

# PACEC

Public and Corporate  
Economic Consultants



**HSC R&D Division**

**Evaluation of the Research Programme in Dementia Care**

**First Annual Report – November 2015**

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# 1 EXECUTIVE SUMMARY

## 1.1 Introduction

PACEC were commissioned by the HSC Research and Development Division to conduct an evaluation of the Research Programme in Dementia Care.

The purpose of the assignment was to evaluate:

- The process for identifying research priorities in Northern Ireland to inform the research topics;
- Organisation of the call for proposals and award process;
- Inter-disciplinary and inter-sectoral relationships developed as a result of joint research projects;
- Capacity built to continue applied dementia care research in NI and attract alternative funding;
- Perceived quality and breadth of dissemination activity; and
- 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.

The requirements are to evaluate the programme across a 4 year period and to produce the following:

- First Annual Report;
- Interim Reporting Years 2 and 3; and
- Summative Assessment/ Final Report Year 4.

This document represents the First Annual Report relating to the period April 2014 – March 2015.

## 1.2 Methodology

The methodology for this First Annual Report involved the following stages:

- A review of the processes used to identify research priorities, the call for proposals and the award process;
- A desk top analysis of key documentation relating to the research programme;
- Telephone and online surveys with Principal Investigators; Research Team members and unsuccessful applicants; and
- One-to-one, face-to-face consultations with key stakeholders including evaluation panel members.

## 1.3 Policy and Research Priorities

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) and charged with delivering the strategy's accompanying action plan.

The research priorities for this Programme were identified through consultation with key stakeholders including service users, health professionals and commissioners in liaison with the DSIG. This consultation exercise used initial topics identified by a national priority setting exercise led by the James Lind Alliance and the Alzheimer’s Society UK.

The programme fits with a number of local and national policies, including DHSSPS Service Framework: Dementia<sup>1</sup> and ‘Transforming Your Care’: A Review of Health and Social Care in Northern Ireland, as it aims to identify new models of care which will ultimately lead to direct improvements in patient care and systemic changes in the way services are commissioned and delivered, improving services for patients with dementia and their carers. The programme also 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 in dementia research once this programme is completed.

## 1.4 Statistical Indicators

Statistical data on dementia prevalence and population projections show that by 2021 there will be almost 25,000 people living with dementia, compared to 19,765 people in 2014, representing an increase of 26%. These population projections demonstrate the scale of the growing problem and the need for further research into the cause, cure and care of dementia.

Alzheimer’s UK have estimated that the annual cost of dementia is £32,250<sup>2</sup> per person; if this cost is applied to the estimated number of people with dementia in Northern Ireland, the cost to the NI economy was £637M in 2014. Furthermore, based on projected figures, it is estimated the cost of dementia in 2021 will increase to £805M. This estimation does not take into account changes in the cost of living.

**Table 1-1 Estimated costs of dementia in NI**

Year	Estimated number of people with dementia	Estimated Cost
2014	19,765	£637M
2021	24,980	£805M

Source: Alzheimer’s Society and Alzheimers UK

## 1.5 The Dementia Research Programme

An open call for proposals for the Research Programme in Dementia Care was first issued in June 2013. The call closed in September 2013. Eight applications were submitted, three of which were awarded funding (£987,228.52 awarded in total). A second call was issued in February 2014 and closed in May 2014. A consultation event was also held on 6<sup>th</sup> March 2014 to provide potential applicants with more detail in relation to the programme and feedback from stage 1. At this stage eight applications were received, four of which were awarded funding (£1,282,651 awarded in total).

<sup>1</sup> DHSSPS Service Framework Dementia [http://www.dhsspsni.gov.uk/sfmhw\\_-\\_dementia.pdf](http://www.dhsspsni.gov.uk/sfmhw_-_dementia.pdf)

<sup>2</sup> Alzheimer’s Society (2014a). Dementia UK: second edition. London: Alzheimer’s Society.

### 1.5.1 Application Process

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. Following peer review, applications were then evaluated by an external panel of international experts in the field of dementia care, members of DSIG and PPI representatives against rigorous criteria 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 3.

Applicants were advised in the specification<sup>3</sup> that their proposals would be evaluated against the following criteria:

- Policy relevance;
- Innovation and novelty of research proposal;
- Knowledge of area and understanding of key issues;
- Quality of the proposal;
- Track record/experience of research team and suitability of environment;
- Value for money;
- Personal Public Involvement;
- Dissemination / Knowledge Transfer.

### 1.5.2 Successful projects

The following table summarises the seven successful projects.

**Table 1-2 Successful applications**

	Project	Relevant research priority	Grant Awarded
1	Pain assessment and management for patients with advanced dementia care nearing the end of life	Management of symptoms	£307,893
2	Risk Communication in Dementia Care	Information and communication	£252,597
3	Promoting informed decision making and effective communication through advance care planning for people with dementia and their family carers	Information and communication	£426,738
4	The development of a comprehensive medicines management approach for persons with dementia	Management of symptoms	£292,925
5	A feasibility study of facilitated reminiscence for people with dementia	Staff training Quality of care Co-ordination of care Information and communication	£278,602

<sup>3</sup> Guidance Notes for Commissioned Research in Dementia Care 2014

	Project	Relevant research priority	Grant Awarded
		Management of behaviours Management of symptoms	
6	Technology enriched supported housing – a study into the lived experience of older people with dementia and their carers	Quality of care	£383,690
7	The evaluation of a Healthcare Passport to improve quality of care and communication for people living with dementia (EQulP)	Information and communication Co-ordination of care	£327,434

HSC R&D monitors the projects on an annual basis. At this stage, three of the projects have submitted an annual progress report. Whilst the project report requires PIs to provide a range of information, it does not have a succinct section which documents project progress against initial timescales.

Some projects have also experienced delays in beginning their projects due to factors such as research governance and staff recruitment; they have however been able to make progress in initial data gathering. However, HSC R&D staff do not monitor the risks of these projects, this is undertaken by the trial management steering group / research board of each project.

## 1.6 Survey Results

Surveys were completed with Principal Investigators (PIs), research team members and unsuccessful applicants. The purpose of the surveys was to gather feedback on their experience on the application process and the intended impacts of the research projects.

In general, most respondents indicated high satisfaction with the organisation of the call for proposals. Practical problems however were noted and it was suggested that it would be useful to have an online submission system.

Respondents also highlighted that the research programme in dementia care has encouraged the development of inter-disciplinary and inter-sectoral relationships as a result of joint research projects. The programme has successfully brought together researchers who have not worked together and who have no previous experience of working in dementia research. It was highlighted that this will enhance capacity and encourage further research into dementia in the future.

All PIs identified impacts they expected from their research in the short, medium and long term, that covered health and well-being, increased knowledge, use to future research, informing policy and economic impacts. The key themes that were identified from the expected impacts included:

### Short / medium term impact:

- Create / enhance knowledge;
- Improve services;
- Use of findings in other research; and
- Identification of best practices in dementia care.

### Long term impact:

- Development of intervention models;
- Implementation of research on a larger scale;
- Improve services;
- Influence policy;
- Develop better ways to support people with dementia and their family members;
- Improve quality of life for people with dementia; and
- Inform other related research development.

However, it was also noted that not all PIs have processes in place to measure the proposed health and well-being and economic impacts of their research.

Whilst all successful projects are currently in their early stages, PIs and research team members indicated that their findings will be disseminated through a range of mechanisms. At this stage, all respondents believed that their projects were capable of influencing dementia services in the future; however all projects did not have mechanisms in place to measure the proposed impacts of the research.

## 1.7 Consultations

The evaluation team completed interviews with a wide range of key stakeholders including representatives from the evaluation panel, Universities, the Dementia Strategy Implementation Group (DSIG) and PPI representatives. The purpose of these interviews was to collate feedback on:

- The process used to define the research priorities;
- Organisation of the call for proposals;
- Partnership element of the programme;
- Assessment of the applications; and
- Impact of the research.

All of the interviewees spoke very positively about the Programme in Dementia Research. It was noted that the process used to define the research priorities was effective and in line with best practice. In general, most stakeholders believed the call for proposals was very well organised, however it was also noted that the call was not widely advertised.

Most interviewees highlighted that the programme was key to developing capacity and expertise in dementia. All interviewees noted that the research projects are in the early stages and acknowledged that factors, such as delays with research governance approval, has meant that some projects have not been implemented as planned. However, in general, stakeholders expressed that they were keen to see the emerging findings of the research. They noted that a range of mechanisms should be used to disseminate research findings. It was suggested that it would be useful to collate the findings of all seven projects on completion and present them at one overall conference or event.

All interviewees noted that the research projects have the potential to influence policies relating to dementia and the way in which dementia services are planned and commissioned. However interviewees did suggest that a pathway to impact plan would be a good mechanism for researchers to outline the steps they can take now in order to maximise any potential impacts of the research.

## 1.8 Conclusions and Recommendations

The process for identifying the research priorities was highly regarded by stakeholders and applicants. It was believed that taking guidance from the James Lind Alliance and Alzheimer's Society UK was in line with best practice and that the research priorities identified have the potential to influence the way dementia services are commissioned and delivered in Northern Ireland.

Both stakeholders and applicants believed that the organisation of the call for proposals was very well organised. However, it was also noted that the call was not widely advertised and it was suggested that increased advertising of the call may encourage a wider scope of applicants. Applicants also noted practical problems when submitting their applications and noted that an electronic application process would be beneficial. PHA noted that they are aware of this issue and are working on being able to accept online applications in the future.

Of the 16 applications received, seven were successful. 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. The templates and pro-formas provided to evaluation panel members ensured that applications were marked fairly and consistently.

Feedback from PIs and other stakeholders has highlighted that inter-disciplinary and inter-sectoral relationships have been developed as a result of joint research projects with PIs indicating they have collaborated with other researchers outside their main discipline. This was viewed as adding value to the research. The research programme in dementia care has brought together collaborative teams who have not worked together before. All PIs noted that the projects created new working relationships and nearly two fifths (37%) of research team members noted that it would have been difficult to gain experience of collaborative research without this programme. Stakeholder discussions and survey findings also indicated that these relationships are key to developing dementia research in the future. It was believed that this should strengthen the research findings as the inclusion of researchers from other disciplines will help to provide a more holistic approach to dementia care and can help to reduce the separation of research and practice.

The research teams brought together a range of researchers who may have no previous experience of dementia research (37%; n=7), creating opportunities to work with experienced dementia researchers in NI and from elsewhere. It was believed this will build capacity for dementia research in Northern Ireland beyond this programme. In total PIs indicated that 12.5 FTE research jobs had been created as a result of this research and this will provide both new and experienced researchers with the opportunity to develop their careers in relation to dementia research.

This is the first year of the evaluation and four of the seven projects have been operational for less than one year; therefore there has been very little dissemination activity so far. Feedback from the PIs has highlighted that they intend to target a range of groups, such as policy makers, commissioners, service providers and people with dementia and their carers when disseminating their findings. It was noted that a range of activities will be used to disseminate research findings, such as presentations/conferences; meetings/seminars and peer reviewed journals. At this stage, two PIs have completed presentations to key stakeholders. In general, stakeholder discussions highlighted that a combination of these activities would be key to enhancing knowledge of the research findings.

The Year 1 evaluation findings have highlighted that stakeholders believe that the research projects have the potential to influence policies relating to dementia and the way in which dementia services are planned and commissioned. It was suggested that a pathway to impact plan would be a good mechanism for researchers to outline the steps they can take now in order to maximise any potential impacts of the research in the future.

We understand that the HSC R&D Division collects performance data from PIs on an annual basis. On previous experience, HSC R&D Division have found that it is not possible to get performance data more frequently and therefore on this basis we note that a recommendation to collect performance data on a bi-annual basis would be impractical. However whilst the project report requires PIs to provide a range of information, it does not have a succinct section which documents project progress against initial timescales. However, since July 2015, all awards now include smart targets and progress against these will be measured in annual and financial reports.

The HSC R&D Division do not manage the risks of these projects, this is undertaken by the trial management steering group / research board of each project. This is something which needs to be considered in the future to ensure the successful delivery of each project. Whilst HSC R&D Division have also noted that projects can be under or over spent in their first / second years due to various reasons such as delays in recruiting staff, it was also highlighted that the budget allocated is usually spent over the course of the project. Nevertheless this is something that the R&D Division monitors closely throughout the project to ensure that budgets remain on course and problems are picked up at an early stage.

### **1.8.1 Recommendations**

This section makes some recommendations based on findings from the Year 1 evaluation.

#### **Pathways to Impact**

Whilst it is acknowledged that the seven projects all have the potential to influence policies relating to dementia and the way in which dementia services are planned and commissioned, it is important that PIs and their research team have a plan in place during the course of their research in order to maximise any potential impacts of their findings. The development of a Pathways to Impact document for each project is therefore recommended. This document should set out clear objectives, highlight the key messages of the research, and plan suitable activities for key audiences in order to share and maximise findings. The Economics and Social Research Council<sup>4</sup> recommend that this should be a living document which should be revisited at least once a year (see Appendix 5).

#### **Recommendation 1:**

**A Pathways to Impact Plan and accompanying Impact Strategy is developed by the researchers for each project which includes timescales and proposed activities.**

<sup>4</sup> The Economic and Social Research Council (ESRC) is the UK's leading research and training agency addressing economic and social concerns

## Research governance

Four PIs have experienced delays in implementing their project due to Trust R&D governance approval. We recommend that HSC R&D Division continue to keep under review the issues associated with research governance within each Trust and consider ways in which processes could be streamlined.

### **Recommendation 2:**

**HSC R&D Division continues to review the issues associated with research governance.**

## ResearchFish

We understand that HSC R&D Division is currently implementing ResearchFish in order to facilitate the submission of progress reports. We recommend that this process continues and that PHA consider how impact data can be collected through this.

### **Recommendation 3:**

**We recommend that HSC R&D Division continues to implement ResearchFish and considers how impact data can be collected through this.**

## Progress Report

Whilst the progress report provides a useful overview of the projects to date, it would be beneficial to have a succinct section which outlines the progress of the project against the initial targets and timescales.

### **Recommendation 4:**

**Amendments to progress report to include project progress against initial targets using a traffic light system.**

## Personal and Public Involvement

The PIs noted the benefits of establishing PPI early on in the research development, as it helps to keep the research focused on real issues for patients and carers and it can be useful when developing data collection tools.

**Recommendation 5:**

**Going forward HSC R&D Division should continue to implement and support PPI in all of their funding schemes.**

## 2 INTRODUCTION AND METHODOLOGY

### 2.1 Introduction

PACEC were commissioned by the HSC Research and Development Division to conduct an evaluation of the Research Programme in Dementia Care.

### 2.2 Terms of Reference

The overall aim of the project, as set in the terms of reference, is to ‘evaluate the research programme in dementia care.’

Table 2.1 below provides an overview of the terms of reference, outlining the relevant sections where these are addressed within this report:

**Table 2-1 Terms of Reference**

Terms of reference	Relevant section
Process for identifying research priorities in Northern Ireland to inform the research topics;	Sections 3, 6 & 7
Organisation of the call for proposals and award process;	Sections 5, 6 & 7
Inter-disciplinary and inter-sectoral relationships developed as a result of joint research projects;	Sections 6 & 7
Capacity built to continue applied dementia care research in NI and attract alternative funding;	Sections 6 & 7
Perceived quality and breadth of dissemination activity; and	Sections 5, 6 & 7
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.	Sections 5, 6 & 7

The requirements are to evaluate the programme across a 4 year period and to produce the following:

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### 2.3 Methodology

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- A review of the processes used to identify research priorities, the call for proposals and the award process;
- A desk top analysis of key documentation relating to the research programme;

- Telephone and online surveys with Principal Investigators; Research Team members and unsuccessful applicants; and
- One-to-one, face-to-face consultations with key stakeholders including evaluation panel members.

## 2.4 Hanney Payback Framework

The model used for this assignment was based on the Hanney Payback Framework<sup>5</sup>. 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 the five categories noted in Table 2.2. This table also highlights how the categories relate to the TOR of this evaluation, and the stage of this evaluation.

**Table 2-2 Payback Framework Categories and your Evaluation Objectives**

Payback Framework Categories		Your terms of reference / evaluation objectives
Category	Definition	
<b>Knowledge</b>	Journal articles conference presentations, research reports etc.	Perceived quality and breadth of dissemination activities. <b>Will be assessed once the projects are at the relevant stage to present findings.</b>
<b>Benefits to future research and research use</b>	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.  <b>Will be assessed once the projects are further developed.</b>
<b>Benefits from informing policy and product development</b>	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. <b>This will be assessed once the projects are further developed.</b>
<b>Health and health sector benefits</b>	Improved health; Cost reduction in delivery of existing services; Qualitative improvements in the	The degree to which the findings of the research has influenced dementia care and support services delivered by Government.

<sup>5</sup> Hanney and Donovan (2011) The Payback Framework explained. Research Evaluation 20 (30) 2011.

Payback Framework Categories		Your terms of reference / evaluation objectives
Category	Definition	
	process of delivery; and Improved equity in service delivery	<b>Will be assessed once the projects are further developed.</b>
<b>Broader economic benefits</b>	Wider economic benefits from commercial exploitation of innovations arising from R&D	Capacity to attract alternative funding <b>Will be assessed once the projects are further developed.</b>

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.

## 2.5 Acknowledgments

The evaluation team would like to thank the staff in HSC R&D Division for providing the necessary information to complete the research. We would also like to express our thanks to the Principal Investigators and their research teams; unsuccessful applicants and relevant stakeholders for taking the time to share their thoughts and experiences of the Programme with us.

## 2.6 Structure of the Report

The report is structured as follows:

- Section 3: Background and Strategic Context;
- Section 4: Statistical indicators of Dementia in Northern Ireland;
- Section 5: Detail on the programme;
- Section 6: Survey Results;
- Section 7: Stakeholder Consultations;
- Section 8: Conclusions and Recommendations.

## 3 BACKGROUND AND STRATEGIC CONTEXT

### 3.1 Introduction

This section sets out the background to the Research Programme in Dementia Care. It looks specifically at key contextual information, providing an overview of the policy context examining the key strategic and policy documents relevant to Research and Development (R&D) within the Department of Health and Social Services and Personal Safety (DHSSPS) in Northern Ireland.

### 3.2 Background to the Research Programme in Dementia Care

#### 3.2.1 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) and charged with delivering the strategy's accompanying action plan.

HSC R&D Division was invited by Atlantic Philanthropies to submit a bid for partnership funding for dementia research in October 2012. HSC R&D Division proposed a 5-year programme of research to enhance knowledge of how best to deliver evidence-based care in NI to people with dementia, in an evidence-informed policy context, and to enhance the local capacity to undertake high quality research relevant to dementia care.

This bid was successful and £2million was allocated to the programme in 2013, with £1million of this coming from The Atlantic Philanthropies and the other £1million from the HSC R&D Division. The programme was funded under the Atlantic Philanthropies Older People's Programme<sup>6</sup>. A key focus of this programme is to improve the quality of health care for those with dementia in Northern Ireland by providing evidence-based approaches to inform policies and practices both in Northern Ireland 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.

#### 3.2.2 Identification of research priorities

In order 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 R&D office to derive a locally agreed priority list of topics on which robust evidence is currently unavailable (refer to Appendix 2 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 Northern Ireland. In total, 30 responses were received. The most frequently mentioned topics were then used to inform the research call.

<sup>6</sup> Atlantic Philanthropies, Ageing <http://www.atlanticphilanthropies.org/ageing-northern-ireland>

The Programme focused on 6 research priorities<sup>7</sup> within a Northern Ireland context in the field of dementia care as highlighted in Table 3.1 below.

**Table 3-1 Research priorities**

Research priorities	Explanation of research priority
Staff and Staff Training:	The best way to train healthcare professionals / care staff to be aware of the needs of dementia patients and in best available care methods; The qualities of a good carer, best ways to select and recruit staff, optimum staffing level.
Quality of Care	How to make the care of people with dementia better in different care settings; How to design and organize care settings and accommodation; How best to maintain quality of life and patient centred care across all care settings; Which place of care setting is better for prognosis / Quality of Life (QoL).
Co-ordination of Care	Supporting carers to keep patients at home/obtaining respite care/role of day care; Best ways to manage and organize care across all care settings/role of one stop shops/one point of contact; Facilitating choice of care; Role of assistive technology in managing independence
Information and Communication	Obtaining a diagnosis; Support and information for carers around diagnosis; Communication problems between health professionals and informal carers; Understanding causes and communicating about risk of dementia; Best ways to disseminate best care strategies
Management of Behaviours	Providing appropriate and stimulating recreational activities and social interaction for people with dementia and the activities that are beneficial for people; Avoiding prescription of anti-psychotic medications to control challenging behaviour; Coping with secrecy, dishonesty and repetitive behaviours; Effectiveness of non-pharmacological and alternative therapies including psychological support; Effectiveness of reality orientation as a management strategy; Difficulties with dentistry, audiology and optometry examinations during dementia
Management of Symptoms	Recognition and management of pain; Managing sleep, changes in sleep patterns and wakefulness in patients with dementia; Incontinence; Medication management and ensuring person with dementia takes prescribed medication; Avoiding anxiety for the patient with dementia; Understanding nutritional requirements and providing appropriate nutrition and vitamin supplementation to people with dementia

The programme seeks to fill those 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.

<sup>7</sup> Guidance Notes for Commissioned Research in Dementia Care 2014

### **3.3 Northern Ireland strategy and policy documents**

As R&D is a key factor in the development and delivery of all aspects of HSC services and DHSSPS policies, there are a wide range of regional, national and international policy and strategic documents that are relevant to the Research Programme in Dementia Care. Table 3.2 summarises the key, relevant strategies to provide an overview of the policy environment in which the programme operates.

**Table 3-2 Relevant Polices and Strategies**

N.I Policy / Strategy	Relevance to Research Programme in Dementia Care
DHSSPS 'Improving Dementia Services in Northern Ireland: A Regional Strategy' (2011) <sup>8</sup>	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 <sup>9</sup>	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 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. <sup>10</sup>
DHPSS 'Transforming Your Care': A Review of Health and Social Care in Northern Ireland (2011)	This report made a number of key areas to address in regards to dementia care: <ul style="list-style-type: none"> <li>• Improve regional standards of care, especially for dementia</li> <li>• 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</li> <li>• Hospital services - people 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 with</li> </ul>

<sup>8</sup>DHSSPS 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>

<sup>9</sup>DHSSPS Service Framework Dementia <http://www.dhsspsni.gov.uk/sfmhw - dementia.pdf>

<sup>10</sup> Guidance Notes for Commissioned Research in Dementia Care 2014

N.I Policy / Strategy	Relevance to Research Programme in Dementia Care
	<p>dementia, research is needed to shift services from hospital settings to closer to home.</p> <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 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.<sup>11</sup></p>
<p>DHSPSS Service Framework: Older People's Mental Health<sup>12</sup></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 with dementia. The programme anticipated applications 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.</p>
<p>Ministerial advisory group on dementia<sup>13</sup></p>	<p>This advisory group identified areas in which dementia research needs improved/how it should be focused:</p> <ul style="list-style-type: none"> <li>• Collaboration is needed between the public and commercial research sectors with greater mutual transparency</li> <li>• The established aim to embed the delivery of research across the full care pathway and in all service sectors</li> <li>• Opportunities for quality scientists from contiguous fields and a strengthened research leadership is needed</li> <li>• To increase the success of the dementia research community in competitive funding contexts and improve the coordination between funders on priorities for dementia research</li> <li>• To extend public engagement in dementia research</li> </ul> <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,<sup>14</sup> therefore enhancing public engagement in dementia research.</p>

<sup>11</sup> HSC R&D division programme bid

<sup>12</sup> DHSPSS Service Framework: Older People's Mental Health [http://www.dhsspsni.gov.uk/sfmhw - older\\_people.pdf](http://www.dhsspsni.gov.uk/sfmhw - older_people.pdf)

<sup>13</sup> Department of Health: Ministerial advisory group on dementia research (2011) [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215558/dh\\_127904.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215558/dh_127904.pdf)

<sup>14</sup> HSC R&D Division Programme Bid

N.I Policy / Strategy	Relevance to Research Programme in Dementia Care
<p>DHSSPS Draft Strategy for Health and Social Care Research and Development in Northern Ireland (2014)<sup>15</sup></p>	<p>This draft strategy aims to improve the health, wellbeing and prosperity of the Northern Ireland population through excellent, world-renowned R&amp;D in health and social care that is led from NI. The strategy is underpinned by four objectives:</p> <p><b>Objective 1:</b> 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.</p> <p><b>Objective 2:</b> To compete successfully for R&amp;D funding, and optimise local funding, to deliver returns on investment for health and wellbeing, academia and commerce.</p> <p><b>Objective 3:</b> 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.</p> <p><b>Objective 4:</b> To increase the emphasis on research relevant to the priorities of the local population.</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 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 Personal and Public 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>

Other relevant policy, strategies and research	Relevance to the Research Programme in Dementia Care
<p>UN Principles for Older Persons (1991)<sup>16</sup></p>	<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>

<sup>15</sup> DHSSPS. Research for Better Health and Social Care: A Strategy for Health and Social Care Research and Development in Northern Ireland. (*Draft for Consultation*). (September 2014): [http://www.dhsspsni.gov.uk/2909142\\_dhssps\\_hsc\\_r\\_d\\_strategy\\_final\\_-\\_minister\\_wells\\_-\\_25\\_september\\_2014.pdf](http://www.dhsspsni.gov.uk/2909142_dhssps_hsc_r_d_strategy_final_-_minister_wells_-_25_september_2014.pdf)

<sup>16</sup> UN Principles for Older Persons (1991) <http://www.un.org/documents/ga/res/46/a46r091.htm>

Other relevant policy, strategies and research	Relevance to the Research Programme in Dementia Care
	<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 with dementia and two projects also look at co-ordination of care.</p>
<p>NICE Guidelines (2006)<sup>17</sup></p>	<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> <ul style="list-style-type: none"> <li>• Cognitive stimulation - evidence suggests that cognitive stimulation is effective in people with dementia.</li> <li>• Psychological interventions for carers of people with dementia - this is vital and more research is needed to generate a better evidence base for this.</li> <li>• Effect of staff training on behaviour that challenges - proportion of people with dementia with behaviour that challenges tends to rise as the dementia progresses; this in turn will require 24 hour care.</li> </ul> <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 and their families and lead to changes in the ways services are commissioned and delivered. Specifically, one of the seven projects funded is looking at the management of behaviour.</p>
<p>Alzheimer's Research UK<sup>18</sup></p>	<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> <ul style="list-style-type: none"> <li>• The need to improve social awareness of the need for dementia research. Increased public funding would signal its importance and encourage greater voluntary giving.</li> <li>• 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;</li> <li>• Research networks need to be strengthened and extended to promote more collaboration and support researchers and</li> </ul>

<sup>17</sup> 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>

<sup>18</sup> Alzheimer'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)

Other relevant policy, strategies and research	Relevance to the Research Programme in Dementia Care
	<p>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.<sup>19</sup></p>

<sup>19</sup> HSC R&D Division Programme Bid

### **3.3.1 Summary**

The strategy and policy documents summarised above note the need for more research into dementia and the need to build dementia research capacity in Northern Ireland. It is in this context that Atlantic Philanthropies and HSC R&D Division provided funding for the Research Programme in Dementia Care. The research priorities for this Programme were identified through consultation with key stakeholders including service users, health professionals and commissioners in liaison with the DSIG. This consultation exercise used initial topics identified by a national priority setting exercise led by the James Lind Alliance and the Alzheimer's Society UK.

The programme fits with local and national policy as it aims to identify new models of care which will ultimately lead to direct improvements in patient care and systemic changes in the way services are commissioned and delivered, improving services for patients with dementia and their carers. The programme also 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 in dementia research once this programme is completed.

## 4 STATISTICAL INDICATORS OF DEMENTIA IN NORTHERN IRELAND

### 4.1 Introduction

In order to contextualise the need for research into dementia care, the following section provides an overview of the key, macro level statistics relating to dementia which emphasize the need for research in this area.

### 4.2 Rates of Dementia

Data from the Alzheimer’s Society indicates that, in 2014, 19,765 people in Northern Ireland were living with dementia.<sup>20</sup> It is also suggested that only 65% of these people will have an actual diagnosis of dementia. The following table shows the estimated number of people with dementia in Northern Ireland and the projected increase by 2021.

**Table 4-1 Estimated current and projected number of people with dementia and / or a diagnosis by Health and Social Care Trust**

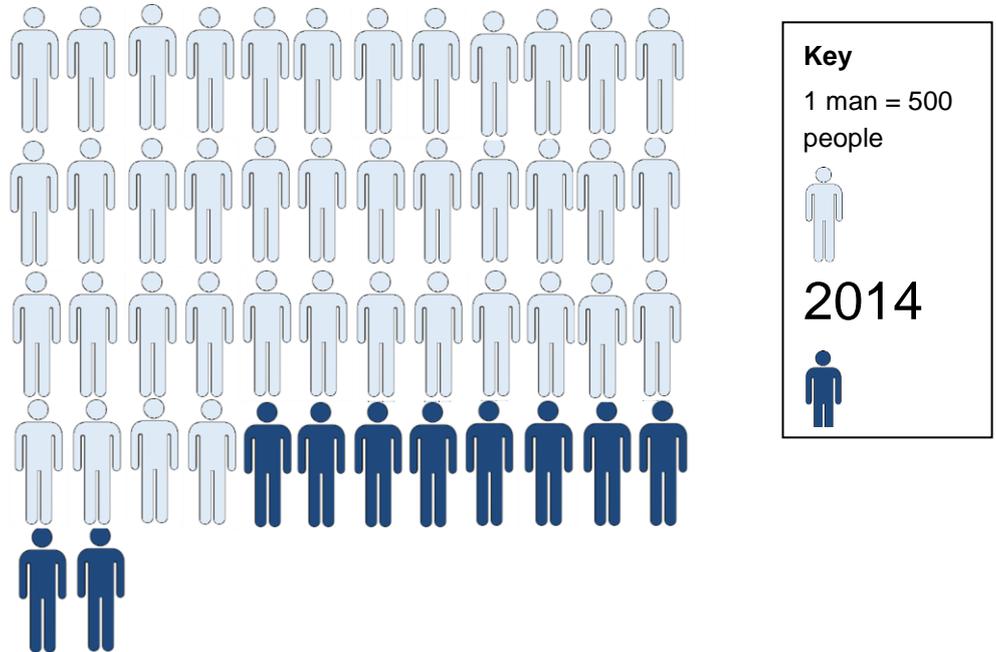
	Health & Social Care Trust					
	Belfast	Northern	South Eastern	Southern	Western	Total
Estimated number of people with dementia in 2014	4083	5244	4132	3477	2830	19,765
% of people with dementia with a diagnosis in 2014	73%	56%	64%	66%	69%	65%
Estimated No of people with dementia in 2021	4315	6848	5335	4677	3805	24,980
No who will have a diagnosis in 2021	2969	3531	3051	2834	2473	14,858
No of people without a diagnosis in 2021	1346	3317	2285	1843	1332	10,123

Source: Alzheimer’s Society Northern Ireland Diagnosis Rates: Progress on improving diagnosis of dementia

The above table illustrates the projected increase in the number of people with dementia by 2021 across all Health and Social Care Trusts (HSCTs). As shown in Figure 4.1, the Alzheimer’s Society estimates that by 2021 there will be almost 25,000 people living with dementia, compared to 19,765 people in 2014, representing an increase of 26%. These population projections demonstrate the scale of the growing problem and the need for further research into the cause, cure and care of dementia, as defined in Improving Dementia Services in Northern Ireland: A Regional Strategy.

<sup>20</sup> Alzheimer’s Society- Northern Ireland Diagnosis Rates: Progress on improving diagnosis of dementia 2013-2014 [http://www.alzheimers.org.uk/site/scripts/download\\_info.php?downloadID=1573](http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1573)

**Figure 4-1 Projected increase in and the number of people with dementia in 2021 compared to 2014**



**26%**

Projected increase in the number of people living with dementia in 2021

### 4.3 Costs of dementia

Alzheimer’s Research UK<sup>21</sup> estimated that dementia costs the UK economy over £26 billion a year through a combination of health and social care costs. Findings for England were grossed to UK-wide prices, taking into account population sizes, as separate data on service use by people with dementia for England, Scotland, Wales and Northern Ireland was not available.

<sup>21</sup> Alzheimer’s Society (2014a). Dementia UK: second edition. London: Alzheimer’s Society.

**Table 4-2 Estimated cost of dementia to the UK economy**

Factors	Costs
Health care	£4.3 billion
Social care	£10.3 billion
Indirect costs – unpaid care	£11.6 billion
Other costs	£0.1 billion
Research	£75 million
<b>Total</b>	<b>£26.3 billion</b>

Overall, this analysis suggests that the direct cost of health and social care associated with dementia in the UK is £14.6 billion (at 2012/13 prices). Unpaid care costs add another £11.6 billion, and other costs (police time, research, advocacy and support by the voluntary sector) amount to approximately £0.1 billion. Aggregating these components gives an overall cost of £26.3 billion, of which the unpaid care element accounts for 44%. It is therefore estimated that the average annual cost is £32,250 per person

This report predicted that, by 2025, expected dementia costs to the UK economy will be £32.5 billion and by 2050 it could cost the UK economy £59.4 billion at today’s prices.

Therefore, based on the Alzheimer’s UK estimated annual cost of dementia of £32,250<sup>21</sup> per person and applying this cost to the estimated number of people with dementia in Northern Ireland, the cost to the NI economy was £637M in 2014. Based on projected figures, it is estimated the cost of dementia in 2021 will increase to £805M. This represents an increase of 26%. This estimation does not take into account changes in the cost of living.

**Table 4-3 Estimated costs of dementia in NI**

Year	Estimated number of people with dementia	Estimated Cost
2014	19,765	£637M
2021	24,980	£805M

Source: Alzheimer’s Society and Alzheimers UK

#### 4.4 Summary

This section highlights the prevalence of dementia in Northern Ireland and the UK, demonstrating the scale, growth and cost of the problem. The Research Programme in Dementia Care seeks to address the increasing prevalence of dementia in NI and the burden it places, and will place, on health and social care staff and resources, and on the quality of life and wellbeing of service users and their wider network of carers. It is hoped that evidence-based interventions and programmes of care that have been subjected to robust evaluation and are found to be effective will be

recommended, commissioned and embedded in services.<sup>22</sup> It is envisaged that this will lead to direct improvements in patient care, improving quality of life and reducing the economic impact of dementia.

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<sup>22</sup> HSC R&D Division Programme Bid

## 5 DETAIL ON THE PROGRAMME

### 5.1 Introduction

This section of the report sets out how the research programme was implemented providing detail on the following aspects of the programme:

- The open call for proposals;
- The application process;
- The assessment of the applications;
- Successful projects;
- Monitoring of the projects; and
- Progress of the projects to date.

### 5.2 Open call for proposals

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

In order to allocate the remaining funding, it was therefore decided to undertake a second call. This was issued in February 2014 and closed in May 2014. It was also advertised through the HSC R&Ds distribution list. A consultation event was held on 6<sup>th</sup> March 2014 in Grosvenor House 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. At this stage 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).

The following table summarises the timeline for the call for proposals.

**Table 5-1 Timescales for the call for proposals**

Date	Activity	Outcome
June 2013	Open Call advertised	
September 2013	Call closes	Eight applicants; Three successful.
February 2014	2nd call launched	
6th March 2014	Consultation event held	Eight attendees
May 2014	2nd call closes	Eight applicants; Four successful

### 5.3 Application Process

Applicants were required to submit an application to the HSC R&D Division. The application required the completion of the following areas:

- Synopsis of proposed research;
- Description of proposed investigation;
- Relevance to HSC;
- Role of project team;
- Personal and Public Involvement (PPI) in the project;
- Research Governance;
- Finance;
- Justification for support; and
- Nominations of referees.

The application form was available from HSC R&D Division in either a paper or electronic format. Applicants were required to submit the following:

- One hard copy of the original signed application form (fully completed);
- One hard copy of the Chief Investigator's and Co-Investigators' current CV (included at the end of original application Annex A);
- One hard copy of the research protocol (included at the end of original application) which must not exceed 8 pages, excluding references; and
- One electronic copy of the application.

### 5.4 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 the R&D Division choose an additional two. All peer reviewers were external, independent experts who reside outside Northern Ireland. Following peer review, applications for this programme were evaluated by an external panel of international experts in the field of dementia care, members of DSIG and PPI representatives against rigorous criteria 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 3.

Applicants were advised in the specification<sup>23</sup> that their proposals would be evaluated against the criteria highlighted in Table 5.2 below.

<sup>23</sup> Guidance Notes for Commissioned Research in Dementia Care 2014

**Table 5-2 Criteria used to evaluate projects**

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

Evaluation panel members were asked to score the application on the 1 – 10 score 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.

Three applications were successful in stage 1 and four were successful in stage 2, three of which 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).

## **5.5 Successful Projects**

Overall, seven projects were awarded funding under this programme of research following evaluation by an external panel of international experts. Table 5.3 provides an overview of the seven successful projects and the research priorities the projects relate to.

**Table 5-3 Successful projects**

	<b>Project</b>	<b>Relevant research priority</b>	<b>Stage Awarded</b>	<b>Project Start Date</b>	<b>Duration of project</b>	<b>Grant Awarded</b>
1	Pain assessment and management for patients with advanced dementia care nearing the end of life	<ul style="list-style-type: none"> <li>• Management of symptoms</li> </ul>	1 <sup>st</sup> call	01.01.14	36 months	£307,893
2	Risk Communication in Dementia Care	<ul style="list-style-type: none"> <li>• Information and communication</li> </ul>	1 <sup>st</sup> call	01.01.14	36 months	£252,597
3	Promoting informed decision making and effective communication through advance care planning for people with dementia and their family carers	<ul style="list-style-type: none"> <li>• Information and communication</li> </ul>	1 <sup>st</sup> call	01.02.14	36 months	£426,738.52
4	The development of a comprehensive medicines management approach for persons with dementia	<ul style="list-style-type: none"> <li>• Management of symptoms</li> </ul>	2 <sup>nd</sup> call	01.11.14	36 months	£292,925
5	A feasibility study of facilitated reminiscence for people with dementia	<ul style="list-style-type: none"> <li>• Staff training</li> <li>• Quality of care</li> <li>• Co-ordination of care</li> <li>• Information and communication</li> <li>• Management of behaviours</li> <li>• Management of symptoms</li> </ul>	2 <sup>nd</sup> call	01.12.14	24 months	£278,602
6	Technology enriched supported housing – a study into the lived experience of older people with dementia and their carers	<ul style="list-style-type: none"> <li>• Quality of care</li> </ul>	2 <sup>nd</sup> call	01.01.15	36 months	£383,690
7	The evaluation of a Healthcare Passport to improve quality of care and communication for people living with dementia (EQuIP)	<ul style="list-style-type: none"> <li>• Information and communication</li> <li>• Co-ordination of care</li> </ul>	2 <sup>nd</sup> call	01.01.15	30 months	£327,434

In total, £2,269,879 was funded for these projects. Whilst the initial budget was £2million, an extra £269,879 was awarded by R&D Division to an extra study that was deemed fundable.

As highlighted in Table 5.3, some of these projects related to more than one research priority. Ultimately it is envisaged that the programme will lead to direct improvements in patient care and systemic changes in the way services are commissioned and delivered. The programme also 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 in dementia research once this programme is completed.

## 5.6 Budget v Expenditure

The following table provides an overview of the initial budgets allocated to each project and the expenditure of each project to date (including predicted expenditure 2015 – 2018).

**Table 5-4 Budget v Expenditure**

	Project	2013/14		2014/15		2015/16		2016/17		2017/18	
		Total at start of project	Total at outturn	Total at start of project	Total at outturn	Total at start of project	Total at outturn	Total at start of project	Total at outturn	Total at start of project	Total at outturn
1	Pain assessment and management for patients with advanced dementia care nearing the end of life	£26711	£105,753	£105,153	£82,432	£108,152	£73,007	£80,534	£58751	n/a	n/a
2	Risk Communication in Dementia Care	£22722	£6691	£82056	£82677	£82080	£83239	£64923	£75363	n/a	n/a
3	Promoting informed decision making and effective communication through advance care planning for people with dementia and their family carers	£36368	£81494	£145584	£117026	£114598	£74444	£44665	£66026	n/a	n/a
4	The development of a comprehensive	n/a	n/a	£52216	£77993	£96093	£70077	£101621	£103688	£42992	£47289

	Project	2013/14		2014/15		2015/16		2016/17		2017/18	
		Total at start of project	Total at outturn	Total at start of project	Total at outturn	Total at start of project	Total at outturn	Total at start of project	Total at outturn	Total at start of project	Total at outturn
	medicines management approach for persons with dementia										
5	A feasibility study of facilitated reminiscence for people with dementia	n/a	n/a	£67932	£11320	£154153	£147416	£56519	£122162	n/a	n/a
6	Technology enriched supported housing – a study into the lived experience of older people with dementia and their carers	n/a	n/a	£70730	£36687	£124853	£107427	£132927	£128482	£57071	£106791
7	The evaluation of a Healthcare Passport to improve quality of care and communication for people living with dementia (EQuIP)	n/a	n/a	£99136	£42486	£132292	£147692	£103226	£108702	£0	£31841

The table highlights that project budgets were re-adjusted from initial predictions, with projects being under or over spent in their first / second years. R&D have indicated this can be to various reasons such as staff salaries, or delays in recruiting staff; highlighting that the budget allocated is usually spent over the course of the project. This is something that R&D monitors closely throughout the projects.

## **5.7 Monitoring of projects**

HSC R&D Division monitor the projects on an annual basis and require Principal Investigators 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 is also required by HSC R&D Division. HSC R&D Division must receive details of all reports or publications stemming from the research supported by this grant and the support of HSC R&D Division must be acknowledged in all publications.<sup>24</sup> Budget monitoring also occurs on a quarterly basis.

The trial management steering group / research board of each project manage the operational risks of the research projects.

In order to monitor and evaluate the outputs and impacts of the research it funds, HSC R&D Division have joined with 74 other UK public and charitable funders in using an online survey database, ResearchFish<sup>25</sup>. This is an online survey database which gathers information about research outputs and outcomes. Work is currently ongoing to align report mechanisms with ResearchFish. All HSC R&D Division award holders will be asked to provide annual information on the outputs and impacts of their research through this system for the duration of their award and for a period of at least three years after completion. The information collected will be similar to that currently collected in the progress report.

<sup>24</sup> Guidance Notes for Commissioned Research in Dementia Care 2014

<sup>25</sup> ResearchFish research outcomes collection and evaluation service for Funders, Researchers and Research Institutes.

## 5.8 Progress of projects to date

The following table summarises the progress to date of each project.

**Table 5-5 Progress of the projects**

	Project	Proposed start date	Actual start date	Spend to date	Summary of project to date
1	Pain assessment and management for patients with advanced dementia care nearing the end of life	01.01.14	01.01.14 On time	£190,726	<ul style="list-style-type: none"> <li>• Ethical and Trust Governance permissions obtained</li> <li>• PPI involvement in project</li> <li>• Data collection tools designed</li> <li>• Face to face interviews completed with healthcare professionals. The size and scope of the sample expanded from that anticipated in the original grant application as emerging findings indicated a more thorough investigation would be necessary</li> <li>• Difficulties in recruitment of bereaved carers. Alternative options being explored and it is anticipated that these changes will enable data saturation</li> <li>• Preliminary analysis started</li> <li>• Phase two of the research programme started</li> <li>• Preliminary data presented at the Palliative Care Research Forum of NI Showcase Event</li> <li>• Training opportunities for Research Fellow</li> <li>• Successful collaborations with healthcare and charitable organisations established</li> </ul>

	Project	Proposed start date	Actual start date	Spend to date	Summary of project to date
2	Risk Communication in Dementia Care	01.01.14	01.01.14 On time	£130,877	<ul style="list-style-type: none"> <li>• Delays in appointing Research Assistant</li> <li>• Ongoing engagement with service users and carers</li> <li>• Systematic literature review completed</li> <li>• Design of data gathering tools completed</li> <li>• Data collection team appointed</li> <li>• Awaiting confirmation of ethical and governance approval before commencing recruitment and data collection</li> <li>• At this stage, no empirical findings to report</li> <li>• Presentations at the Health and Social Care Cross Trust Dementia Strategy Group meetings</li> <li>• Appropriate training for Research Assistant</li> </ul>
3	Promoting informed decision making and effective communication	01.01.14	01.02.14 Delayed	£214,535	<ul style="list-style-type: none"> <li>• Ethics approval received from ORECNI in July 2014</li> <li>• Ongoing engagement with PPI representatives</li> <li>• Data collection completed in Nursing Home pair#1</li> <li>• Amendments made to wording of questionnaires following feedback</li> <li>• Commencement of data collection for Nursing Home pair#2</li> <li>• Presentation of findings at regional and national conferences</li> <li>• Training opportunities for Research Fellow</li> <li>• Application to Alzheimer's society for other awards/grants</li> </ul>
4	The development of a comprehensive medicines management approach for persons with dementia	01.09.14	01.11.14 Delayed	£80,548	Annual progress report not yet due
5	A feasibility study of facilitated reminiscence for people with dementia	30.09.14	02.03.15 Delayed	£78,043	Annual progress report not yet due
6	Technology enriched	01.09.14	13.01.15	£73,982	Annual progress report not yet due

	Project	Proposed start date	Actual start date	Spend to date	Summary of project to date
	supported housing		Delayed		
7	The evaluation of a Healthcare Passport to improve quality of care and communication for people living with dementia (EQulP)	01.07.14	01.01.15 Delayed	£110,592	Annual progress report not yet due

As shown in Table 5.5, five of the seven successful projects experienced delays in starting their project.

At this stage of the programme, applicants (3) who were successful in the first stage have submitted an annual progress report at the end of the financial year in 2015.

The format of the progress report however does not provide a succinct section which outlines the progress of the project against the initial targets and timescales. The narrative section does highlight that, in some instances, PIs experienced delays in beginning their projects due to research governance. Nevertheless, progress reports highlight that all projects have designed data collection tools and in some cases, begun data collection and preliminary data analysis. Some PIs have also given presentations to key stakeholders. All PIs who have submitted progress reports have also noted that research team members have been able to avail of suitable training.

## 5.9 Summary

This section of the report provides an overview of how the call was organised and how applicants were assessed by evaluation panel members. Three projects were successful in stage 1. Therefore, in order to allocate the remaining funding a second call was organised and four projects were successful in this stage. Overall, seven projects were funded and the total £2million budget was awarded indicating that the call attracted a high level of fundable projects.

HSC R&D monitors these projects on an annual basis. At this stage, three of the projects have submitted an annual progress report. Whilst the project report requires PIs to provide a range of information, it does not have a succinct section which documents project progress against initial timescales. It would be beneficial to have a template which requires the project leads to confirm whether they are on target/ budget or if they are ahead/ behind- using a traffic light system.

Some projects have also experienced delays in beginning their projects due to factors such as research governance and staff recruitment, they have however been able to make progress in initial data gathering. However, HSC R&D staff do not monitor the risks of these projects, this is undertaken by the trial management steering group / research board of each project.

## 6 SURVEY RESULTS

### 6.1 Introduction

PACEC undertook surveys with those involved in the Research Programme in Dementia care, namely:

- Principal Investigators;
- Research team members; and
- Unsuccessful applicants.

The purpose of these interviews was to gather feedback from applicants on their experience on the application process.

### 6.2 Principal Investigators Survey

As part of the evaluation, PACEC conducted seven surveys with the Principal Investigators of the seven successful research projects (100% response rate). The surveys were structured around the following key themes:

- The application process;
- The collaborative nature of the research; and
- The anticipated outputs, outcomes and impacts of the research.

#### 6.2.1 Application Process

An open call for proposals for the Research Programme in Dementia Care was first issued in June 2013 and closed in September 2013 and three applications were awarded funding at this stage. In order to allocate the remaining funding, it was therefore decided to undertake a second call. This was issued in February 2014 and closed in May 2014. A consultation event was held on 6th March 2014 in Grosvenor House to provide potential applicants with more detail in relation to the programme and feedback from stage 1 of the call.

This 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.

The majority of the PIs (71%; n=5) believed the call for research proposals was very well organised, whilst 29% (n=2) of PIs indicated that they felt the call was somewhat organised. Table 6.1 below provides an overview of the PIs level of satisfaction with aspects of the call for proposals.

**Table 6-1 Level of satisfaction with the call for proposals**

Aspect of the call for proposal	Level of satisfaction
Advertising	71% (n=5) very satisfied; 29% (n=2) satisfied
Length of time to respond	14% (n=1) very satisfied 71% (n=5) satisfied 14% (n=1) neither / nor
Level of advice and assistance provided	86% (n=6) very satisfied 14% (n=1) satisfied
Identification / Clarity of research priorities	57% (n=4) very satisfied 43% (n=3) satisfied
The feedback following the application	57% (n=4) very satisfied 29% (n=2) satisfied 14% (n=1) neither / nor

The above table shows high levels of satisfaction with various aspects of the call for proposals. While one respondent thought that the length of time to respond to the proposal was tight, they acknowledged that this was not unique to these types of applications.

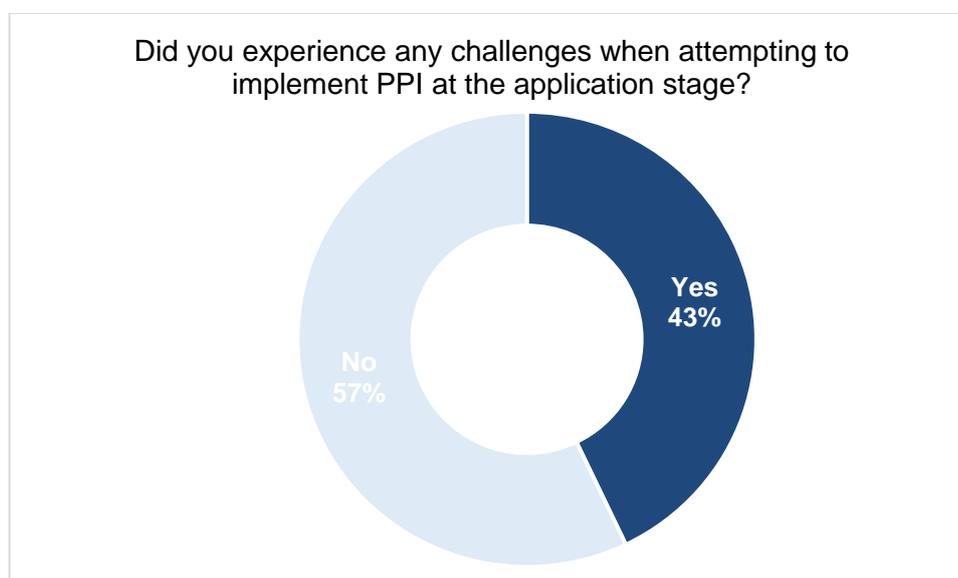
Furthermore, prior to submitting their application, the majority of PIs (86%; n=6) submitted queries. Of those who submitted queries, all indicated that they were very satisfied with the response provided and the timescale the response was delivered in. A few PIs highlighted that the support from the R&D Division, (in particular, Gail Johnston), was excellent and helped significantly during the application process.

### 6.2.2 Personal and Public Involvement (PPI)

A key element of the application process was Personal and Public Involvement (PPI)<sup>26</sup>. All PIs implemented PPI prior to submitting their application and consulted with organisations and individuals when developing their application. As shown in Figure 6.1, 43% (n=3) PIs indicated that they experienced challenges when attempting to implement PPI at the application stage.

<sup>26</sup> 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.

**Figure 6-1 Challenges implementing PPI**



Of those who indicated they experienced challenges, one PI stated that it was sometimes difficult to sustain people’s engagement and continued commitment to attend meetings. In contrast, one PI indicated that implementing PPI was very difficult due to the lack of time between the call for proposals and the submission date as time restrictions meant it was difficult to integrate PPI into the application. For those who did not experience challenges in implementing PPI at the application stage, this was due to having already established links with service users and organisations such as the Alzheimer’s Society.

Table 6:2 below indicates that most PIs (86%; n=6) believed implementing PPI was relatively easy.

**Table 6-2 Level of ease in implementing PPI**

Level of ease in implementing PPI	Number of PI’s
Very easy	29% (n=2)
Somewhat easy	57% (n=4)
Very difficult	14% (n=1) neither / nor

Overall, all PIs indicated that there were key benefits in implementing PPI at the application stage. PPI was also viewed as an important mechanism in the development of data collection tools, in terms of identifying how best to engage with service users and carers. The following verbatim comments emphasize some of the perceived benefits of PPI at the application stage:

*“Affirmation that what we’re seeking to do was a worthwhile thing for people involved in dementia on a regular basis.”*

*“Useful in terms of developing materials; questionnaires; letters...helpful with commenting on material in a meaningful way.”*

*“It’s reassurance that work is going in the right direction.”*

*“Helped our team develop a realistic methodology.”*

All PIs indicated that they intend to engage with users during the implementation of their research. Some examples of how they intend to do this are stated below:

- Engage with service users / carers as part of the research;
- Inform service users / carers of research results; and
- Organise conferences with PPI organisations.

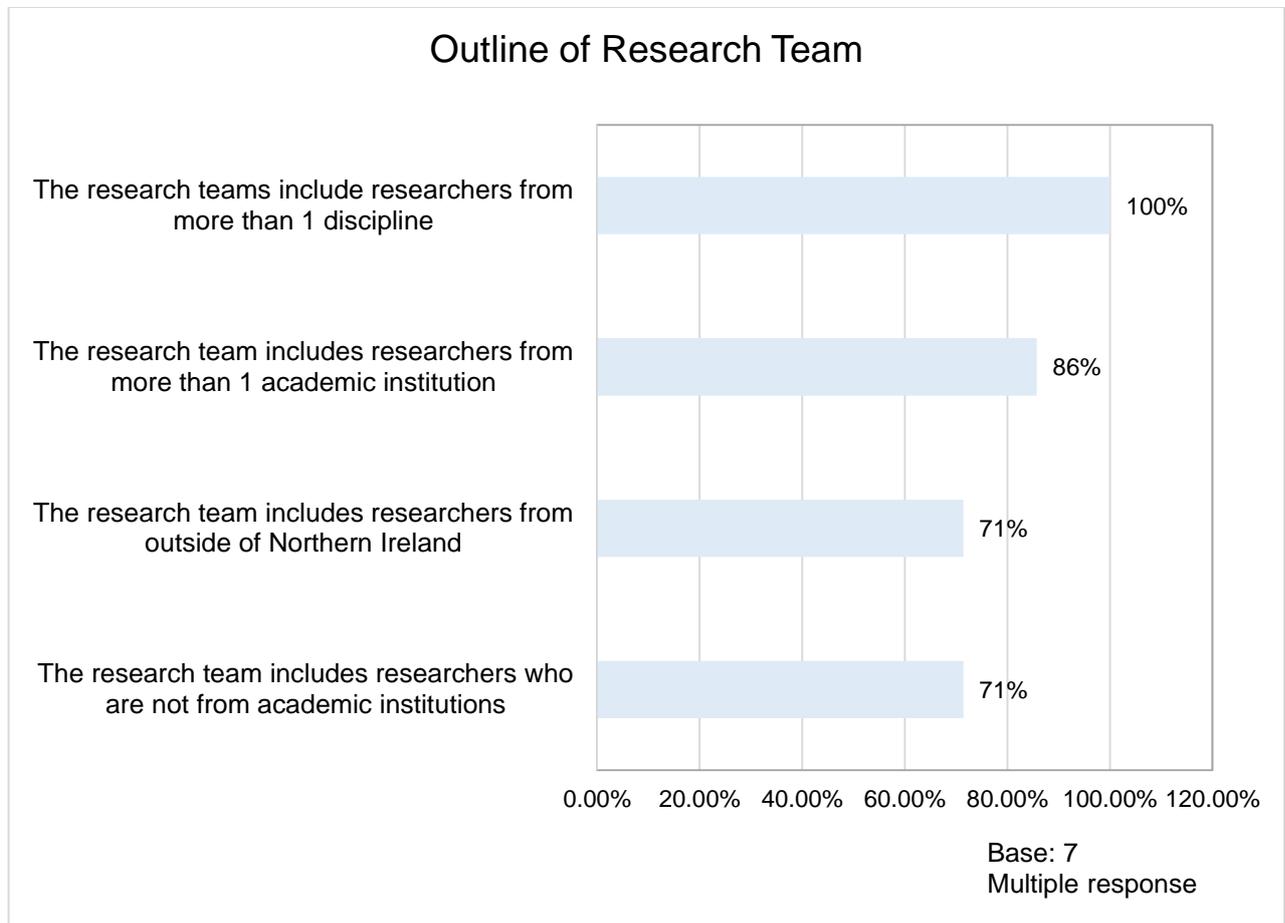
However, most PIs (57%; n=4) indicated that they saw challenges in sustaining PPI during the course of their research. These included:

- Maintaining links with people;
- Lack of attendance at meetings; and
- Lack of meaningful involvement.

### **6.2.3 Collaboration / Partnership Working**

Collaboration was a key element of the Research Programme in Dementia Care. Figure 6.2 provides an overview of the Research Teams.

**Figure 6-2 Outline of Research Team**



The following verbatim comments highlight some of the key benefits identified of working collaboratively:

*“Range of different perspectives, skills and strengths that are able to develop project.”*

*“Different disciplines bring different experience and other new knowledge to the project.”*

*“Broader knowledge; relationship building; useful in terms of future research.”*

**6.2.4 Implementation of the research**

In terms of the implementation of their research, nearly all PIs (86%; n=6) indicated that they encountered factors which impacted on their ability to start the research as planned. The two main factors identified were:

1. Research governance;
2. External factors i.e. recruitment of team members

#### 6.2.4.1 Research governance

Applying for Research governance approval, in particular, within the Belfast Trust, delayed the start of four projects. The following verbatim comments indicate PIs' views on the research governance approval process and their frustrations with the process. Although it should be noted that they were referring to the Trust governance approval process and not the overall approval from the Northern Ireland Office of Research Ethics Committees (ORECNI), which is required prior to the Trust governance approval.

*“Ethics needs speeded up. Difficult to get in contact with. They don't answer calls/emails and don't give a receipt of receipt when you send them stuff and respond weeks later. The whole thing needs overhauled.”*

*“Trust research governance - time consuming. Still not fully through research governance - it's too bureaucratic!”*

*“Ethics committee delayed it by 2 months by raising objections that could have been dealt with if they had have asked questions - it went back and forth - was time consuming.”*

*“Research governance a major factor - Belfast Trust extremely slow - would put you off doing research - quite significant delays in the research - they do their best but are under resourced.”*

#### 6.2.4.2 External factors

Factors that were external to the PIs' control such as the length of time it took to recruit people for their team impacted on a few PIs' (43%, n=3) ability to start their research as planned as shown in the following verbatim comments:

*“Human Resources - (took) months to advertise post for job for study.”*

*“HR and getting a Research Assistant in place for start date - too short of notice.”*

*“Recruitment protocol - university process; time consuming.”*

Seven Research Steering Groups were established by the PIs (one for each PIs' project). Representation on these Research Steering Groups included:

- PPI representative;
- Relevant organisations representation;
- Lecturers from multi-disciplinary backgrounds;
- Representation from HSC Trust; and
- GPs.

#### 6.2.5 Anticipated outputs, outcomes and impacts of the research

PIs indicated that they intend to produce a range of data from their project as shown in Table 6:3 below; most PIs intend to produce scientific data.

**Table 6-3 Type of data intended to be produced**

Type of data	Number of PI's
Scientific <sup>27</sup>	71% (n=5)
Normative <sup>28</sup>	14% (n=1)
Evaluative <sup>29</sup>	43% (n=3)

All PIs also indicated that they anticipated their research would add to new knowledge in dementia care as shown in Table 6:4.

**Table 6-4 Anticipation research will add to new knowledge**

Area	Number of PI's
Research Methods / Methodologies <sup>30</sup>	71% (n=5)
Concepts	14% (n=1)
Practices	100% (n=7)

The following verbatim comments provide an insight into how the PI's anticipate that their research would add to new knowledge:

<sup>27</sup> Scientific data is information that is collected using specific methods for a specific purpose of studying or analysing. Data collected in a lab experiment done under controlled conditions is an example of scientific data.

<sup>28</sup> Normative data is data from a reference population that establishes a baseline distribution for a score or measurement, and against which the score or measurement can be compared. Normative data is typically obtained from a large, randomly selected representative sample from the wider population.

<sup>29</sup> Evaluative data is that which is collected in order to determine the significance, worth or quality of an intervention or object.

<sup>30</sup> The Payback Framework generally refers to knowledge as the primary outcomes of research, for example how has the research increased knowledge on the issue, how will findings from the research inform new/future research methodologies, concepts, research practices of healthcare practice? Often these take the form of research reports or presentations

*“When you do a study you tend to think using best methods; in any study you find that you can do things better so hope experience of doing this can refine methods. It’s an ongoing programme so hope to influence practices eventually.”*

*“Looked at current research and thought what can we do to add to this? Weaknesses of existing research is that it’s more generic so ours is addressing this by being more specific.”*

*“It’s a new methodology because it’s a new way of engaging with people. It sits nicely with dementia care and Transforming Your Care and people staying at home.”*

*“Knowledge to inform practices - help inform professionals so that they communicate better to families.”*

In order to maximise their opportunity to influence policy and service delivery, PIs indicated that they intend to implement a range of activities as shown in Table 6:5.

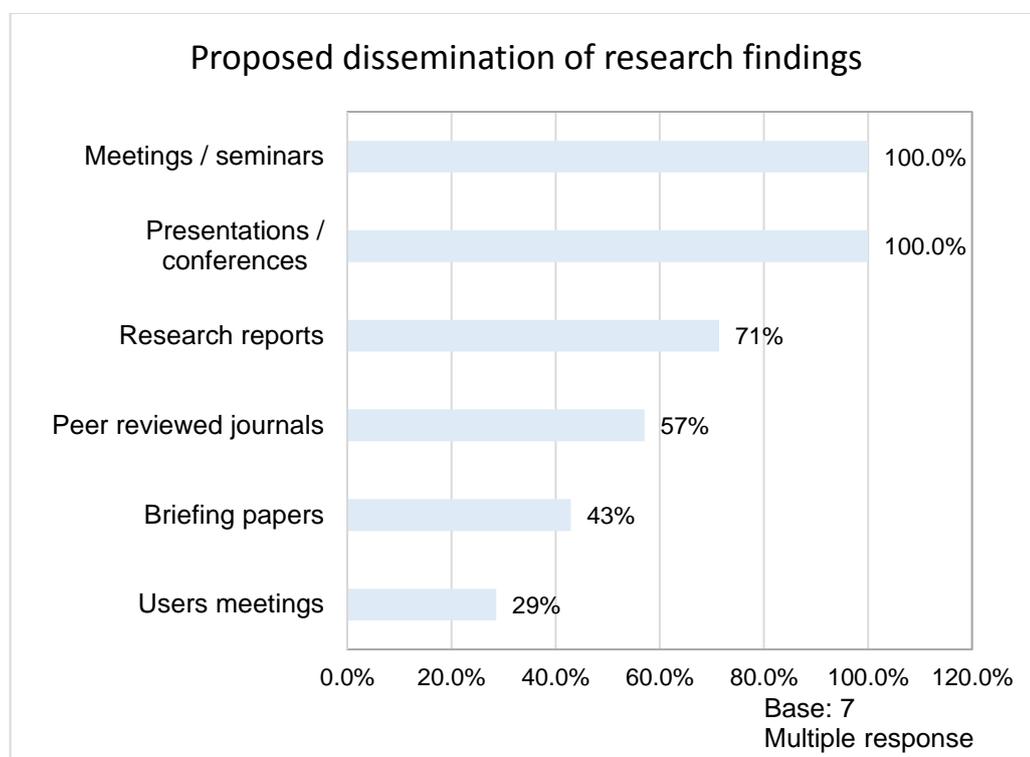
**Table 6-5 Intended activities to influence policy and service delivery**

Activity	Number of PI’s
Presentations	86% (n=6)
One to one meetings (e.g. with Assistant Directors of Dementia)	57% (n=4)
Papers issued / referenced	100% (n=7)

All PIs noted that having the opportunity to present their findings in the right forum where you can reach the right people (e.g. MLAs, members of the community and voluntary sector etc.), such as through conferences and meetings, would be key to influencing decisions in policy and service delivery.

PIs also indicated that they would disseminate their research findings through a range of mechanisms in order to share knowledge and maximise knowledge transfer. As shown in Table 6:6, the two most common dissemination methods identified were presentations / conferences and meetings / seminars.

**Table 6-6: Proposed dissemination of research findings**



PIs also indicated that they intend to target specific groups in the dissemination of their research findings as shown in Figure 6.7. All PIs aimed to target policy makers and people with dementia and their carers during dissemination of their research findings. For example, one PI noted that they would have a session to disseminate their findings in each Trust area, to which the community and voluntary sector would also be invited to attend.

**Table 6-7 Specific groups to be targeted during dissemination**

Method	Number of PI's
NGOs	86% (n=6)
People with dementia and their carers	100% (n=7)
Policy makers	100% (n=7)
Service providers	86% (n=6)
Service commissioners	86% (n=6)

All PIs anticipated that their research would generate direct impacts on the health and well-being of people with dementia and / or their carers. Table 6:8 below indicates the anticipated health and well-being impacts of the research:

**Table 6-8 Anticipated health and well-being impacts of the research**

Anticipated impact	Number of PI's
Increased access to the most effective intervention models	71% (n=5)
Improved symptom management	14% (n=1)
Improved health and well-being amongst people with dementia	71% (n=5)
Improved palliative/end of life care for people with dementia	43% (n=3)
Improved health and well-being amongst carers e.g. reduction in stress	71% (n=5)
Improved services/models of care	71% (n=5)
Improved communication with persons with dementia, their carers and staff	86% (n=6)

However, although PIs anticipated their research would impact upon the health and well-being of people with dementia and their carers, three indicated that they did not have any processes in place to measure / collect data against these proposed impacts. Of those who stated they had processes in place, they indicated the following:

- Standardised outcome measures;
- Measure impact by looking at outcomes against the research question; and
- Collection of data during research and use these findings to measure impact.

In terms of the economic impacts of the research, all PIs noted that their research had created / supported research jobs. In total, PIs indicated that 12.5 FTE research jobs had been created as a result of this research as shown in Table 6:9.

**Table 6-9 Research jobs created**

PI	Number of posts	Length of posts
1	2 posts	<ul style="list-style-type: none"> <li>• Research Fellow – 3 years</li> <li>• PHD Student – 2-3 years</li> </ul>
2	1 post	<ul style="list-style-type: none"> <li>• Full time, 3 years</li> </ul>
3	2 posts	<ul style="list-style-type: none"> <li>• 1 Research post – 30 months</li> <li>• 1 Research post – 12 months</li> </ul>

PI	Number of posts	Length of posts
4	1 post	<ul style="list-style-type: none"> <li>• Duration of project</li> </ul>
5	3 posts	<ul style="list-style-type: none"> <li>• IT Research Assistant – 1 year</li> <li>• Research Assistant – 18 months</li> <li>• Trainer – 4 months</li> </ul>
6	1.5 posts	<ul style="list-style-type: none"> <li>• 1 full time post – Duration of project</li> <li>• 1 part time post – Duration of project</li> </ul>
7	2 posts	<ul style="list-style-type: none"> <li>• 1 post – 3 years</li> <li>• 1 post – 1.5 years</li> </ul>

Furthermore, two PIs also indicated that they were in the process of attracting additional funding through the following funders:

- Housing schemes;
- Alzheimer’s Society; and
- Economic Social Research Council.

At this stage, applications had been submitted or were in the process of being submitted to the aforementioned organisations and are currently being considered.

Additionally, five PIs indicated that they anticipated their research would ensure a more efficient delivery of care for people with dementia services. A few PIs indicated that their research may encourage people with dementia to stay at home and place less of a reliance on institutional care.

However, only two PIs had processes in place to measure / collect data against the proposed economic impacts. These processes included:

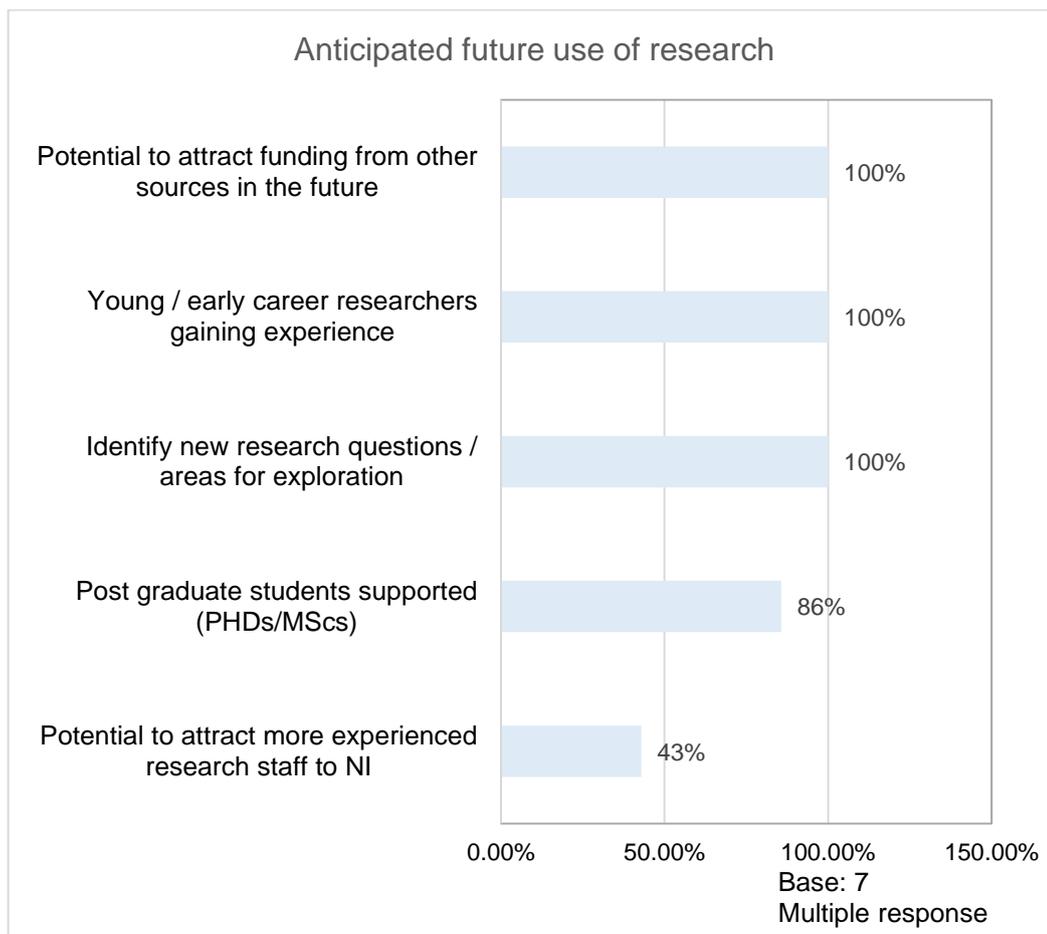
- Economic analysis component of research through asking questions in the data collection process which will measure if there has been less reliance on the health service due to their participation in this research; and
- Looking at hospitalisations for those participating in the study. Findings may suggest a cost-effective relationship.

### 6.2.6 Future use of the research

All PIs believed that their research would be of use to future research in dementia care,<sup>31</sup> as shown in Table 6:10.

**Table 6-10 Anticipated future use of research**

<sup>31</sup> The Payback Framework defines use to future research as: Better targeting of future research; Development of research skills, personnel and overall research capacity; A critical capacity to absorb and utilise appropriately existing research including that from overseas (this would include attracting experienced researchers to collaborate or, to come and work with local research teams); Staff development and educational benefits.



### 6.2.7 Summary of anticipated impacts

The following table provides an overview of the overall aim of each research project:

**Table 6-11**

	<b>Project</b>	<b>Aim</b>
1	Pain assessment and management for patients with advanced dementia care 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)
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 with dementia stay in the community for longer
3	Promoting informed decision making and effective communication	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

	Project	Aim
		family carers in decisions and promote person-centred care for individuals living with dementia
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 with dementia and their carers can work together to improve medicines management
5	A feasibility study of facilitated reminiscence for people with dementia	This study aims to assess whether reminiscence is a satisfactory criteria that can help alter behaviour, ultimately improving quality of life and care for people with dementia and their carers.
6	Technology enriched supported housing	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.
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 with dementia.

All PIs identified impacts they expected in the short, medium and long term as a result of their research project. PIs did however indicate that there was an overlap in the short / medium term impact of their research. Generally speaking, the following themes were identified:

**Short / medium term impact:**

- Create / enhance knowledge;
- Improve services;
- Use of findings in other research; and
- Identification of best practices in dementia care.

**Long term impact:**

- Development of intervention models;
- Implementation of research on a larger scale;
- Improve services;
- Influence policy;
- Develop better ways to support people with dementia and their family members;
- Improve quality of life for people with dementia; and
- Inform other related research development.

However, all PIs did not have processes in place to measure the proposed health and well-being and economic impacts of their research.

### 6.2.8 Improvements to the Research Programme in Dementia Care

Overall, all PIs indicated that they were satisfied with the Research Programme in Dementia Care and the support provided by HSC R&D, however six of the PIs made suggestions in relation to how the programme could be improved. These included:

- Practical improvements with application e.g. use of e-signature instead of original signatures;
- An electronic application process would be beneficial;
- Following announcement of award, time to get research team in place before research begins;
- Greater awareness of support and advice available from the R&D Division during application process;
- It was suggested that instead of initial rejection of an application, there should be an opportunity to address the reviewer comment before a final decision is made; and
- Improve signposting to other funding opportunities.

### 6.3 Research Team Survey

PACEC conducted surveys with the research teams of the seven successful research projects. The surveys were structured around the following key themes:

- The application process;
- The collaborative nature of the research; and
- The anticipated outputs, outcomes and impacts of the research.

In total, 19 responses<sup>32</sup> were received out of a possible 41 (46.3% response rate). Table 6.12 provides a summary of the number of responses by each research team.

**Table 6-12 Number of responses from each research team**

	Project	Number of responses
1	Pain assessment and management for patients with advanced dementia care nearing the end of life	2
2	Risk Communication in Dementia Care	2
3	Promoting informed decision making and effective communication	2
4	The development of a comprehensive medicines management approach for persons with dementia	3
5	A feasibility study of facilitated reminiscence for people with dementia	5
6	Technology enriched supported housing	4

<sup>32</sup> Please note not all respondents completed every question in the survey. As a result, the base for each question may differ

	Project	Number of responses
7	The evaluation of a Healthcare Passport to improve quality of care and communication for people living with dementia (EQuIP)	1

The following section provides an overview of key findings from the research team survey (see Appendix 4 for a full breakdown of results).

### 6.3.1 Application Process

Of those who responded to the research team survey, over two thirds (68%; n=13) stated that they were involved in the application process for their research project, as shown in Figure 6.3 below.

**Figure 6-3 Research team involvement in the application process**

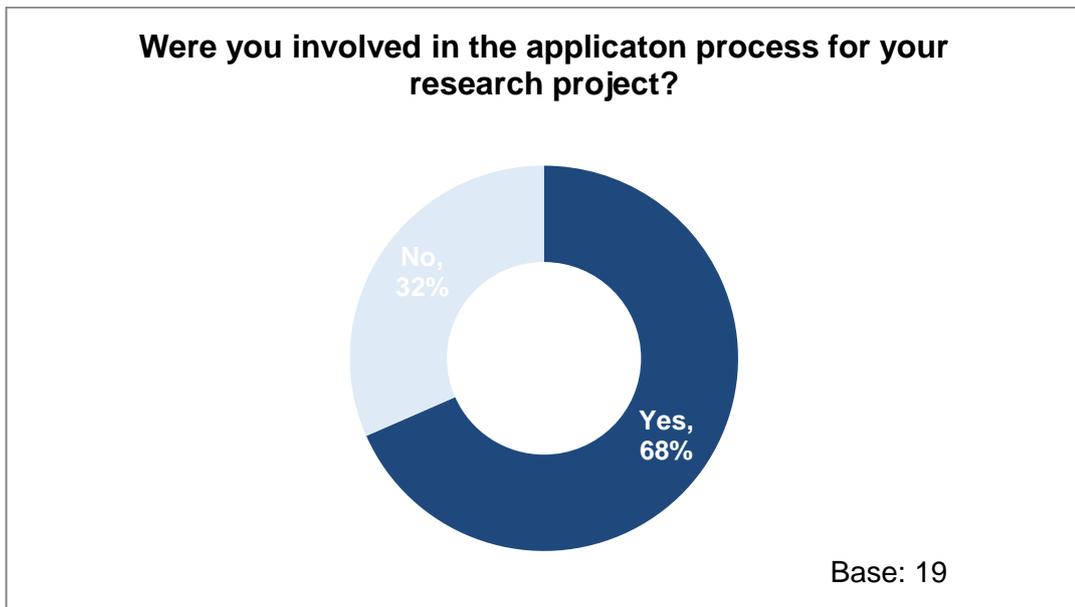


Figure 6.4 shows that of those research team members who were involved in application process, the majority (77%) of respondents believed the call for proposals was organised.

**Figure 6-4 Organisation of the call for proposals**

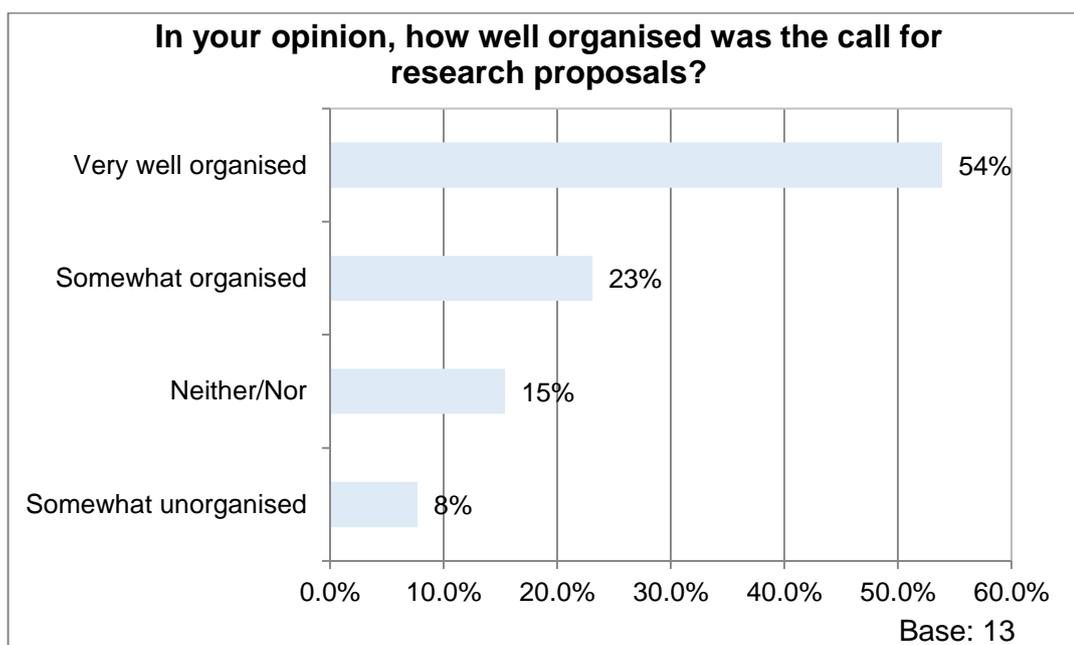


Table 6.13 below provides an overview of respondents’ level of satisfaction with aspects of the call for proposals.

**Table 6-13 Level of satisfaction with call for proposals**

Level of satisfaction with the following aspects of the call for proposals						
	Very Satisfied	Satisfied	Neither / Nor	Dissatisfied	Very Dissatisfied	Response total
Advertising for proposals	31% (4)	46% (6)	15% (2)	8% (1)	0% (0)	13
Length of time to respond to the proposal call/due date	23% (3)	54% (7)	15% (2)	0% (0)	8% (1)	13
Level of advice and assistance provided	50% (6)	8% (1)	33% (4)	8% (1)	0% (0)	12
Identification/Clarity of research priorities	39% (5)	31% (4)	31% (4)	0% (0)	0% (0)	13
The feedback received following application	39% (5)	46% (6)	8% (1)	8% (1)	0% (0)	13
Criteria that applications were scored against	25% (3)	42% (5)	25% (3)	8% (1)	0% (0)	12

Overall, the majority (75% +) of research team members were either very satisfied or satisfied with the various aspects of the call for proposals, indicating high satisfaction with the organisation of the call for proposals.

One third of respondents (39%; n=5) indicated that they believed the application process could be improved. Of those respondents who indicated that the application process could be improved, suggestions included:

- The introduction of an online application system; and
- Timely provision of information.

### 6.3.2 Personal and Public Involvement

Nearly all respondents (91%; n=10) indicated that PPI was implemented in the development of the project application as shown in Table 6:14 below.

**Table 6-14 Implementation of PPI**

Did your project implement PPI (Personal and Public Involvement) in the development of your application?	Response (Base=11)
Yes	91% (n=10)
No	9% (n=1)

At this stage of the application process, PPI was mainly used to provide feedback and comments on the proposed research, as highlighted in the following verbatim comments:

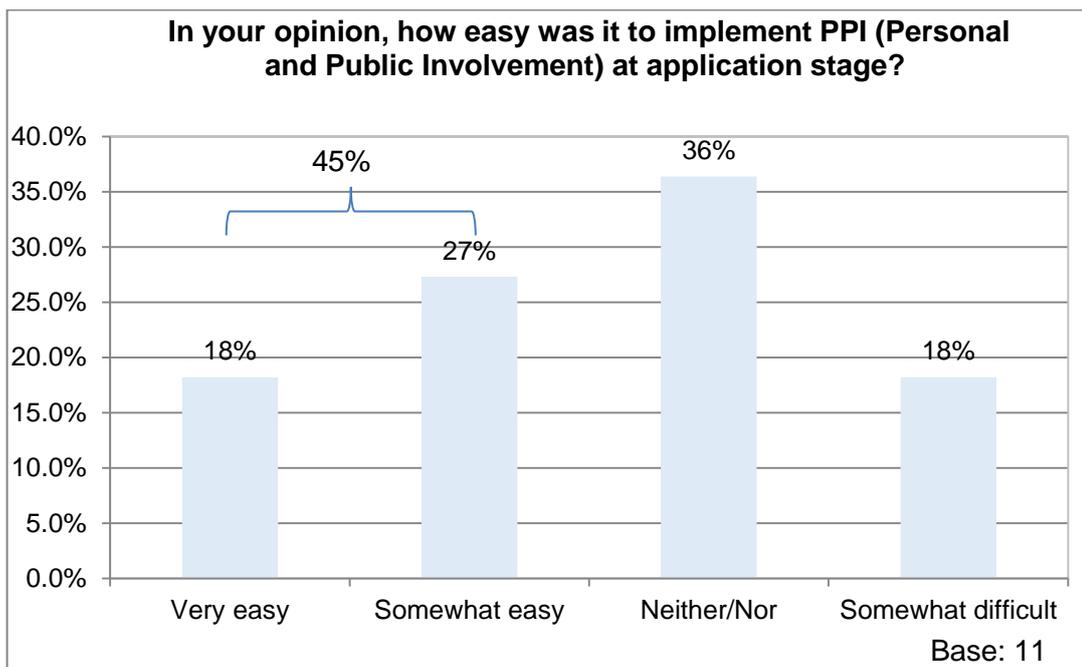
*“Our PPI representative on the Project Management Group was involved from the outset in the design of the study at application stage with regards to the focus of the study and research question development.”*

*“They were approached for advice and clarification of different elements of the suggested study design”*

*“They were heavily involved in reviewing the interview questions for health professionals, carers and healthcare assistants and provided constructive feedback on question phrasing, sequencing and appropriateness for use.”*

Over two fifths of respondents (46%; n=5) indicated that implementing PPI was either very easy (18%; n=2) or somewhat easy (27%; n=3); whilst 36% (n=4) indicated that it was neither easy nor difficult. Figure 6.5 provides an overview of how easy research team members felt it was to implement PPI.

**Figure 6-5 Level of ease of implementing PPI**



The PIs provided a range of reasons as to why they found it easy or difficult to implement PPI, for example, two PIs noted that they had previous relationships with appropriate voluntary and community sector organisations, which allowed them to progress relatively easily. One PI who noted that it was difficult, and one who noted that it was easy to establish PPI noted that it takes time to establish relationships and that Dementia focused V&C sector organisations are inundated with requests for support, this created additional pressure in the time allowed to submit the application.

Nearly all respondents (91%; n=10) indicated that they saw benefits of implementing PPI at the application stage. All respondents believed that PPI was useful as it provided affirmation that the research proposed to do was worthwhile as highlighted in the following verbatim comments:

*“Ultimately this helped to cement the research team’s plans”*

*“This early involvement is key in ensuring that academic research projects are grounded in real experiences and practices”*

*“It keeps the focus on the needs of those who the research should serve most”*

Nearly all respondents (90%; n=17) indicated that their research project aims to engage with service users and carers during the implementation of the research. This included:

- Engage with service users / carers as part of the research; and
- Inform service users / carers of research results

### 6.3.3 Anticipated outputs, outcomes and impacts of the research

Research team members indicated that their projects intended to produce a range of data with most respondents (79%; n=15) indicating that their project intended to produce scientific data

**Table 6-15 Type of data intended to be produced**

What type of data do you intend to produce from your project?	Response (Base=19; multiple response)
Scientific	79% (n=15)
Normative	26% (n=5)
Evaluative	74% (n=14)
Other	11% (n=2)

Research team members also indicated that they anticipated their research would add to new knowledge in dementia care with nearly all research team members (95%; n=18) anticipating their research would add to new knowledge in relation to practices in dementia care.

**Table 6-16 Anticipation research will add to new knowledge**

Area	Response (Base=19; multiple response)
Methods	53% (n=10)
Concepts	53% (n=10)
Practices	95% (n=18)
Other	11% (n=2)

In order to maximise their opportunity to influence policy and service delivery, respondents indicated that their project intended to implement a range of activities as shown in Table 6:17. All respondents indicated that presentations would be carried out. Other includes: development of an online app; production of a leaflet and attendance at a Knowledge Exchange event.

**Table 6-17 Activities to influence policy and service delivery**

What specific activities does your team intend to put in place in order to maximise your opportunity to influence policy and service delivery?	Response (Base=19; multiple response)
Presentations	100% (n=19)
One to one meetings	58% (n=11)
Papers issued / referenced	95% (n=18)
Other	26% (n=5)

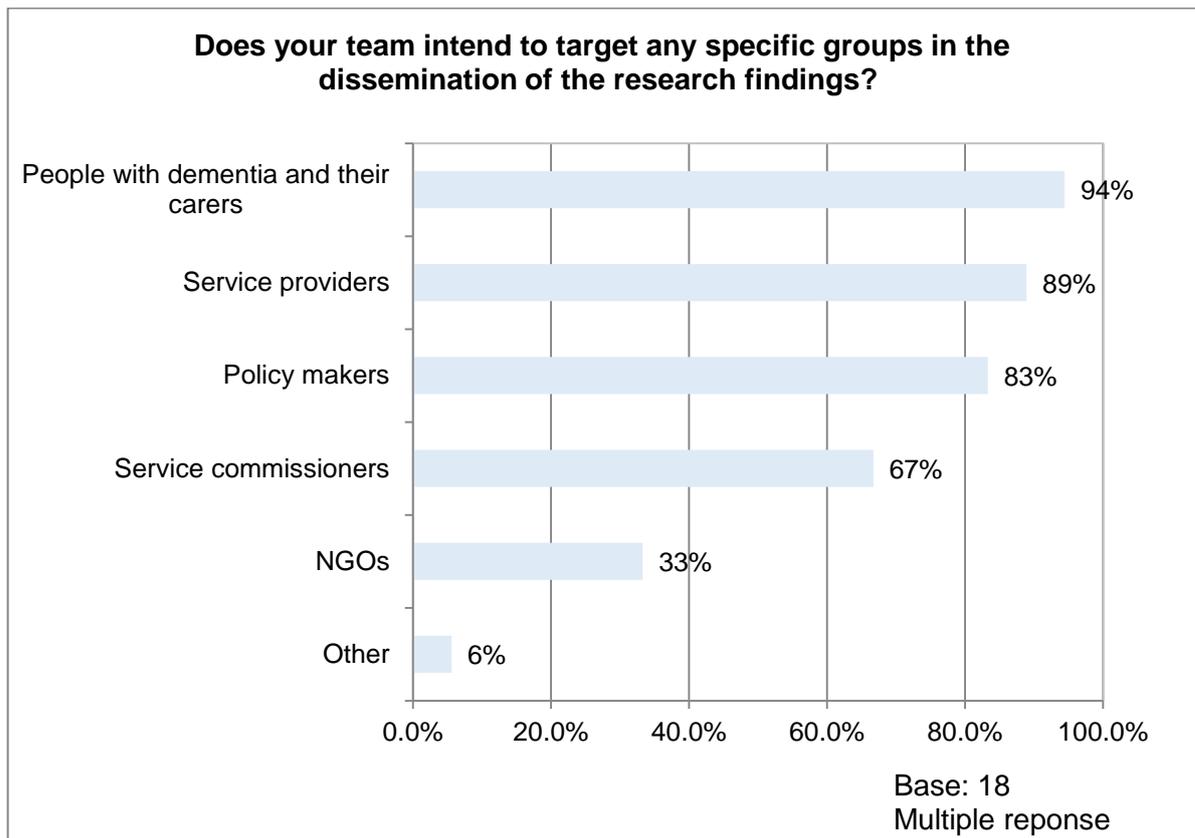
Respondents also indicated that research findings would be disseminated through a range of mechanisms in order to share knowledge and maximise knowledge transfer. As shown in Figure 6.6, the two most common dissemination methods identified were presentations / conferences (100%; n=18) and meetings / seminars (94%; n=17).

**Figure 6-6 Dissemination of research findings**



Respondents also indicated that their team intended to target specific groups in the dissemination of their research findings. As shown in Figure 6.7, most respondents (94%; n=17) aimed to target people with dementia and their carers during dissemination of their research findings.

**Figure 6-7 Target specific groups**



Most respondents (90%; n=17) anticipated that their project would generate direct impacts on the health and well-being of people with dementia and / or their carers as shown in Table 6:18.

The most common anticipated impacts were

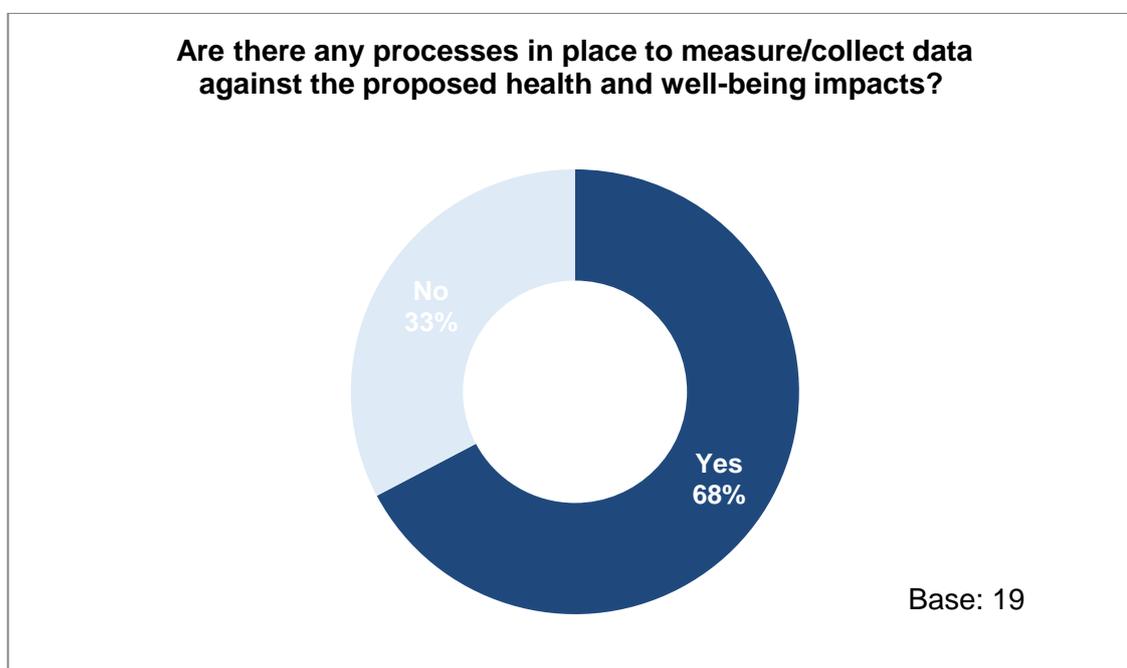
- improved communication with persons with dementia (88%; n=14);
- improved communication with persons with dementia, their carers and staff (88%; n=14); and
- improved health and well-being amongst people with dementia (88%; n=14).

**Table 6-18 Anticipated health and well-being impacts of the research**

Anticipated Impact	Response (Base=16; multiple response)
Increased access to the most effective intervention models	69% (n=11)
Improved symptom management	63% (n=10)
Improved health and well-being amongst people with dementia	88% (n=14)
Improved palliative/end of life care for people with dementia	50% (n=8)
Improved health and well-being amongst carers e.g. reduction in stress	88% (n=14)
Improved communication with persons with dementia, their carers and staff	88% (n=14)

As shown in Figure 6.8, over two thirds of respondents (68%; n=13) indicated that there were processes in place to measure/collect data against the proposed health and well-being impacts of the research. Of those who indicated ‘Yes’, the main way impact would be measured was through a series of data collection tools.

**Figure 6-8 Processes in place to measure health and well-being impact**



In terms of the economic impacts of the research, over half of respondents (58%; n=11) indicated that they did not anticipate their project would generate any direct economic impacts. Of those who indicated ‘Yes’ (42%; n=8), all indicated that they anticipated their research project would contribute to a more efficient delivery of care for people with dementia (i.e. savings to the Health Service).

All respondents identified impacts they expected in the short, medium and long term as a result of their research project. Generally speaking, the following themes were identified:

**Short / medium term impact:**

- Create / enhance knowledge;
- Improve services;
- Use of findings in other research.

**Long term impact:**

- Development of intervention models;
- Implementation of research on a larger scale;
- Independent living of people with dementia;
- Influence policy;
- Inform other related research development.

**6.3.4 Future use of the research**

All respondents believed that their research project would be of future use with the majority of respondents (95%; n=18) indicating that their research project had the potential to attract funding from other sources in the future (Table 6.19).

**Table 6-19 Anticipated future use of research**

Future Use	Response (Base=19; multiple response)
Post graduate students supported (PHDs/MScs)	53% (n=10)
Young / early career researchers gaining experience	68% (n=13)
Potential to attract funding from other sources in the future	95% (n=18)
Other	21% (n=4)

**6.3.5 Collaboration**

Table 6:20 below provides an overview of respondents experience of collaboration prior to participating in this research. Overall, more respondents had no experience of collaborating with:

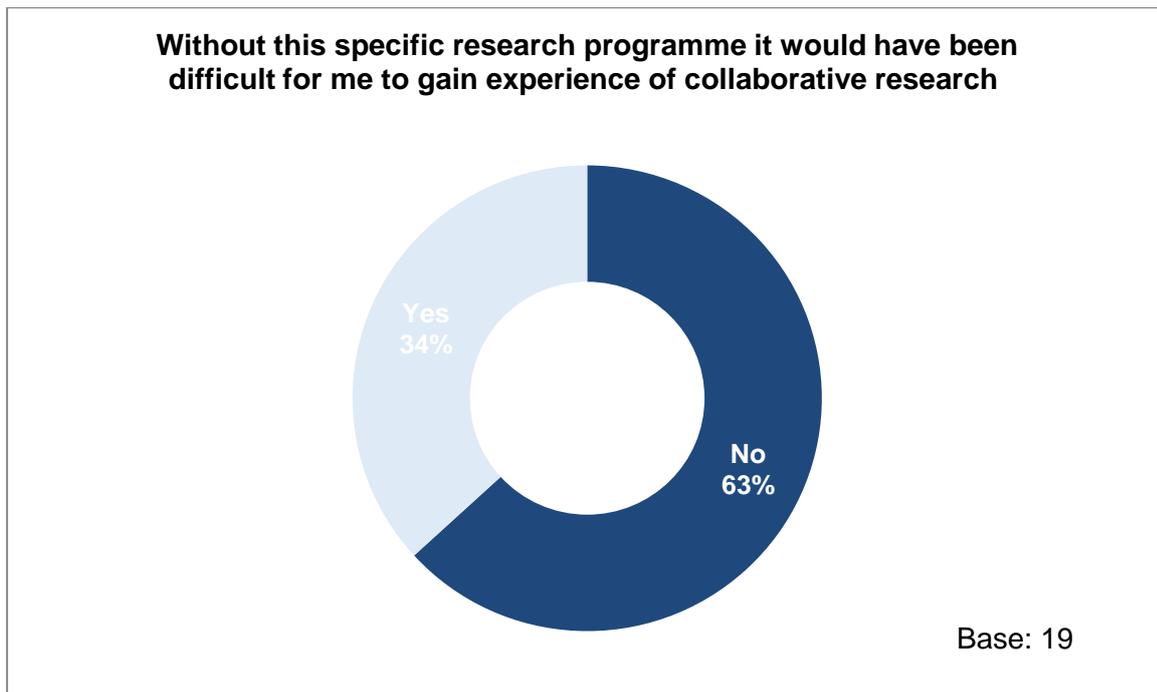
- Researchers from other academic institutions (71%; n=12);
- Researchers from outside of Northern Ireland (77%; n=13);
- Researchers who are not from academic institutions (58%; n=11); and
- Researchers from other disciplines (61%; n=11)

**Table 6-20 Respondents experience of collaboration**

<b>Prior to participating in the research I had not collaborated with:</b>			
	<b>Yes</b>	<b>No</b>	<b>Response</b>
Researchers from other academic institutions	29% (n=5)	71% (n=12)	Base=17
Researchers from outside of Northern Ireland	24% (n=4)	77% (n=13)	Base=17
Researchers who are not from academic institutions	42% (n=8)	58% (n=11)	Base=19
Researchers from other disciplines	39% (n=7)	61% (n=11)	Base=18

As shown in Figure 6.9, over one third of respondents (34%; n=7) indicated that it would have been difficult to gain experience of collaborative research without this programme.

**Figure 6-9 Experience of collaborative research**



All respondents saw benefits in working collaboratively as highlighted in the following verbatim comments:

*“Advancing knowledge through working in partnership with people”*

*“Working collaboratively on this type of research has the advantage of learning from people/organisations looking at the same problem from different perspectives. This is very enriching and beneficial.”*

*“Brings together a multidisciplinary perspective”*

As shown in Table 6.21 most respondents (90%; n=17) indicated that they were more likely to consider collaborative research in the future due to their involvement in this project.

**Table 6-21 Future collaborative work**

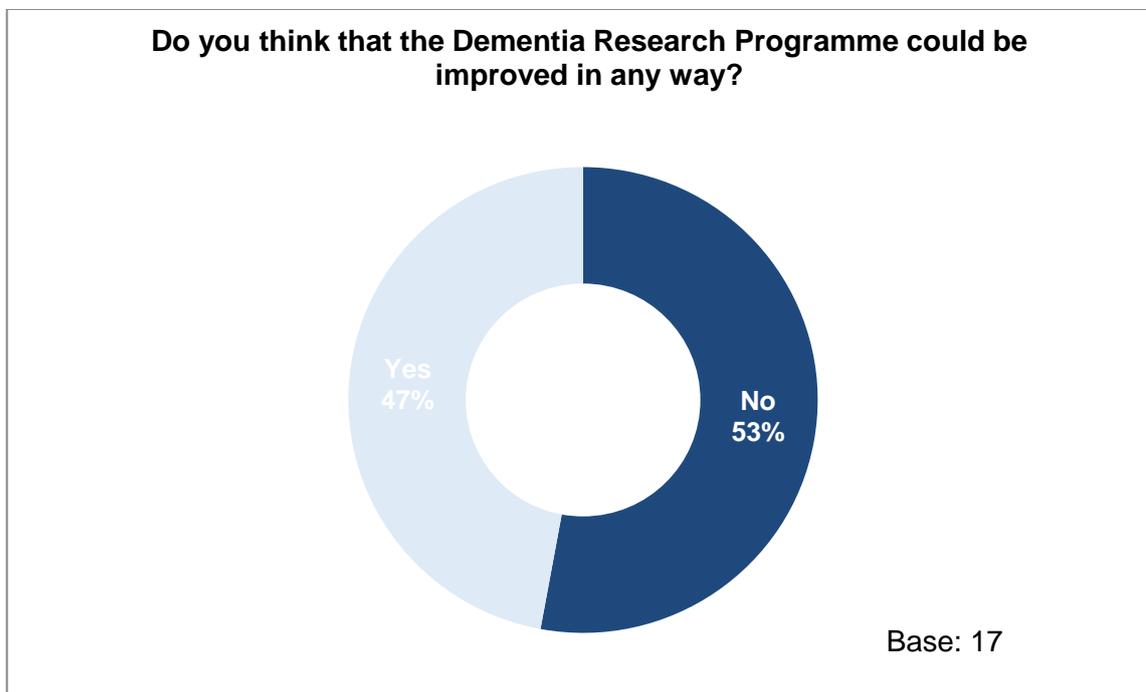
Are you more likely to consider collaborative research in the future because of your experience with this project?	Response (Base=19)
Yes	90% (n=17)
No	10% (n=2)

Furthermore, over one third of respondents (37%; n=7) indicated that they would not be undertaking research into dementia if it was not for their participation in this programme. Nearly all respondents (90%; n=17) also indicated that they intended to apply for further funding into dementia care in the future.

### **6.3.6 Improvements to the Research Programme in Dementia Care**

As Figure 6.10 shows, 47% (n=8) of respondents indicated that the research programme in dementia care could be improved.

**Figure 6-10 Improvements to the programme**



Suggestions included:

- More opportunities for researchers of different projects to meet;
- Improved research governance; and
- Raising the profile of the research.

## 6.4 Unsuccessful Applicants Survey

In total five applications were submitted by researchers who were unsuccessful in both the first call and the second call.

PACEC conducted surveys with three (60% response rate) of these applicants.

### 6.4.1 Application Process

The consultation event prior to the second call for proposals was attended by one unsuccessful applicant. This applicant felt that the event was very well organised and very useful in providing a clearer understanding of the research priorities.

Two of the applicants believed the call for research proposals was very well organised, whilst one applicant indicated that they felt the call was neither organised nor disorganised. Table 6.22 provides an overview of the applicants' level of satisfaction with aspects of the call for proposals.

**Table 6-22 Level of satisfaction with the call for proposals**

Aspect of the call for proposal	Level of satisfaction
Advertising	2 satisfied; 1 dissatisfied
Length of time to respond	2 satisfied; 1 dissatisfied
Level of advice and assistance provided	1 very satisfied; 2 neither/nor
Identification / Clarity of research priorities	3 satisfied
The feedback following the application	1 very satisfied 1 satisfied 1 neither / nor

In general, applicants were satisfied or very satisfied with most aspects of the call for proposals. However one applicant did indicate that they were unhappy with the advertising of the call for proposals and one applicant also indicated that they were dissatisfied with the length of time to respond to the call for proposals.

### Personal and Public Involvement

All applicants implemented PPI prior to submitting their application and consulted with organisations and individuals when developing their application. PPI was mainly used to provide feedback and comments on the proposed research. All applicants indicated that they did not experience any difficulties in implementing PPI during the application and believed PPI was a useful element to applications as highlighted in the following comments:

*“Academics have a good idea of the research questions but experts by experience have a different perspective and it's a major advantage that they can look at it. Access to a person with dementia and a carer adds a different dimension to the research”.*

*“Good links built up over years so always good - challenging area, but good networks build up so this helped”*

### 6.4.2 Feedback

All applicants were given feedback on their application for funding. Two applicants believed this feedback was somewhat useful, whilst one applicant felt it was very useful indicating their satisfaction with the feedback provided.

### 6.4.3 Improvements to the Programme in Dementia Care

Two applicants believed the process for awarding funding could be improved. One applicant identified that it would be useful to have a greater understanding of the required involvement of HSC Trusts in the applications. Another applicant highlighted that it would have been useful to have been more aware that applicants who were unsuccessful in stage one could also re-apply in stage two.

*“More clarity about involvement of HSC Trusts”*

*“Main thing is make it clearer to people that some people they were competing with in stage two had applied in stage one and they had feedback so it was more of an advantage for them.”*

### 6.4.4 Future Funding

Of those who were unsuccessful, none of the applicants received funding for their project elsewhere. All applicants indicated that they would apply to the Research Programme in Dementia Care in the future<sup>33</sup>.

## 6.5 Summary

This section provides an overview of the key findings from the surveys conducted with Principal investigators; research team members and unsuccessful applicants. In general, most respondents indicated high satisfaction with the organisation of the call for proposals. Practical problems however were noted and it was suggested that it would be useful to have an online submission system.

Respondents also highlighted that the research programme in dementia care has encouraged the development of inter-disciplinary and inter-sectoral relationships as a result of joint research projects. The programme has successfully brought together researchers who have not worked together and who have no previous experience of working in dementia research. It was highlighted that this will enhance capacity and encourage further research into dementia in the future.

Whilst all successful projects are currently in their early stages, PIs and research team members indicated that their findings will be disseminated through a range of mechanisms. At this stage, all respondents believed that their projects were capable of influencing dementia services in the future however all projects did not have mechanisms in place to measure the proposed impacts of the research.

<sup>33</sup> The HSC R&D Division are not planning another call for proposals but would hope that research teams are enabled to secure external funding through collaborations developed.

## 7 STAKEHOLDER CONSULTATIONS

### 7.1 Introduction

PACEC undertook telephone consultations with stakeholders involved in the Research Programme in Dementia care, namely:

- Evaluation panel members (3);
- Members of DSIG (2);
- Representatives from Atlantic Philanthropies (2);
- Pro-Vice Chancellors of Research (QUB & UU); (2)
- PPI representatives (2); and
- HSC R&D Division (2).

These consultations focused on the following key areas:

- The process used to define the research priorities;
- Organisation of the call for proposals;
- Partnership element of the programme;
- Assessment of the applications; and
- Impact of the research.

The following paragraphs provide a summary of key themes / common issues that were highlighted during the interviews.

### 7.2 Consultation feedback

#### 7.2.1 Process used to define research priorities

All of the stakeholders who were interviewed noted that they believed that the process used to define the research priorities was effective and the right research priorities were identified. It was generally agreed that taking guidance from the James Lind Alliance and Alzheimer’s Society was in line with best practice. The James Lind Alliance was viewed as appropriate to take guidance from as it makes contact with clinicians and service users rather than academics.

*“Appropriate priorities - fell directly within remit of the R&D office; wider PHA and DHSSPS.”*

#### 7.2.2 Organisation of the call for proposals

Interviewees believed that the call for proposals was very well organised. Based on the quality of the applications submitted, interviewees believed that applicants were very well briefed prior to submitting their application. Whilst members of the evaluation panel were not aware of the detail of how the call was advertised, a few interviewees did note that the call was not widely advertised and enhanced advertising and greater awareness of the call would encourage more applications.

### 7.2.3 Partnership element of the programme

The interviewees highlighted the importance of the partnership aspect of the programme. It was noted that the requirement to work in collaboration with others should strengthen the research findings as the inclusion of researchers from other disciplines will help to provide a more holistic approach to dementia care and can help to reduce the separation of research and practice.

Furthermore it was noted that by creating opportunities to work with experienced dementia researchers from elsewhere this will build capacity for dementia research in Northern Ireland.

*“Partnerships are very important - money is tight so funders should get the best - very important to applications - helped improve quality of applications”*

*“Genuine partnership is useful - good in this programme”*

*“This call has incentivised people to come to do dementia research – so it’s building capacity in research community and brings a wide breadth of experience ...the R&D office has done a good job by bringing together good researchers for future dementia research”*

### 7.2.4 Assessment of the applications

The interviewees, particularly those who were on the evaluation panel, spoke highly of the processes that were put in place to evaluate the applications that were received. It was felt that the right people were involved in the decision making process and it was also believed that the methods used to assess the applicants were in line with best practice. The templates and proformas that were provided to evaluation panel members were highly regarded and those who were interviewed noted that they helped to ensure that the applications were marked fairly and consistently.

*“Panel worked really well. Had funders, people who had knowledge of ageing research; PPI rep - so everyone got opportunity. Was a well-managed process and was well chaired. Overall, it was a thorough process.”*

*“Every funder has different approach - this was robust. It was open for discussion and conversation on the day as well, so this was helpful to discuss it on a group dynamic - very good, robust process”*

*“Better than any other calls I’ve seen - information was there; applicants clearly understood what the funders were looking for”*

Other stakeholders who were not part of the panel noted that the right people were involved in the decision making process and it was also believed that the methods used to assess the applicants were in line with best practice.

### 7.2.5 Impact of the research

All of those interviewed agreed that it was vital that the researchers maximise the impacts of their research findings.

All interviewees noted that it was crucial that research findings were shared in order to maximise impact. It was suggested that research could be shared in numerous ways, such as through conferences and via the voluntary and community sector. It was also suggested that it would be useful to collate the findings of all seven projects on completion and present them at one overall conference or event. Representatives from R&D indicated that they intend to have a launch event once the work is complete. A few interviewees also suggested that researchers under this programme should be given opportunities to network with each other over the course of completing the projects.

Interviewees also believed that the research projects had the potential to influence policies relating to dementia and the way in which dementia services are planned and commissioned.

*“Potential to make practical impact to people”*

It was suggested that DSIG should be kept informed of the research progress and emerging findings as they are aware of how the research fits with the wider dementia context in NI. Interviewees also believed researchers need to work with Trusts and commissioners to build awareness of the research and to understand potential wider impacts findings could make. Interviewees suggested that it would be useful to have earlier engagement with commissioners and early collaboration with Trusts and HSCB during the research in order to maximise the ability of the research to influence services. It was also highlighted that commissioners are likely to look for evidence of the effectiveness and efficiency that can be derived, for example, through savings to other parts of the health service.

*“Early engagement; gather commissioners and researchers right from the start when the call is issued”*

*“Researchers should engage with practitioners early on”*

All interviewees highlighted that demonstrating impact is vital for the research projects. Some interviewees also suggested that researchers should develop a pathway to impact plan in line with current best practice from research councils. It was believed that this would be a good mechanism for researchers to outline the steps they can take now in order to maximise any potential impacts of the research.

### **7.2.6 Other issues**

A few interviewees highlighted that some of the projects were delayed in starting their research due to delays in getting Trust research governance approval. Interviewees were concerned about the impact this had on the research and suggested that there needs to be a more effective research governance approval process across Northern Ireland. This is something which HSC R&D Division is aware of and are reviewing.

Interviewees also believed that PPI was an important element of the application stage. It was believed that this was useful at this stage of the application process as it provided affirmation that the research proposed to do was worthwhile. Interviewees indicated that PPI was key to developing the practical element of the application and how the research could make a difference to people with dementia and their carers' everyday lives.

### 7.3 Summary

All of the stakeholders who were interviewed spoke very positively about the Programme in Dementia Research. It was noted that the process used to define the research priorities was effective and in line with best practice. In general, most stakeholders believed the call for proposals was very well organised, however it was also noted that the call was not widely advertised.

Specifically, interviewees viewed the programme as key to developing capacity and expertise in dementia. All interviewees noted that the programme and the research is currently in the early stages and acknowledged that factors, such as delays with research governance, has meant that some projects have not been implemented as planned. However, in general, stakeholders expressed that they were keen to see the emerging findings of the research. They noted that a range of mechanisms should be used to disseminate research findings. It was suggested that it would be useful to collate the findings of all seven projects on completion and present them at one overall conference or event.

All interviewees noted that the research projects have the potential to influence policies relating to dementia and the way in which dementia services are planned and commissioned. However interviewees did suggest that a pathway to impact plan would be a good mechanism for researchers to outline the steps they can take now in order to maximise any potential impacts of the research.

## 8 CONCLUSIONS AND RECOMMENDATIONS

### 8.1 Introduction

The following section provides conclusions and recommendations based on each of the Terms of Reference:

- Process for identifying research priorities in Northern Ireland to inform the research topics;
- Organisation of the call for proposals and award process;
- Inter-disciplinary and inter-sectoral relationships developed as a result of joint research projects;
- Capacity built to continue applied dementia care research in NI and attract alternative funding;
- Perceived quality and breadth of dissemination activity; and
- 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.

### 8.2 Process for identifying research priorities in Northern Ireland to inform the research topics

The process for identifying the research priorities was highly regarded by stakeholders and participants of the research programme in dementia. It was believed that taking guidance from the James Lind Alliance and Alzheimer's Society UK was in line with best practice and the research priorities identified have the potential to influence the way dementia services are commissioned and delivered in Northern Ireland.

### 8.3 Organisation of the call for proposals and award process

This evaluation has highlighted that stakeholders believed that the organisation of the call for proposals was very well organised. However, it was also noted that the call was not widely advertised and it was suggested that increased advertising of the call may encourage a wider scope of applicants. Applicants also noted practical problems when submitting their applications and noted that an electronic application process would be beneficial. PHA noted that they are aware of this issue and are working on being able to accept online applications in the future.

In total, 16 applications were received and seven were successful. It was felt that the processes used to evaluate the applications were highly regarded by key stakeholders and the evaluation panel and were regarded as being in line with best practice. The templates and pro-formas provided to evaluation panel members ensured that applications were marked fairly and consistently.

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

This evaluation has highlighted that inter-disciplinary and inter-sectoral relationships have been developed as a result of joint research projects with PIs indicating they have collaborated with other researchers outside their main discipline. This was viewed as adding value to the research.

The research programme in dementia care has brought together collaborative teams who have not worked together before. All PIs noted that the projects created new working relationships and nearly two fifths (37%) of research team members noted that it would have been difficult to gain experience of collaborative research without this programme. Stakeholder discussions and survey findings also indicated that these relationships are key to developing dementia research in the future. It was believed that this should strengthen the research findings as the inclusion of researchers from other disciplines will help to provide a more holistic approach to dementia care and can help to reduce the separation of research and practice.

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

The research programme in dementia care has brought together multi-disciplinary teams in dementia research. Specifically, the research team has brought together a range of researchers who may have no previous experience of dementia research (37%; n=7), creating opportunities to work with experienced dementia researchers in NI and from elsewhere.

It was believed this will build capacity for dementia research in Northern Ireland beyond this programme. In total PIs indicated that 12.5 FTE research jobs had been created as a result of this research and this will provide new and experienced researchers with the opportunity to develop their careers in relation to dementia research.

### **8.6 Perceived quality and breadth of dissemination activity**

As this is the first year of the evaluation, four projects have been operational for less than one year and there has been very little dissemination activity so far. Feedback from the PIs has highlighted that they intend to target a range of groups, such as policy makers, commissioners, service providers and people with dementia and their carers when disseminating their findings. It was noted that a range of activities will be used to disseminate research findings, such as presentations/conferences; meetings/seminars and peer reviewed journals. At this stage, two PIs have completed presentations to key stakeholders. In general, stakeholder discussions highlighted that a combination of these activities would be key to enhancing knowledge of the research findings. It was also suggested that it would be useful to collate the findings of all seven projects on completion and present them at one overall conference or event. Representatives from R&D indicated that they intend to have a launch event once the work is complete.

### **8.7 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**

The research programme in dementia care is currently in the early stages and factors, such as delays with governance approval, have meant that some projects have not been implemented as planned. However, Year 1 evaluation findings have highlighted that stakeholders believe that the research projects have the potential to influence policies relating to dementia and the way in which dementia services are planned and commissioned. It was suggested that a pathway to impact plan would be a good mechanism for researchers to outline the steps they can take now in order to maximise any potential impacts of the research in the future.

The trial management steering group / research board of each project manage the operational risks of the research projects.

## 8.8 Other issues

We understand that HSC R&D Division collectS performance data from PIs on an annual basis. On previous experience, HSC R&D Division has have found that it is not possible to get performance data more frequently and therefore on this basis we note that a recommendation to collect performance data on a bi-annual basis would be impractical. However whilst the project report requires PIs to provide a range of information, it does not have a succinct section which documents project progress against initial timescales. However, since July 2015, all awards now include smart targets and progress against these will be measured in annual and financial reports.

HSC R&D Division does not manage the risks of these projects, this is undertaken by the trial management steering group / research board of each project. This is something which needs to be considered in the future to ensure the successful delivery of each project. Whilst HSC R&D Division has also noted that projects can be under or over spent in their first / second years due to various reasons such as staff salaries, or delays in recruiting staff; it was also highlighted that the budget allocated is usually spent over the course of the project. Nevertheless this is something that R&D monitors closely throughout the project to ensure that budgets remain on course and problems are picked up at an early stage.

## 8.9 Recommendations

This section makes some recommendations based on findings from the Year 1 evaluation.

### Pathways to Impact

Whilst it is acknowledged that the seven projects all have the potential to influence policies relating to dementia and the way in which dementia services are planned and commissioned; it is important that PIs and their research team have a plan in place during the course of their research in order to maximise any potential impacts of their findings. The development of a Pathways to Impact document for each project is therefore recommended. This document should set out clear objectives, highlight the key messages of the research and plan suitable activities for key audiences in order to share and maximise findings. The Economics and Social Research Council<sup>34</sup> recommend that this should be a living document which should be revisited at least once a year (see Appendix 5).

#### **Recommendation 1:**

**A Pathways to Impact Plan and accompanying Impact Strategy is developed for each project by the researchers which includes timescales and proposed activities.**

<sup>34</sup> The Economic and Social Research Council (ESRC) is the UK's leading research and training agency addressing economic and social concerns

## Research governance

Four PIs have experienced delays in implementing their project due to Trust R&D governance approval. We recommend that HSC R&D Division continues to keep under review the issues associated with research governance within each Trust and consider ways in which processes could be streamlined.

### **Recommendation 2:**

**HSC R&D Division continues to review the issues associated with research governance.**

## ResearchFish

We understand that HSC R&D Division is currently implementing ResearchFish in order to facilitate the submission of progress reports. We recommend that this process continues and that HSC R&D Division considers how impact data can be collected through this.

### **Recommendation 3:**

**We recommend that HSC R&D Division continues with the implementation of ResearchFish and considers how impact data can be collected through this.**

## Progress Report

Whilst the progress report provides a useful overview of the projects to date, it would be beneficial to have a succinct section which outlines the progress of the project against the initial targets and timescales.

### **Recommendation 4:**

**Amendments to progress report to include project progress against initial targets using a traffic light system.**

## Personal and Public Involvement

The PIs noted the benefits of establishing PPI early on in the research development, as it helps to keep the research focused on real issues for patients and carers and it can be useful when developing data collection tools.

### **Recommendation 5:**

**Going forward HSC R&D Division should continue to implement and support PPI in all of their funding schemes.**



## APPENDIX 1: JAMES LIND ALLIANCE DEMENTIA RESEARCH PRIORITIES

The James Lind Alliance<sup>35</sup> outlines the top ten dementia research priorities as highlighted in Table 9.1 below. The following questions were prioritised by people 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 27<sup>th</sup> June 2013.

**Table 9-1 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?

<sup>35</sup> <http://www.lindalliance.org/top-tens.asp>

2	How can the best ways to care for people 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 with dementia?
5	What is the best way to care for people with dementia in a hospital setting when they have acute health care needs?
6	What are the most effective ways to encourage people with dementia to eat, drink and maintain nutritional intake?
7	What are the most effective ways of supporting carers of people 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?

## APPENDIX 2: HSC R&D DIVISION – TOPICS FOR STAKEHOLDER PRIORITY SETTING LIST

Via an electronic priority setting list, key stakeholders were asked by HSC R&D to prioritise five topics from the following list in order of importance which they thought were most salient to the care of patients with dementia and their carers in Northern Ireland.

Main topic	Subthemes
Staff and staff training	<ul style="list-style-type: none"> <li>• The best way to train healthcare professionals/care staff to be aware of the needs of dementia patients and in best available care methods</li> <li>• The qualities of a good carer, best ways to select and recruit staff, optimum staffing levels</li> </ul>
Quality of care	<ul style="list-style-type: none"> <li>• How to make the care of people with dementia better in different care settings</li> <li>• How to design and organize care settings and accommodation</li> <li>• How to best to maintain quality of life and patient centred care across all care settings</li> </ul>

Main topic	Subthemes
	<ul style="list-style-type: none"> <li>• Which place of care setting is better for prognosis/Quality of Life (QoL)</li> </ul>
Coordination of care	<ul style="list-style-type: none"> <li>• Supporting carers to keep patients at home/obtaining respite care/role of day care</li> <li>• Best ways to manage and organize care across all care settings/role of one stop shops/one point of contact</li> <li>• Facilitating choice of care</li> <li>• Role of assistive technology in managing independence</li> </ul>
Information and communication	<ul style="list-style-type: none"> <li>• Obtaining a diagnosis</li> <li>• Support and information for carers around diagnosis</li> <li>• Communication problems between health professional and informal carers</li> <li>• Understanding causes and communicating about risk of dementia</li> <li>• Best ways to disseminate best care strategies</li> </ul>
End of life care	<ul style="list-style-type: none"> <li>• Maintaining dignity</li> <li>• Role of hospice</li> <li>• Practical and ethical issues faced by carers at end of life</li> </ul>
Management of behaviours	<ul style="list-style-type: none"> <li>• Providing appropriate and stimulating recreational activities and social interaction for people with dementia/what activities are beneficial</li> <li>• Avoiding prescription of anti-psychotic medications to control challenging behaviour</li> <li>• Coping with secrecy, dishonesty and repetitive behaviours</li> <li>• Effectiveness of non-pharmacological and alternative therapies including psychological support</li> <li>• Effectiveness of reality orientation as a management strategy</li> <li>• Difficulties with dentistry, audiology and optometry examinations during dementia</li> </ul>
Management of symptoms	<ul style="list-style-type: none"> <li>• Recognition and management of pain</li> <li>• Managing sleep, changes in sleep patterns and wakefulness in patients with dementia</li> <li>• Incontinence</li> <li>• Medication management and ensuring person with dementia takes prescribed medication</li> <li>• Avoiding anxiety for the patient with dementia</li> <li>• Understanding nutritional requirements and providing appropriate nutrition and vitamin supplement to people with dementia</li> </ul>
Prevention	<ul style="list-style-type: none"> <li>• Effectiveness of diet and physical activity</li> </ul>
Needs of particular groups	<ul style="list-style-type: none"> <li>• Specific care needs of young people with dementia</li> <li>• Specific care needs of people with a learning disability who develop dementia</li> </ul>
Equal treatment	<ul style="list-style-type: none"> <li>• Healthcare versus social care</li> <li>• Funding of dementia care</li> <li>• Equal rights</li> </ul>

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Main topic	Subthemes
Maintaining personal beliefs and faith during dementia	<ul style="list-style-type: none"><li>• Importance which care settings attach to spiritual needs of dementia patients</li><li>• Practicing faith; how faith communities can embrace the person with dementia and the carer</li></ul>

## APPENDIX 3: MEMBERS OF THE EVALUATION PANEL

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

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	Voting member

	Alzheimer's Society	
Ms Angela Hodkinson (Observer)	Programme Executive The Atlantic Philanthropies	Voting member
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 4: RESEARCH TEAM SURVEY RESULTS**

The following section provides a breakdown of the analysis of the research team survey by individual question:

<b>Q1. Did you attend the consultation event?</b>	<b>Response (Base =19)</b>
Yes	16% (n=3)
No	84% (n=16)

<b>Q2. In your opinion, how well organised was the consultation event?</b>	<b>Response (Base=3)</b>
Very well organised	67% (n=2)
Somewhat organised	33% (n=1)

<b>Q3. How useful was the consultation event?</b>	<b>Response (Base=3)</b>
Very useful	67% (n=2)
Somewhat useful	33% (n=1)

<b>Q4. Following the consultation event, did you have a clearer understanding of what the research priorities were?</b>	<b>Response (Base=3)</b>
A lot clearer	33% (n=1)
Somewhat clearer	67% (n=2)

<b>Q5. Were you involved in the application process for your research project?</b>	<b>Response (Base=19)</b>
Yes	68% (n=13)
No	32% (n=6)

<b>Q6. In your opinion, how well organised was the call for research proposals?</b>	<b>Response (Base=13)</b>
Very well organised	54% (n=7)
Somewhat organised	23% (n=3)
Neither / Nor	15% (n=2)
Somewhat unorganised	8% (n=1)
Not well organised	n/a

**Q7. Please indicate your level of satisfaction with the following aspects of the call for proposals**

	Very Satisfied	Satisfied	Neither / Nor	Dissatisfied	Very Dissatisfied	Response total
Advertising for proposals	31% (4)	46% (6)	15% (2)	8% (1)	0% (0)	13
Length of time to respond to the proposal call/due date	23% (3)	54% (7)	15% (2)	0% (0)	8% (1)	13
Level of advice and assistance provided	50% (n=6)	8% (1)	33% (4)	8% (1)	0% (0)	12
Identification/Clarity of research priorities	39% (5)	31% (4)	31% (4)	0% (0)	0% (0)	13
The feedback received following application	39% (5)	46% (6)	8% (1)	8% (1)	0% (0)	13
Criteria that applications were scored against	25% (3)	42% (5)	25% (3)	8% (1)	0% (0)	12

**Q8. Did you/your research team submit any queries prior to submitting your application for funding?**

**Response (Base=13)**

Yes	39% (n=5)
No	61% (n=8)

**Q9. Were you satisfied with how your query was dealt with?**

	Very Satisfied	Satisfied	Neither / Nor	Dissatisfied	Very Dissatisfied	Response Total
Response provided	60% (3)	0% (0)	40% (2)	0% (0)	0% (0)	5
Response timescale	60% (3)	0% (0)	20% (1)	20% (1)	0% (0)	5

**Q10. Do you think that the application process could be improved?**

**Response (Base=13)**

Yes	39% (n=5)
No	61% (n=8)

<b>Q11. Did your project implement PPI (Personal and Public Involvement) in the development of your application?</b>	<b>Response (Base=11)</b>
Yes	91% (n=10)
No	9% (n=1)

<b>Q12. Did your research team experience any challenges when attempting to implement PPI at the application stage?</b>	<b>Response (Base=11)</b>
Yes	91% (n=10)
No	9% (n=1)

<b>Q13. In your opinion, how easy was it to implement PPI (Personal and Public Involvement) at application stage?</b>	<b>Response (Base=11)</b>
Very easy	18% (n=2)
Somewhat easy	27% (n=3)
Neither / Nor	36% (n=4)
Somewhat difficult	18% (n=2)
Very difficult	n/a

<b>Q14. Did you see any benefits in implementing PPI (Personal and Public Involvement) at application stage?</b>	<b>Response (Base=11)</b>
Yes	91% (n=10)
No	9% (n=1)

<b>Q15. Do you see any challenges in sustaining PPI (Personal and Public Involvement)?</b>	<b>Response (Base=11)</b>
Yes	18% (n=2)
No	82% (n=9)

<b>Q16. Does your research project intend to engage with users/patients</b>	<b>Response (Base=19)</b>
-----------------------------------------------------------------------------	---------------------------

<b>with dementia during the implementation of the research?</b>	
Yes	90% (n=17)
No	10% (n=2)

<b>Q17. Is the engagement with users linked to any relevant impact strategy?</b>	<b>Response (Base=15)</b>
Yes	80% (n=12)
No	20% (n=3)

<b>Q18. Are there any factors that impacted on your ability to start the research as planned? (e.g., recruitment/research governance)</b>	<b>Response (Base=17)</b>
Yes	47% (n=8)
No	53% (n=9)

<b>Q19. Has a Research Board been established for the project, (e.g., who would oversee the progress of the research against planned timescales and review emerging findings)?</b>	<b>Response (Base=18)</b>
Yes	94% (n=17)
No	6% (n=1)

<b>Q20. Do you anticipate that the Dementia Research Programme will support the development of tailored ethical guidance for dementia research?</b>	<b>Response (Base=14)</b>
Yes	71% (n=10)
No	29% (n=4)

<b>Q21. What type of data do you intend to produce from your project?</b>	<b>Response (Base=19)</b>
Scientific	79% (n=15)
Normative	26% (n=5)
Evaluative	74% (n=14)
Other	11% (n=2)

<b>Q22. Do you anticipate that the research will add to new knowledge in dementia care?</b>	<b>Response (Base=19)</b>
Yes	100% (n=19)
No	-

<b>Q23. Please indicate what type of knowledge the research will bring to dementia care</b>	<b>Response (Base=19)</b>
Methods	53% (n=10)
Concepts	53% (n=10)
Practices	95% (n=18)
Other	11% (n=2)

<b>Q24. What specific activities does your team intend to put in place in order to maximise your opportunity to influence policy and service delivery?</b>	<b>Response (Base=19)</b>
Presentations	100% (n=19)
One to one meetings	58% (n=11)
Papers issued / referenced	95% (n=18)
Other	26% (n=5)

<b>Q25. Are you aware of plans to disseminate your research findings to share knowledge and maximise knowledge transfer?</b>	<b>Response (Base=18)</b>
Presentations / conferences	100% (n=18)
Research reports	83% (n=15)
Briefing papers	28% (n=5)
Peer reviewed journals	89% (n=16)
Meetings / seminars	94% (n=17)
Users meetings	78% (n=14)
Other	17% (n=3)

<b>Q26. Do you anticipate that your project will generate any direct impacts on health and well-being of people with dementia and/or their carers?</b>	<b>Response (Base=19)</b>
Yes	90% (n=17)
No	10% (n=2)

<b>Q27. What are the anticipated health and wellbeing impacts of the research?</b>	<b>Response (Base=16)</b>
Increased access to the most effective intervention models	69% (n=11)
Improved symptom management	63% (n=10)
Improved health and well-being amongst people with dementia	88% (n=14)
Improved palliative/end of life care for people with dementia	50% (n=8)
Improved health and well-being amongst carers e.g. reduction in stress	88% (n=14)
Improved communication with persons with dementia, their carers and staff	88% (n=14)

<b>Q28. Are there any processes in place to measure/collect data against the proposed health and well-being impacts?</b>	<b>Response (Base=19)</b>
Yes	68% (n=13)
No	33% (n=6)

<b>Q29. Do you anticipate that your project will generate any direct economic impacts?</b>	<b>Response (Base=19)</b>
Yes	42% (n=8)
No	58% (n=11)

<b>Q30. Are there any processes in place to measure/collect data against the proposed economic impacts?</b>	<b>Response (Base=19)</b>
Yes	35% (n=6)
No	65% (n=11)

<b>Q31. Do you anticipate your project will be of use the future research?</b>	<b>Response (Base=19)</b>
Yes	100% (n=19)
No	-

<b>Q32. How do you anticipate this research will be of future use?</b>	<b>Response (Base=19)</b>
Post graduate students supported (PHDs/MScs)	53% (n=10)
Young / early career researchers gaining experience	68% (n=13)

Potential to attract funding from other sources in the future	95% (n=18)
Other	21% (n=4)

<b>Q33. Is your involvement in the research linked to the achievement of any academic qualifications?</b>	<b>Response (Base=18)</b>
Yes	11% (n=2)
No	89% (n=16)

<b>Q34. Prior to participating in the research I had not collaborated with:</b>			
	<b>Yes</b>	<b>No</b>	<b>Response</b>
Researchers from other academic institutions	29% (n=5)	71% (n=12)	Base=17
Researchers from outside of Northern Ireland	24% (n=4)	77% (n=13)	Base=17
Researchers who are not from academic institutions	42% (n=8)	58% (n=11)	Base=19
Researchers from other disciplines	39% (n=7)	61% (n=11)	Base=18

<b>Q35. Without this specific research programme it would have been difficult for me to gain experience of collaborative research ?</b>	<b>Response (Base=19)</b>
Yes	37% (n=7)
No	63% (n=12)

<b>Q36. Do you see any particular challenges in working collaboratively in this piece of research?</b>	<b>Response (Base=19)</b>
Yes	16% (n=3)
No	84% (n=16)

<b>Q37. Are you more likely to consider collaborative research in the future because of your experience with this project?</b>	<b>Response (Base=19)</b>
Yes	90% (n=17)
No	10% (n=2)

<b>Q38. In absence of this research project would you still be undertaking</b>	<b>Response (Base=19)</b>
--------------------------------------------------------------------------------	---------------------------

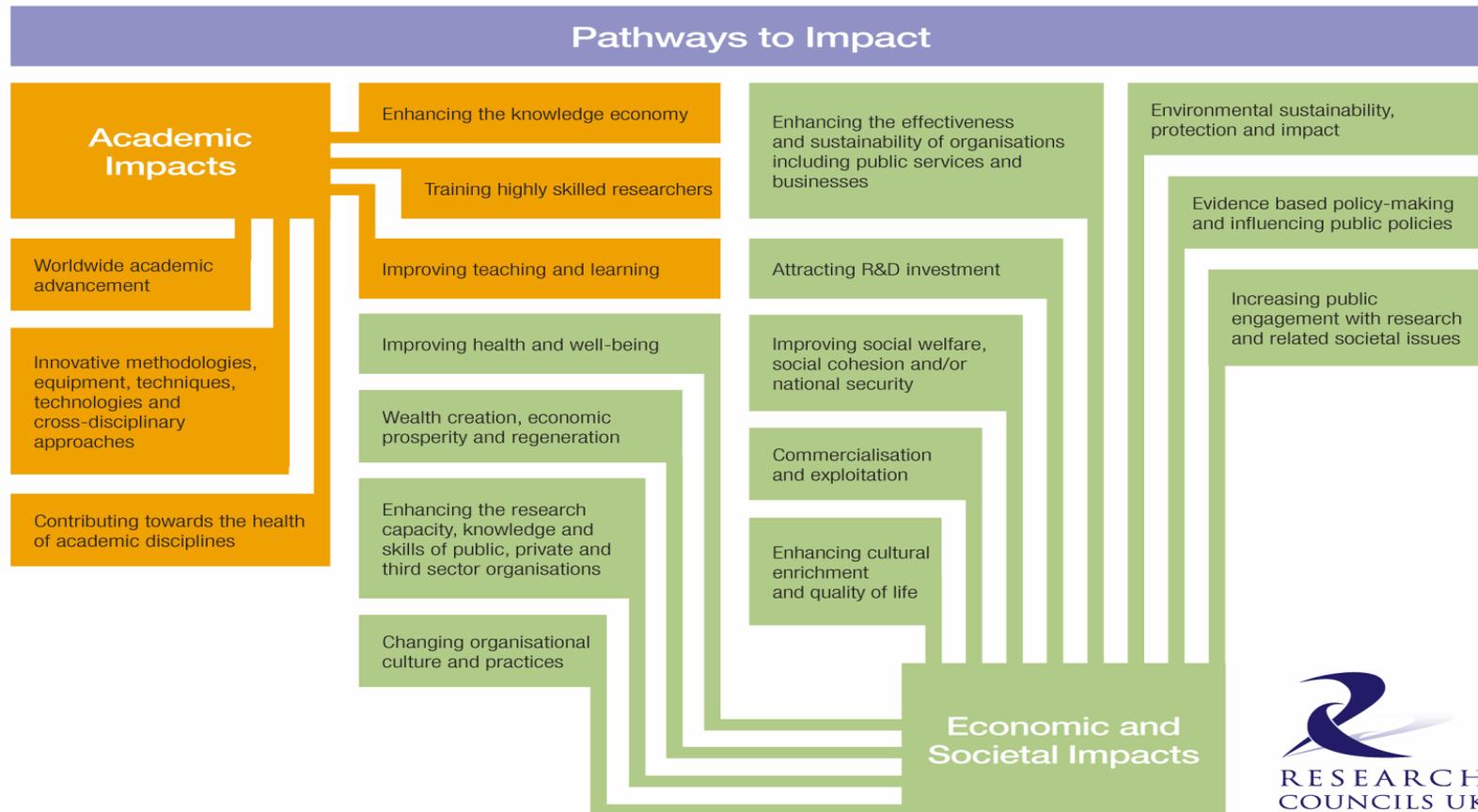
research into dementia?	
Yes	63% (n=12)
No	37% (n=7)

Q39. As a result of your experience gained so far in this research do you intend to apply for funding for further research into dementia care in the future?	Response (Base=19)
Yes	90% (n=17)
No	10% (n=2)

Q40. Do you think that the Dementia Research Programme could be improved in any way?	Response (Base=19)
Yes	47% (n=8)
No	53% (n=9)

## **APPENDIX 5: RCUK EXAMPLE OF A PATHWAYS TO IMPACT AND ESRC GUIDANCE ON CREATING AN IMPACT AND COMMUNICATIONS STRATEGY**

### RCUK Example of a Pathways to Impact<sup>36</sup>



<sup>36</sup> <http://www.rcuk.ac.uk/RCUK-prod/assets/documents/impacts/RCUKPathwayspresentation.pdf>

## ESRC guidance on creating an Impact and Communications Strategy<sup>37</sup>

According to the Economic and Social Research Council, an Impact and Communications Strategy is a more comprehensive plan to achieve and maintain your outlined Pathway to Impact. Guidance on creating an Impact Strategy is outlined below.

### Setting Objectives

Do not just restate the objectives of the research programme itself. Impact objectives revolve around getting your research known and used amongst those who can benefit most from it. The following questions provide a useful starting point:

- What are the likely outcomes of this research?
- Who will benefit from this research?
- How will they benefit from this research?
- How can you involve potential beneficiaries in this research?
- How will you know if it has made a difference?

It is important that you set SMART objectives: **S**pecific; **M**easurable; **A**chievable; **R**elevant; and **T**ime-bound.

### Developing Messages

An effective strategy has clear, succinct messages that summarise your research. As the research develops, it is worth scheduling review points to consider what messages may be emerging from the project and how these can be incorporated into your strategy.

### Targeting Audiences

It is vital to know who key audiences are. Since time and money are often limited, it is useful to rank each of your potential audiences and user groups according to their importance and influence relative to your strategy.

### Choosing Channels

It is important to consider the most appropriate channels to reach your target audience (e.g. through press articles, workshops, bulletins, or conferences). This will require finding out how the target audience prefers to receive information. Two-way communication is important in building relationships with your key audiences. It is therefore useful to consider the following questions: What channels are you going to use to get feedback, and how are you going to communicate what you did with that feedback?

### Planning Activities

An impact strategy must include a full list of all the activities you are going to carry out. When planning these activities it is important to target the activities effectively; not underestimate the

<sup>37</sup> <http://www.esrc.ac.uk/research/evaluation-and-impact/developing-an-impact-strategy/>

resources involved; concentrate on the most important and influential audiences; and prioritise high impact/low cost activities

### **Allocating Resources**

Once the project plan has been developed, you can begin costing the time and money involved. The project plan should include a timetable showing the main activities that will be carried out, key deadlines, milestones, and review points. It is important not to underestimate the time involved; allow contingency time to take account of unexpected opportunities; allow enough time for 'warming up' key contacts by creating initial interest in the project; not assume that your audience is working to the same timeframe; be aware of how your schedule fits in with other key events; think about the cycle of the year for relevant audiences; and provide training for team members so that more people can field media enquiries, speak at conferences and draft articles.

### **Measuring Success**

Good evaluation requires a good set of objectives as the usual starting point is to evaluate the activity against its objectives in order to determine whether the project achieved what it set out to achieve. However, other issues such as whether the programme changed any of the participants (audience or researchers) or whether there were any unexpected outcomes can also be evaluated. The evaluation could also seek to identify any aspects of the process that were particularly effective – this learning can be very useful for other researchers undertaking public engagement.

## Impact Strategy Template

### Setting Objectives

The key impact and communication objectives are:

- 
- 
- 

### Developing Messages

The key messages to communicate are:

- 
- 
- 

### Targeting Audiences

<b>Prioritised Audience</b>  (most research investments will need to target governments/parliamentarians; business/private sector; civil society; media/public etc.)	<b>Please give details</b>  (e.g. which government departments, which sectors specifically etc.)	<b>Overview of engagement activities and communication channels</b>

## Planning Activities

Activity	Budget (how much will this cost?)	Staff and other resources required (who will do this?)	Deadline/ timeframe	Success criteria (how will you know this has been effective?)
<b>Identity</b>				
Examples include: branding - development of logo, printing of stationery, website development and maintenance				
	<b>Subtotal £</b>			
<b>Internal communication</b>				
Examples include: newsletters, intranet, key meetings				
	<b>Subtotal £</b>			
<b>Events – stakeholder and academic</b>				
Examples include: launch event (if appropriate), stakeholder events, seminars/conferences, networking, public or schools events/activities				
	<b>Subtotal £</b>			
<b>Digital communications</b>				

Activity	Budget (how much will this cost?)	Staff and other resources required (who will do this?)	Deadline/ timeframe	Success criteria (how will you know this has been effective?)
<p>Examples include: Twitter and other social networking sites, blogs, podcasts (ESRC has produced a guide to social media in our impact toolkit (<a href="http://www.esrc.ac.uk/impact-toolkit">www.esrc.ac.uk/impact-toolkit</a>) and offers digital media training)</p>				
	<b>Subtotal £</b>			
<b>Media relations</b>				
<p>Examples include: engagement of university press office, ESRC press team and other funders' press offices, developing links with key media people/publications (are you aware ESRC offer media training?)</p>				
	<b>Subtotal £</b>			
<b>Publications</b>				
<p>This will include uploading to the Research Outcomes System (ROS) Examples include: policy</p>				

Activity	Budget (how much will this cost?)	Staff and other resources required (who will do this?)	Deadline/ timeframe	Success criteria (how will you know this has been effective?)
and evidence briefings, stakeholder publications, journal articles, leaflets, booklets and books				
	<b>Subtotal £</b>			
<b>Stakeholder engagement</b>				
Examples include: members on advisory groups, meetings, select committees etc				
	<b>Subtotal £</b>			
<b>Data deposition</b>				
This will include contacting UK Data Service and setting up systems to ease data deposition				
	<b>Subtotal £</b>			

## Evaluating Success

**Date to review strategy:**