing dementia care

14. Have the research findings and the programme as a whole influenced, or are they likely to influence, the way in which dementia services are planned, delivered or commissioned? Why do you say that?
15. If you were developing a service specification for dementia care, how would you use the findings from this research or the programme as a whole to influence this specification?
16. Have the research findings/ the programme had any influence on policies relating to dementia, or are they likely to in the near future, in:
 - a. Northern Ireland?
 - b. The UK/ Ireland?
 - c. Internationally?
17. Are there any other ways in which the findings of the research or from the programme as a whole could be used in the future? What would need to be in place to make this happen?

Impacts (from the Payback Framework / RCUK Pathways to Impact)

Refer consultee to the Pathways to Impact diagram (at end of this discussion guide).

18. Looking at the RCUK Pathways to Impact diagram, which 3 areas do you feel this project/ programme has achieved most/ least with regards to **academic impacts** (listed below)? Why do you say that?
 - a. Local/ national/ international academic advancement?
 - b. Innovative methodologies, equipment, techniques, technologies or cross-disciplinary approaches?
 - c. Contributing towards the health or academic disciplines?
 - d. Enhancing the knowledge economy?
 - e. Training highly skilled researchers?

- f. Improving teaching and learning?
19. Looking at the RCUK Pathways to Impact diagram, which 3 areas do you feel this project/ programme has achieved most/ least with regards to **economic and social impacts** (listed below)? Why do you say that?
- a. Improving health and wellbeing?
 - b. Wealth creation, economic prosperity and regeneration?
 - c. Enhancing the research capacity, knowledge and skills of public, private and third sector organisations?
 - d. Changing organisational culture and practices?
 - e. Enhancing the effectiveness and sustainability of organisations including public services and businesses?
 - f. Attracting R&D investment?
 - g. Improving social welfare, social cohesion and/or national security?
 - h. Commercialisation and exploitation?
 - i. Enhancing cultural enrichment and quality of life?
 - j. Environmental sustainability, protection and impact?
 - k. Evidence based policy making and influencing public policies?
 - l. Increasing public engagement with research and related societal issues?

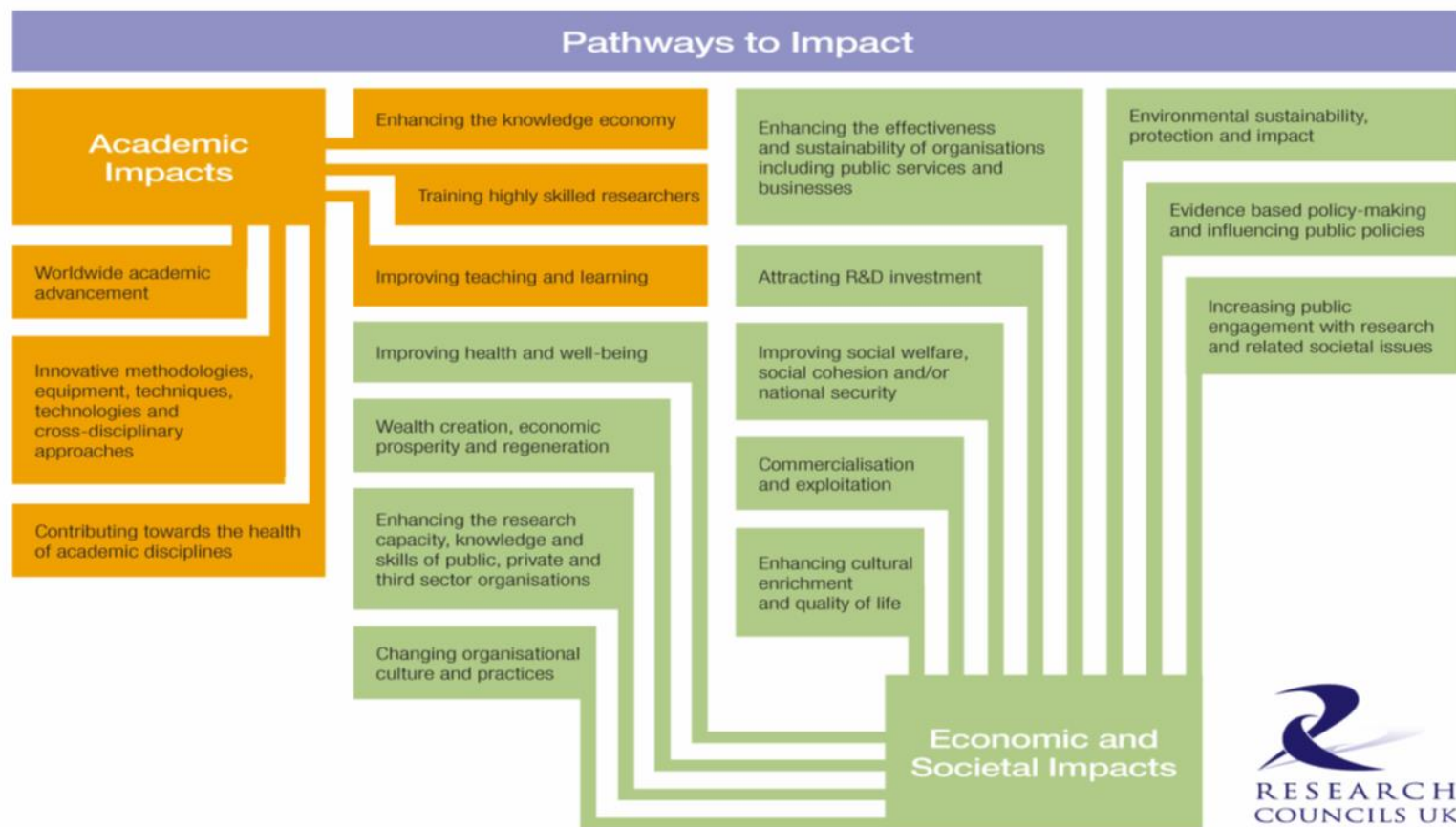
Final questions / other

20. Overall, to what extent would you say that the Research Programme/ project(s) has met the original aims and objectives, using the following scale: to a great extent, to some extent, to limited extent, not at all?
- a. Why do you say that?
 - b. Is there anything which could have helped the programme/ project meet it's aims and objectives to a greater degree?
21. Has there been any unintended or unanticipated effects (or benefits) from the programme/ project(s)?
22. Is there anything else that you would like to mention to us about the Research Programme in Dementia Care, that you would like us to take into account within this evaluation?

Thank and close

Appendix 3 RCUK Pathways to Impact

RCUK Example of a Pathways to Impact³⁷



³⁷ <http://www.rcuk.ac.uk/RCUK-prod/assets/documents/impacts/RCUKPathwayspresentation.pdf>

Appendix 4 Hanney Payback Framework

The Hanney Payback Framework³⁸ is a tool designed to measure the impact of health R&D funding and has been used extensively in a number of Health and Social Care Research projects. It assesses the impact of research against the five categories noted in Table 7.2. This table also highlights how the categories relate to the TOR of this evaluation, and the stage of this evaluation.

Table 7.2 Payback Framework Categories and your Evaluation Objectives

Payback Framework Categories		Your terms of reference / evaluation objectives
Category	Definition	
Knowledge	Journal articles conference presentations, research reports etc.	Perceived quality and breadth of dissemination activities. Will be assessed once the projects are at the relevant stage to present findings.
Benefits to future research and research use	Better targeting of future research; Development of research skills, personnel and overall research capacity; Critical capacity to absorb & utilise appropriately existing research; and Staff development and educational benefits	The development of inter-disciplinary and inter-sectoral relationships; and the capacity built to continue applied dementia care research in NI. Will be assessed once the projects are further developed.
Benefits from informing policy and product development	Improved information bases for political & executive decisions; Other political benefits from undertaking the research; Development of pharmaceutical products and therapeutic techniques; and Development of new models of care / influencing new models of care	The degree to which the research projects have influenced dementia care and support services delivered by Government and have the potential for future influence. This will be assessed once the projects are further developed.
Health and health sector benefits	Improved health; Cost reduction in delivery of existing services; Qualitative improvements in the process of delivery; and Improved equity in service delivery	The degree to which the findings of the research has influenced dementia care and support services delivered by Government. Will be assessed once the projects are further developed.
Broader economic benefits	Wider economic benefits from commercial exploitation of innovations arising from R&D	Capacity to attract alternative funding Will be assessed once the projects are further developed.

This framework informed the design of data collection tools and interview questions with key stakeholders. Much of the evidence needed will not be available until the projects are much further developed. However, it provided an opportunity to check if the researchers had the processes in place to ensure they will be focused in the future.

³⁸ Hanney and Donovan (2011) The Payback Framework explained. Research Evaluation 20 (30) 2011.

Appendix 5 Policies and Strategies

Table 7.3 Relevant policies and Strategies

N.I Policy / Strategy	Relevance to Research Programme in Dementia Care
DHSSPS 'Improving Dementia Services in Northern Ireland: A Regional Strategy' (2011) ³⁹	This strategy made a number of key recommendations regarding the promotion of dementia research. It concluded that research is needed in three main areas: cause, cure and care and that there is a need for a coordinated approach to research, pooling talents and resources. This strategy noted that in order to grow the local research effort on dementia, access to and effective use of expertise and funding are both required. It suggested that this could be achieved through collaboration with substantial dementia research groups based elsewhere and support for multi-disciplinary, multi-professional research with strong involvement of HSC Trusts, patients, carers and organisations that represent and support them. The Research Programme in Dementia Care focuses on 'care'. It seeks to build research capacity in dementia and expertise in NI researchers thereby increasing their ability to apply for other sources of grant funding which builds on the proposed Programme once completed.
DHSSPS Service Framework: Dementia ⁴⁰ (2014)	The Service Framework for Dementia outlines the importance and need for dementia research. It states that further funding and research is needed in order to inhibit early assessment, investigation, treatment and support of dementia, as well as to improve the quality and range of services and support in order to enhance care. The Research Programme in Dementia Care provides funding for dementia research with the overall aim of improving the quality of life of people living with dementia. The ultimate aim of this Programme is that findings from this work will be translated into improvements in care for patients and their families and embedded in practice and service delivery. ⁴¹
Department of Health. Health and Well-being 2016: Delivering Together (2016)	The Delivering Together report notes that the current structures to deliver health and social care services in Northern Ireland are unsustainable to continue delivering a world class health system. An aging population is highlighted as one of the challenges to the health and social care system in Northern Ireland and it is suggested that by 2026, for the first time, there will be more over 65s than under 16s. The aging population presents huge demands and pressures on health and social care services. This report notes that to realise a new model of person-centered care it essential to make better use of technology and data. Specifically, it is noted that consolidated and common patient and user records are required with fewer separate IT systems. It is anticipated that a more consolidated health record will support the

³⁹DHSSPS Improving Dementia Services in Northern Ireland: A Regional Strategy (2011) <http://www.dhsspsni.gov.uk/improving-dementia-services-in-northern-ireland-a-regional-strategy-november-2011.pdf>

⁴⁰ DHSSPS Service Framework Dementia http://www.dhsspsni.gov.uk/sfmhw_-_dementia.pdf

⁴¹ Guidance Notes for Commissioned Research in Dementia Care 2014

N.I Policy / Strategy	Relevance to Research Programme in Dementia Care
	<p>better use of patient information and the design of new interventions and support for people in managing their conditions. Specifically relating to dementia, the report highlighted that a programme of work to improve the use of health analytics, focused on dementia patients, will start in 2017.</p> <p>The report lists 18 actions that should be implemented, specifically; <i>Expand the range of information and interaction available to citizens online and development of a patient portal for dementia patients</i>. It is anticipated that the portal will go live in September 2018.</p>
<p>DHPSS 'Transforming Your Care': A Review of Health and Social Care in Northern Ireland (2011)</p>	<p>This report made a number of key areas to address in regards to dementia care:</p> <ul style="list-style-type: none"> Improve regional standards of care, especially for dementia Need for greater provision of services for older people at home and in the community - the decline in the number of nursing homes is not matched with the growth in cases of dementia Hospital services - people living with dementia stay longer in hospital than other people undergoing the same procedure which can have a detrimental effect on the symptoms of dementia. More support in the community is needed, and an effective model of care needed to speed up hospital admission time. Lack of quality and availability of respite care for people living with dementia, research is needed to shift services from hospital settings to closer to home. <p>The Research Programme in Dementia Care aims to directly improve patient care and systemic changes in the way services are commissioned and delivered. Priorities identified as part of the Programme include: staff and staff training; quality of care; information and communication; management of behaviours and management of symptoms. An open call was issued with applicants invited to submit proposals in these areas. Research in these areas can enhance standards of care for people living with dementia facilitating less reliance on institutional care. The aim of this Programme is to ultimately lead to improvements in care for patients and their families and lead to changes in the way services are commissioned and delivered.⁴²</p>
<p>DHSPSS Service Framework: Older People's Mental Health (2014)⁴³</p>	<p>This framework aims to improve the health and social well-being of older people in Northern Ireland, to promote evidence-based practice, to safeguard vulnerable individuals and groups and to enhance multidisciplinary working.</p> <p>The Research Programme in Dementia Care seeks to enhance multi-disciplinary research in dementia care with the overall aim of improving standards of care for people living with dementia. The Programme anticipated applications</p>

⁴² HSC R&D Division programme bid

⁴³ DHSPSS Service Framework: Older People's Mental Health http://www.dhsspsni.gov.uk/sfmhw - older_people.pdf

N.I Policy / Strategy	Relevance to Research Programme in Dementia Care
	from teams of researchers, clinicians, policy makers and service users to address the agreed priorities. However, it also encouraged collaborations with experts from outside of NI.
Ministerial advisory group on dementia (2011) ⁴⁴	<p>This advisory group identified areas in which dementia research needs improved/how it should be focused:</p> <ul style="list-style-type: none"> Collaboration is needed between the public and commercial research sectors with greater mutual transparency The established aim to embed the delivery of research across the full care pathway and in all service sectors Opportunities for quality scientists from contiguous fields and a strengthened research leadership is needed To increase the success of the dementia research community in competitive funding contexts and improve the coordination between funders on priorities for dementia research To extend public engagement in dementia research <p>The Research Programme in Dementia Care seeks to build research capacity in dementia and expertise in NI researchers thereby increasing their ability to apply for other sources of grant funding which builds on the proposed Programme once completed. A key element of the Programme is also Personal and Public Involvement which should be incorporated at every element of the research process in all projects,⁴⁵ therefore enhancing public engagement in dementia research.</p>
Research for Better Health & Social Care - A Strategy for Health & Social Care Research and Development in Northern Ireland (2016 – 2025) ⁴⁶	<p>This strategy aims to improve the health, wellbeing and prosperity of the Northern Ireland population through excellent, world-renowned R&D in health and social care that is led from NI. The strategy is underpinned by five objectives:</p> <ul style="list-style-type: none"> Objective 1 – To support research, researchers and the use of evidence from research to improve the quality of both health and social care and for better policy-making. Objective 2 – To compete successfully for R&D funding, and optimise local funding, to deliver returns on investment for health and wellbeing, academia and commerce. Objective 3 – To support all those who contribute to health and social care research, development and innovation by enhancing our research infrastructure, benefitting from local, national and international partnerships.

⁴⁴Department of Health: Ministerial advisory group on dementia research (2011)
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215558/dh_127904.pdf

⁴⁵ HSC R&D Division Programme Bid

⁴⁶ Research for Better Health & Social Care - A Strategy for Health & Social Care Research and Development in Northern Ireland (2016 – 2025)
https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/research-and-development-strategy-2016-25_1.pdf

N.I Policy / Strategy	Relevance to Research Programme in Dementia Care
	<p>Objective 4 – To increase the emphasis on research relevant to the priorities of the local population.</p> <p>Objective 5 – To disseminate research findings in such a way as to promote understanding and knowledge, support and share best practice, stimulate further research and celebrate achievement.</p> <p>The Research Programme in Dementia Care aims to enhance local capacity to undertake high quality research relevant to dementia care in order to improve the quality of health care for people living with dementia in Northern Ireland and inform practice and policy in Northern Ireland and globally. Key elements of the Research Programme include collaborations/partnership working between researchers (both local and international), and Public and Patient Involvement (PPI). For example, service users were among the key stakeholders who were involved in the consultation exercise to identify the most salient research priorities in dementia care in Northern Ireland.</p>
<p>The Northern Ireland Dementia Learning and Development Framework 2016⁴⁷</p>	<p>The Northern Ireland Dementia Learning and Development Framework 2016, outlines the knowledge and skills health and social care staff need to respond to the needs of people living with dementia. The framework aims to standardise education in dementia care to ensure consistency in standards and approach for all health and social care staff, and is organised into 13 core themes. The themes cover: dementia awareness, communication, diagnosis, person-centered and relationship-centered dementia care; promoting physical, psychological and social well-being, holistic approaches; promoting enabling environments; legal and ethical considerations; equality and cultural diversity; palliative and end of life care; working with families and carers; evidence-based practice; and leadership.</p> <p>The framework has been informed by best practice guidance, reviews of the literature reviews and consultation with people living with a dementia, carers, professionals, academics and regulators. It was jointly by the NI Executive and Atlantic Philanthropies and is relevant for all employers and educational organisations that provide training to health and social care staff and students in Northern Ireland. It will support these organisations to:</p> <ul style="list-style-type: none"> • standardise the content of education in dementia care to ensure consistency in standards and approach; • guide the focus and aims of dementia training; • encourage continuing professional and vocational development; • improve the quality and availability of dementia education;

⁴⁷ http://www.hscboard.hscni.net/download/PUBLICATIONS/dementia/26092016_Learning_Development_Framework.pdf

N.I Policy / Strategy	Relevance to Research Programme in Dementia Care
	<ul style="list-style-type: none"> • enhance the experiences of people living with a dementia, their families and carers. <p>The Delivering Social Change Dementia initiative was launched with a budget of £6.25m over a three year period, and is funded jointly by the Executive and Atlantic Philanthropies.</p>
<p>Department of Health, Social Services and Public Safety Northern Ireland (DHSSPSNI) Personal and Public Involvement (PPI) Guidelines</p>	<p>The DHSSPSNI issued guidance to the HSC in September 2007 which was intended to strengthen the various programmes of work/requirements for service users and carers in the planning and delivery of health and social care services. It also introduced and defined the concept of Personal and Public Involvement (PPI) as an agreed regional terminology for all aspects of user involvement within health and social care. PPI aims to improve health and social care service provision in Northern Ireland and the individual experiences of those who use these services. This guidance recognises the need for future work to develop a PPI label that is more easily and widely understood.⁴⁸</p> <p>Since this guidance was issued, the legislation for the Health and Social Care (Reform) Act (Northern Ireland) 2009 ('the Reform Act') was enabled.⁴⁹ The Reform Act a statutory duty of public involvement and consultation on Health and Social Care organisations. Therefore, organisations have a statutory duty to involve service users, carers and the public in the commissioning, planning and delivery of all Health and Social Care (HSC). Individuals have decisions about their specific care or treatment and consulting members of the public and the wider community on the design, delivery and location of services.</p>
<p>Assessing cognition in older people: a practical toolkit for health professionals⁵⁰</p>	<p>The Alzheimer's Society have produced a toolkit – developed by an expert writing group and supported by Department of Health. It is aimed to help health professionals determine the most appropriate cognitive assessment tool for use with patients in their setting. Measuring someone's cognitive function is an important assessment clinicians make, particularly those in old age psychiatry and geriatric medicine, and is key to detecting dementia and delirium. Cognitive assessments cover a very broad range of activities. They can take place:</p> <p>in a number of settings – primary care, specialist memory clinics, acute care and care homes, for a variety of purposes – screening, diagnosing, staging and measuring change, over a number of domains – memory, language, visuospatial ability and executive function.</p>
<p>Other relevant policy, strategies and research</p>	<p>Relevance to the Research Programme in Dementia Care</p>

⁴⁸ https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/HSC%20%28SQSD%29%2003-12_0.pdf

⁴⁹ http://www.legislation.gov.uk/ni/2009/1/pdfs/ni_20090001_en.pdf

⁵⁰ https://www.alzheimers.org.uk/download/downloads/id/3475/alzheimers_society_cognitive_assessment_toolkit.pdf

N.I Policy / Strategy	Relevance to Research Programme in Dementia Care
UN Principles for Older Persons (1991) ⁵¹	<p>These principles should be considered by all organisations and regarded as a framework for policy. The United Nations Principles for Older Persons were adopted by the UN General Assembly (Resolution 46/91) on 16 December 1991. There are 18 principles which are grouped under five themes: independence, participation, care, self-fulfilment and dignity.</p> <p>The principles acknowledge the diversity in the situations of older persons, the rise of the ageing population, that scientific research disproves many stereotypes, that opportunities must be provided for willing and capable older persons to participate in the ongoing activities of society and the strain on family life requires support for those providing care to older persons.</p> <p>This Programme aims to improve services for patients with dementia and their carers. Specifically, two projects focus on making improvements to the quality of care of people living with dementia and two projects also look at co-ordination of care.</p>
NICE Guidelines (2006) ⁵²	<p>This document identified key areas for implementation in areas including non-discrimination, valid consent, rights of carers, coordination and integration of health and social care managers and treatments and services provided. NICE also made a number of research recommendations including:</p> <p>Cognitive stimulation - evidence suggests that cognitive stimulation is effective in people living with dementia.</p> <p>Psychological interventions for carers of people living with dementia - this is vital, and more research is needed to generate a better evidence base for this.</p> <p>Effect of staff training on behaviour that challenges - proportion of people living with dementia with behaviour that challenges tends to rise as the dementia progresses; this in turn will require 24-hour care.</p> <p>Research funded under the Research Programme in Dementia Care is framed around the following key priorities: staff and staff training; quality of care; co-ordination of care; information and communication; management of behaviours and management of symptoms. The aim of this Programme is to ultimately lead to improvements in care for patients</p>

⁵¹ UN Principles for Older Persons (1991) <http://www.un.org/documents/qa/res/46/a46r091.htm>

⁵² NICE Guidelines (2015) Supporting people with dementia and their carers in health and social care <https://www.nice.org.uk/guidance/cg42/resources/guidance-dementia-pdf>

N.I Policy / Strategy	Relevance to Research Programme in Dementia Care
	and their families and lead to changes in the way's services are commissioned and delivered. Specifically, one of the seven projects funded is looking at the management of behaviour.
Alzheimer's Research UK ⁵³	<p>Research was conducted to identify the quality and quantity of time spent on dementia research. It identified that capacity in UK dementia research, in terms of the number of researchers, is low, particularly when compared to other major disease areas. It was estimated the ratio of researchers working on dementia to those working, for example, on cancer is roughly 1:6.</p> <p>The report also made a number of research recommendations with the intent of informing the capacity building process, the most relevant of which include:</p> <p>The need to improve social awareness of the need for dementia research. Increased public funding would signal its importance and encourage greater voluntary giving.</p> <p>Funding for research and the training pathway for clinicians wishing to undertake research in the dementia field need to be more flexible, to accommodate both the time and income required to carry out clinical work and research, or;</p> <p>Research networks need to be strengthened and extended to promote more collaboration and support researchers and institutions beyond centres of excellence.</p> <p>The Research Programme in Dementia Care seeks to build capacity and expertise in NI researchers which will in turn increase their ability to apply for other sources of grant funding in the future, continuing to develop capacity and expertise once this Programme is completed.⁵⁴</p>
Mental Capacity Act ⁵⁵	<p>The Mental Capacity (Northern Ireland) Act 2016 came in to force in March 2016. The Act is a significant step forward for promoting the dignity, autonomy and human rights of citizens, to combine both mental health and mental capacity law. This ensures that if a person has capacity, they can make decisions about their medical treatment even if they have a mental health condition. In addition, the Act provides a framework for making decisions on behalf of people who lack capacity and uses the principle of best interests to guide this.</p> <p>Therefore, the Act will support people living with dementia to make decisions about their own health, welfare and finance when they have capacity to do so and will require those responsible for their care to respect those decisions in practice.</p>

⁵³Alzheimer's Research UK Defeating dementia, building capacity to capitalise on the UKs research strengths [http://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/ARUK_Defeating_Dementia - Building capacity to capitalise on the UKs research strengths.pdf](http://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/ARUK_Defeating_Dementia_-_Building_capacity_to_capitalise_on_the_UKs_research_strengths.pdf)

⁵⁴ HSC R&D Division Programme Bid

⁵⁵ <http://www.legislation.gov.uk/nia/2016/18/contents>

Appendix 6 External Assessment Panel members

The following table 7.4 provides an overview of members of the evaluation panel:

Table 7.4 External Assessment Panel members

Name	Organisation	Status/Voting Member
Professor Bernadette Hannigan	Director of R&D HSC Research & Development Division	Not a voting member – acted as chair of the panel
Dr Janice Bailie	Assistant Director HSC Research & Development Division	Not a voting member – there in capacity as assistant director of R&D
Dr James Pickett	Senior Research Manager Alzheimer's Society	Voting member
Ms Angela Hodkinson (Observer)	Programme Executive The Atlantic Philanthropies	Not a Voting member-there in capacity as co-funder
Dr Roger O'Sullivan	Director Centre for Ageing Research & Development in Northern Ireland	Voting member
Professor Antony Bayer	Personal Chair Institute of Primary Care & Public Health	Voting member
Professor June Andrews	Professor in Dementia Services Dementia Knowledge Exchange	Voting member
Professor Pat Schofield	Professor of Nursing University of Greenwich	Voting member
Dr Louise McCabe	Senior Lecturer University of Stirling	Voting member
Mr Seamus McErlean	Social Care Commissioning Lead Health & Social Care Board	Voting member
Dr Gail Johnston	Programme Manager	Not a voting member – there in capacity as programme manager for the scheme
Ms Theresa Clarke	PPI Representative	Voting member
Ms Corinna Hammond	Carer Representative	Voting member
Mrs Kathleen Roulston	Strand Administrator	Not a voting member – there in capacity as strand administrator for the scheme

Appendix 7 Progress of Projects to date

The following table 7.5 summarises the outputs and impacts of the projects to date

Table 7.5 Project Progress to date

	Project	Sample	Summary of project
1	Pain assessment and management for patients with advanced dementia nearing the end of life 01.01.14	3 bereaved carers, 23 doctors, 24 nurses and 14 healthcare assistants. 5 TeleECHO clinics and pre-clinic=119 staff	<p>Outputs:</p> <ul style="list-style-type: none"> • 5 Publications • 4 oral presentations • 1 Seminar • 1 Poster <p>Successful collaborations with healthcare and charitable organisations established</p> <p>Expected/actual impacts:</p> <p>Participants from research strongly agreed and welcomed further ECHO clinics in dementia, pain and other chronic conditions.</p>
2	Risk Communication in Dementia Care 01.01.14	17 people living with dementia, 22 carers, 160 community professionals	<p>Outputs:</p> <ul style="list-style-type: none"> • 7 Publications • 11 oral presentations • 3 Poster • Public information booklet • Summary booklet for professionals <p>Expected/actual impacts:</p> <p>Findings have been communicated to HSC staff practising in dementia care throughout the project lifespan and these have been well received.</p> <p>The public information leaflet has been designed to provide practical advice for people living with dementia and their families on making decisions about risk in everyday life.</p>

	Project	Sample	Summary of project
			<p>Throughout the project there has been communication with Dr Priya Bahri, Principle Scientific Administrator at the European Medicines Agency.</p> <p>Collaborative work with the Max Planck Institute for Human Development</p> <p>Publications have generated interest and they have been approached for their advice on another study.</p>
3	<p>Promoting informed decision making and effective communication through advance care planning for people with dementia and their family carers</p> <p>01.02.14</p>	<p>197 family carers across 24 nursing home sites, 10 nursing home managers and 1 ACP facilitator.</p>	<p>Outputs:</p> <ul style="list-style-type: none"> • 6 Publications • 5 oral presentations • 6 Posters • Comfort care booklet <p>Expected/actual impacts:</p> <p>Further funding has been secured for the expansion of the project from the Joint Programme - Neurodegenerative Diseases and the Alzheimer's society: Scaling up the Family Carer Decision Support Intervention: A transnational effectiveness-implementation evaluation.</p> <p>Integration into nursing course curriculum.</p>
4	<p>The development of a comprehensive medicines management approach for persons with dementia</p> <p>01.11.14</p>	<p>Prescribing data reviewed for 6 826 persons identified on EPD. Interviews with 18 patients, 5 carers, 15 GPs and 15 community pharmacists</p>	<p>Outputs:</p> <ul style="list-style-type: none"> • 2 Publications and 2 pending publications • 4 oral presentations <p>An abstract has been prepared and accepted for presentation at the Health Services Research & Pharmacy Practice Conference in April 2019.</p> <p>Expected/actual impacts:</p> <p>The research team will now focus on further feasibility and pilot testing in order to work towards a larger randomised controlled trial to provide evidence to support</p>

	Project	Sample	Summary of project
			the use of the developed intervention in clinical practice. In conducting the present project, we have also been able to generate important data relating to the appropriateness of prescribing for people living with dementia in primary care, and this will contribute to wider prescribing knowledge in NI through appropriate dissemination. We also intend to use these findings to inform future exploratory work.
5	A feasibility study of facilitated reminiscence for people with dementia 01.12.14	60 patients and carers (30 dyads)	<p>Outputs:</p> <ul style="list-style-type: none"> • 6 Publications • 12 presentations • 1 Poster • Play • Young writers' seminar • Seminars <p>Expected/actual impacts:</p> <p>Developing the project into an RCT</p> <p>Increase in the number of reminiscence facilitators within the Trust</p> <p>Expansion of the play to be shown across NI</p>
6	Technology enriched supported housing – a study into the lived experience of elders with dementia and their carers 01.01.15	Records of 243 tenants in 9 TESA facilities were reviewed. Interviews with 25 tenants, 25 informal carers and 21 formal carers. 64 tenants took part in focus groups across 8 facilities	<p>Outputs:</p> <ul style="list-style-type: none"> • 1 Publications 2 pending • 1 oral presentation • Artwork displays <p>Expected/actual impacts:</p> <p>Integration of results into Occupational Therapy course Curriculum</p>
7	The evaluation of a Healthcare Passport to improve quality of care and communication for	26 patients and 25 carers followed longitudinally and 5 GPs +2 service user engagement groups	<p>Outputs:</p> <ul style="list-style-type: none"> • 1 Publication and 1 pending • 2 oral presentations

	Project	Sample	Summary of project
	people living with dementia (EQuIP)		<ul style="list-style-type: none"> • EQuIP Launch <p>Throughout 2018 they have presented the study at Universities and conferences in the UK.</p> <p>Expected/actual impacts:</p> <p>Strong ties have been formed between the memory clinic, the university and the Alzheimer's Society. There has been communication between the industry professionals from tech companies on how ICT could help develop the passport further.</p>

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