

**Proceedings from the
Dementia Research Knowledge Exchange Event
Department of Health, 30 April 2019**



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Foreword

It gives us great pleasure to present this report, which captures the proceedings from the Dementia Research Knowledge Exchange Event, held at the Department of Health on 30 April 2019.

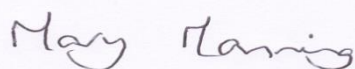
The Health Research Board's (HRB) programme of applied dementia research, funded with Atlantic Philanthropies (AP) and supported by the Department of Health, had strategic relevance to the implementation of the National Dementia Strategy. The aim of this research programme was to support applied research projects in the areas of organisation and delivery of dementia services; management and decision making in dementia care; and social, economic and policy issues in dementia care. Given the relevance of these themes, the National Dementia Office (part of the Health Service Executive) and the HRB collaborated on this knowledge exchange event, marking an important step towards bridging the gaps between research, policy and practice.

The aim of the knowledge exchange event was to give researchers funded under the HRB–AP applied dementia research programme, as well as those funded under other HRB funding schemes, an opportunity to highlight evidence emerging from their research in dementia and bring this evidence to a wide research and policy audience. It was also an opportunity for attendees to consider the current scale and scope of dementia research across different specialities in Ireland and to reflect on future priorities.

There are over 55,000 people living with dementia in Ireland, and if trends continue this number will increase exponentially in the coming years. Evidence on what works to support people with dementia to live as well as possible is critical to ensure the wellbeing of this growing population. Dementia not only affects those who have the condition but also their families, friends and those who provide care. Many of the research studies presented at the event, whose findings are reflected in this report, provide evidence on how we can support family carers.

The voices of those with lived experiences of dementia form a central component of the work of both our organisations, and this was evident in the many examples of public and patient involvement in the research studies that were presented. Dr Helen Rochford Brennan, Chair of the European Working Group of People with Dementia, addressed attendees on the importance of involving people living with dementia in research and the role they can play, not only as research participants but also as experts who can inform the broader research agenda.

We would like to extend our thanks to those who took part, to those who attended and particularly to our colleagues in the Department of Health for their support of this knowledge exchange event.



Mary Manning
General Manager
National Dementia Office



Dr Mairead O'Driscoll
Director of Research Funding and Strategy
Health Research Board

Overview of event

This report presents the proceedings of the Dementia Research Knowledge Exchange Event held at the Department of Health on 30 April 2019. The participants were drawn from the policy, practice and research community relating to dementia.

The structure of the report reflects the order of the day, which commenced with a welcome and introductory address by Dr Kathleen Mac Lellan, Assistant Secretary, Social Care, Department of Health. This address was followed by a consideration of the value of research in dementia, with a particular focus on the involvement and participation of people with a diagnosis of dementia in research. This presentation was delivered by Dr Helen Rochford Brennan, the current chairperson of the European Working Group of People with Dementia.

This was followed by a presentation by Geoff Huggins, leader of the EU's Second Joint Action on Dementia. He gave an overview of the joint action, which is titled Act On Dementia, and outlined some learning arising from the EU's first joint action, titled Alcove.

Findings from six research projects, funded through a number of different Health Research Board (HRB) award programmes, were presented by researchers based at various research institutions in Ireland, including University College Dublin, Trinity College Dublin, the National University of Ireland, Galway and University College Cork. The programmes under which these grants were awarded include the Applied Research Projects in Dementia grant awards, the Research Leader Award programme, the HRB–Atlantic Philanthropies dementia research funding initiative and Investigator Led Projects.

The day concluded with a panel discussion that focused on practice and policy changes arising from Irish and international research, strengths and weaknesses of dementia research in Ireland, issues arising in respect of knowledge exchange, and public and patient involvement. Throughout the discussion, consideration was given to the development of future research agendas around dementia research.

Programme

Date: Tuesday 30 April 2019
Time: 10.00–13.30
Venue: Townhall, Department of Health, Baggot Street Lower, Dublin

Time	Title	Speaker
10.00–10.30	Registration, tea/coffee	
10.30–10.45	Welcome and introductory address	Dr Kathleen Mac Lellan
10.45–11.00	The value of research in dementia	Dr Helen Rochford Brennan
11.00–11.25	Case studies from HRB-funded dementia researchers	
	Connected Health Supporting Home Stay in Dementia (CHESS)	Professor Catherine Blake
	Dementia friendly Irish hospitals: opportunities, barriers, costs and solutions	Professor Desmond O’Neill
	Resource allocation, priority setting and consensus in dementia care in Ireland	Dr Fiona Keogh
11.25–12.00	Second EU Joint Action on Dementia: theory and practice	Geoff Huggins
12.00–12.20	Break	
12.20–12.45	Case studies from HRB-funded dementia researchers	
	The prescribing of antipsychotics to nursing home residents with dementia	Dr Kieran Walsh
	Validation of the Profile for Communication Abilities in Dementia (P-CAD)	Dr Margaret Walshe
	The Model for Dementia Palliative Care Project: enabling implementation of national policy	Dr Suzanne Timmons
12.45–13.30	Panel discussion: Addressing the evidence gaps: the future of dementia research	<i>Chair:</i> Professor Eamon O’Shea; <i>Participants:</i> Geoff Huggins, Professor Sean Kennelly, Dr Emer Begley and Dr Bernadette Rock

Welcome and introductory address

Speaker: Dr Kathleen Mac Lellan

Good morning, everyone. On behalf of the Department of Health and our colleagues in the Health Service Executive's National Dementia Office and the Health Research Board (HRB), I would like to welcome you to today's dementia research knowledge exchange.

In particular, I want to welcome our keynote speaker, Mr Geoff Huggins, Director of Health and Social Care Integration with the Scottish government and the Director of NHS Education for Scotland. Geoff is responsible for improving joint working and the integration of health and social care in Scotland, an area that we here in Ireland have begun to develop. Geoff is also the leader of the Second EU Joint Action on Dementia, and he will outline the theory and practice of the joint action in his presentation later this morning.

A particular welcome also goes to Dr Helen Rochford Brennan, who will speak today about her experiences of living with dementia. Public and patient involvement is critical to the successful implementation of the National Dementia Strategy, and indeed the patient and service user must be central to all of our work, whether in research, policy making, or service planning and delivery.

I would also like to thank our colleagues in the National Dementia Office and the HRB for working to bring today's event to fruition.

A number of the presentations you will hear today were funded through the HRB Applied Research Projects in Dementia awards. Funding for these awards was provided jointly by Atlantic Philanthropies and the Department of Health, and I would like to take this opportunity to acknowledge the important role played by Atlantic, not just in funding dementia research but also in funding the National Dementia Strategy implementation programme and many other initiatives in the social care sphere aimed at promoting a person-centred approach to care.

The Applied Research Projects in Dementia awards focus on questions of clear strategic relevance to the National Dementia Strategy in the areas of organisation and delivery of dementia services; management and decision making in dementia care; and social, economic and policy issues in dementia care.

This event offers an opportunity for dementia researchers to present their findings, and it will enable the sharing of knowledge between dementia researchers and policy makers. It will give a flavour of the current scale and scope of applied research across different specialities. Of course, while they may cover diverse areas, they all focus on gathering information that seeks to have an impact on future policy and practice and, ultimately, improve the lives of people with dementia.

The research that will be presented today encompasses studies on creating dementia-friendly hospitals, the use of antipsychotics in nursing homes, a practice-based model for palliative care for people with dementia in the community, an assessment tool that can profile communication difficulties, and supporting people wishing to remain living in their communities through connected healthcare. Mindful of how resources are spent, value for money in research is important, and we will also hear about work carried out to set priorities and reach a consensus in dementia care. We will also have a panel discussion, which will cover the gaps in evidence today, how to address these, and the future of dementia research.

From an operational perspective, advanced dementia research allows us to learn where services are working and, more importantly, where they are not helping people with dementia as fully as they could.

Knowledge acquired through in-depth research means services can be amended in a conscious way, reflecting the challenges faced by people with dementia. As an example, being admitted to an acute hospital can be challenging for anyone, but it can be particularly frightening and distressing for someone with dementia, because of the unfamiliar and busy nature of the setting. Funding from the HRB has allowed for the development of dementia-friendly hospital design guidelines, with the aim of enabling hospitals to become more comfortable and therapeutic places for people with dementia.

From a policy and practice perspective, information is crucial in providing the evidence that shows what is needed in the myriad care settings all over the country. An example of this is the development of a clinical guideline on the use of psychotropics for the management of dementia. Psychotropics are used in a range of settings, including acute hospitals and nursing homes. While in many cases they are used appropriately, sometimes they are not. It therefore became evident that an evidence-based national clinical guideline was needed on the appropriate management of psychotropic medication. The guideline was prioritised by the National Clinical Effectiveness Committee last October and a final review is being conducted at present.

Research is one of six priority action areas contained in the National Dementia Strategy. The strategy notes that research can inform the organisation and delivery of future services to achieve optimum health outcomes. Having a better understanding of how dementia affects people allows us to develop better supports.

Although we are hopeful that research will, in the long term, make prevention or cure for dementia a reality, non-clinical psychosocial research has been able to give us an improved understanding of how people live with dementia today, what challenges they face and what can be done to address these. This insight is crucial in determining what needs to be provided and what benefit these solutions can offer.

Extensive research was undertaken in advance of the development of the Dementia: Understand Together campaign, which has provided a central website containing information, resources and a service finder showing supports available in every county. The campaign has also highlighted the issue of dementia in wider society through its extensive public awareness component, by addressing the challenges faced by people with dementia in communities across Ireland. The most effective part of this campaign is how it shows that people with dementia remain a valuable part of society and are still capable of contributing to the fabric of national life.

With over 55,000 people living with dementia across Ireland today, and an expected trebling of these numbers in the next 30 years, it is crucially important that we gain a greater understanding of what dementia is, how it impacts the lives of people and their families, and how to treat and manage it.

You will all be aware that Sláintecare is the 10-year vision for the reform of our health and social care services. Sláintecare aims to shift the focus of care to the community and to provide services at the lowest appropriate level of complexity. As part of the Sláintecare Action Plan, we have committed to continue to implement the National Dementia Strategy and also to develop a Social Care Strategy.

The Social Care Strategy will set out how we will provide services in the future to older people and people with disabilities in the community in an integrated way. This will include considering the needs of the growing numbers of people with dementia and their family carers.

The evidence base generated through the research presented here today will doubtless be of assistance as we seek to turn our vision of transforming the health and social care of a rapidly increasing and ageing population into a reality.

I wish you all every success in today's event and I look forward to taking part in the panel discussion later.

Speaker biography: Dr Kathleen Mac Lellan

Dr Kathleen Mac Lellan is Assistant Secretary, Social Care, Department of Health. Previously she was Director of the National Patient Safety Office (NPSO) in the Department of Health, leading a programme of patient safety policy and legislation, and the national clinical effectiveness framework. The NPSO collaborated with the Health Information and Quality Authority and the Health Service Executive to deliver the first National Patient Experience Survey, which took place in May 2017. As Director of Clinical Effectiveness, Kathleen supported the publication of 14 national clinical guidelines. Previous roles include Nurse Advisor in the Department of Health, Head of Professional Development with the National Council for the Professional Development of Nursing and Midwifery, Project Lead on the Nursing and Midwifery Board of Ireland's Scope of Practice Framework, and Assistant Director of Nursing at St James's Hospital.

The value of research in dementia

Speaker: Dr Helen Rochford Brennan

Good morning, everybody. I am delighted to be here today. Collaboration with all the stakeholders in this room is critical for the success of research.

The first thing I want to speak about is how dementia research has informed my thinking and involvement in dementia activities in Ireland.

The time after my diagnosis was dark and depressing. I had always been an active member of my community but after my diagnosis I lost my confidence and my sense of purpose. I withdrew from my public activities. My professional life was over and my work as a community activist finished abruptly. Whereas before I had had a full life, one of active citizenship, I now sat at home depressed – no plans, no strategies and certainly no support. But some light began to come back into my life after I took action on the advice of a nurse at Western Alzheimer to get involved in research. I contacted Professor Robinson at Trinity College and became involved in a cognitive rehabilitation therapy project with Dr Michelle Kelly and the NEIL (Neuro-Enhancement for Independent Lives) programme at Trinity. This led me to the Alzheimer Society of Ireland and ultimately the Irish Dementia Working Group (an advocacy group of people living with dementia).

It is hard to explain the joy I felt to finally meet people who were just like me.

That research project was the first step I took towards becoming a national and international dementia advocate. When you are diagnosed, you don't think about research; it is up to researchers to reach out and show those of us living with dementia the potential value of engaging with the research community.

I have also been asked to speak about public and patient involvement (PPI). My perspective on PPI has evolved as I have evolved as an advocate. When I first spoke about living with dementia and was asked to participate in research, I was delighted, grateful and eager to have my voice heard. But now I have come to view PPI as a fundamental aspect of any research project – not an add-on and certainly not something for which I should be grateful. People living with dementia can be denied their human rights from the time of diagnosis. We are not always respected or informed. As we live with the disease, we navigate systems and structures that are not person centred or rights based. As a result, either deliberately or by omission our human rights are denied.

A rights-based approach to research can begin to address this inequality. High-quality patient engagement should underpin all research projects and such engagement must be carried out from a human rights perspective. This engagement is only worthwhile if the person is empowered and if there is shared power and decision making. I believe best practice is to involve people living with dementia from the start. I do not simply want to answer questions; I want to set the questions and think about the issues that merit questioning. We must move from being research participants to being research instigators. And, critically, we have a right to be involved in the governance and management of a research project.

I am not an expert in law or medicine or human rights. But I am an expert in my own experience. People living with dementia must be valued like other experts. That means we should be remunerated for our time and not have lengthy waits for reimbursement of expenses. When I speak at conferences or attend research events, I may be the only person in the room not being paid to be there. That is probably the case here

today! Not everyone can do what I do because many people who would like to get involved in research do not have the money to do so. Therefore, we must ask the question, should they receive an honorarium?

Prompt payment of expenses and, if possible, ensuring that the person with dementia does not have to pay for travel and costs up front has two critical effects. Firstly, it places a value on the lived experience. Secondly, it allows for diverse people living with dementia to become involved in research. Financial barriers can be prohibitive for some experts by experience.

I am heartened by the number of invitations that I receive. I am a proud member of many research committees, steering groups, boards and panels. But not everyone who issues an invitation has a clear understanding of how to support me or my colleagues appropriately. People living with dementia need support to disseminate reports and research documents. We need time and space to work and should not be put under pressure. We need a designated person to be our regular contact. We need opportunities to ask questions and discuss material informally before a formal meeting. We also need practical support with travel, expenses and planning. I want to be very clear, however, that we do not need a paternalistic approach – rather, one that is inclusive and transparent. Requiring support does not make me less of a person or participant.

People whose dementia has progressed should be communicated with by skilled research professionals who understand their unique and individual communication needs. Particular effort should be made to ensure that their voice is heard and that the research community is not oversampling those living with young onset dementia. Due consideration must also be given to the aftermath of research. If I take part in research, I want to know the outcomes. Too often people living with dementia are asked for their opinion or to share their lived experience and have no idea where this information goes. What happened next? Did the work influence public policy or care practice? Is there a next step and does that next step continue to involve people living with dementia?

Being involved in research is empowering. From a personal perspective, it gives me a sense of hope. The Alzheimer Society of Ireland and Alzheimer Europe have supported my involvement and I want to acknowledge their support and that of my volunteer travel companion, Carmel Geoghegan. It is my hope that the European Research community will place PPI at the heart of its dementia research and that robust patient engagement will become the norm.

I know a dementia research prioritisation exercise is currently being undertaken by the Dementia and Neurodegeneration Network Ireland and the Alzheimer Society of Ireland. This will help to identify priority research areas, and I am delighted that there will be a strong PPI element within this.

Another important topic to consider is how more people living with dementia can get involved in research. Well, I want to remind everyone that there is no onus on us, as people living with dementia, to get involved in research. But if people choose to participate – sit on steering groups and get involved in research projects – then researchers must provide the right supports to enable them to participate. And people with dementia must also speak up and be assertive – we must say when we can't understand and let people know when we don't think we should engage in a particular project.

The principle of citizenship is that people have rights and responsibilities. We should have a right to be involved but take responsibility to be involved in the most meaningful way possible. I get many invitations to participate in research and I am glad to have my voice heard. But I challenge all of you here to ask yourselves

– is Helen the easy option? I have colleagues in the Irish Dementia Working Group all over Ireland. People living in rural areas with no transport, people living alone with no support to prepare and travel. People who do not use email, or whose sight is poor and who need support with documents. You need to reach out to those people and take practical steps to support diverse voices in research. Don't take the easy option.

Preparing for today, I read a quote about inclusion. It said:

Diversity is being invited to the party, inclusion is being asked to dance.

Well I can tell you there are people all over Ireland with their dancing shoes on, ready to contribute, but you have to ask and show us to the dancefloor! And, importantly, you must give us time to understand the research project. Sometimes organisations put people forward and the person goes along to support the organisation, or even the researcher, without fully knowing what the project about, what the expectation is and what their responsibilities are. That preparatory work is often overlooked or not factored in. All the time, we must be working towards meaningful participation. As people with dementia, we need to work towards helping people to avoid tokenism. It's about quality rather than quantity: as demand increases, we need to deliver well on a small number of projects. Quality research is far better than meeting, in a limited way, the demand of a large number.

In my work in Alzheimer Europe we, the European Working Group of People with Dementia, challenge researchers to engage with us in a meaningful way. We invest a huge amount of time in research and expect the same back. I am very grateful to be facilitated to have my voice heard by the Alzheimer Europe team. When I was part of the development of national guidelines on psychotropic prescribing with Dr Suzanne Timmons, I needed significant support – I was a lay person trying to understand complex prescribing. I am grateful to Suzanne for facilitating and supporting me to engage in a meaningful way. This must be the norm.

I participate in research because it gives me hope and a sense of purpose. That is my payment: hope to improve the lives of people living with dementia and their families. But our government needs to think seriously about research. Funding often comes to an end and then where is the continuity? How do we put research into practice? I am so grateful to funding streams such as Atlantic Philanthropies and the Dormant Accounts Fund, but I am concerned about this constant fighting and scraping for funding. It is not sustainable and it certainly is not respectful to my colleagues and I who give our time to research. I do not want to contribute to a report to sit on a dusty shelf. I want to see action and improved practice. But that takes ring-fenced, multi-annual funding.

The Alzheimer Society of Ireland is now prioritising PPI, and yesterday I attended the first meeting of the Dementia Research Advisory Team. This is a panel of people living with dementia and caregivers who will work with researchers in a PPI capacity. Over the next year, the Alzheimer Society of Ireland will support us experts by experience to be authentically involved in research. This gives me hope and I am enjoying mentoring new experts by experience!

I have enjoyed the many projects on which I have worked with the National Dementia Office with Anna de Siún and Dr Emer Begley, but even more importantly I am starting to see them influence public policy. I am seeing them become real. I want to see more of that; I want to witness the change that research tells us is possible.

I am standing before a group today who have the skills to make that happen. I encourage you to work together, to involve people with dementia and to at all times focus on turning research into policy.

Thank you.

Speaker biography: Dr Helen Rochford Brennan

Dr Helen Rochford Brennan is the current chairperson of the European Working Group of People with Dementia and is the group's nominee to the board of Alzheimer Europe. She is a former Chair of the Irish Dementia Working Group and continues to sit on the steering committee. Helen is on the Monitoring Committee of Ireland's first National Dementia Strategy. She is also an Alzheimer type of dementia consultant and a global dementia ambassador. In 2018 she was awarded an honorary doctorate for her work as an advocate for a rights-based approach to dementia. In the same year, she contributed to two books on human rights.

Helen was diagnosed with early onset Alzheimer's seven years ago, at the age of 62, and has since written very personally about living with an Alzheimer type of dementia. She hopes her participation in research will help researchers to one day find a cure and to facilitate a better quality of life for people living with dementia, and she is passionate about incorporating personhood and citizenship into dementia research. Helen lives in Tubbercurry in Sligo with her husband, Sean; has one son, Martin; and is an active participant in the life of her local community.

Second EU Joint Action on Dementia: theory and practice

Speaker: Geoff Huggins

Act On Dementia is the EU's second joint action on dementia. The first, Alcove, was managed and run by colleagues in France, colleagues who were involved in the second action as well. The aim is:

To promote collaboration through collaborative actions among member states to improve the lives of people living with dementia and their carers.

I think that is quite important, in that the focus is not to know more. The focus of the joint action is to improve the lives of people living with dementia, and that is a key component of the thinking behind the joint action.

I am going to say a bit about the work that we're currently involved in. I'm not going to say that much about the research findings from phase one of the joint action. A key component of the work that we wanted to do through this joint action was to begin to think about the translation between knowledge and information, on the one hand, and action, on the other, and the degree to which there was a foundation for evidence-based practice. I think that is one of the questions that arises across all areas of health and care, in that we now know so much about what works and about appropriate interventions, but the experience of people living with dementia or with other conditions doesn't always reflect that knowledge.

This caused us to decide that we would structure this joint action differently. Each of the previous joint actions across dementia (and across other areas that the EU has funded) has tended to focus on developing the evidence base but has paid little attention to the application of that evidence base. When we looked at Alcove, the previous joint action, we saw that it contained some really interesting work and had a focus on determining the best methodologies for assessing dementia prevalence within populations, but we also saw that it is in use in only four EU countries. So a project costing many hundreds of thousands of euros and spanning multiple years identified the best methodology and put that methodology out there, but almost no countries within the EU are using the methodology promoted.

We broke the second joint action into two parts. Over the first year (beginning in March 2016), we reviewed the evidence base in each of the substantive areas of the joint action. Then, in years two and three, we applied aspects of that evidence base to actually understand the practical implications of trying to put evidence into practice, because that is the point at which people are meant to benefit. People benefit whenever we do things that change how we deliver services.

While there are a number of countries involved, those countries that are most involved are Scotland, Spain, France, Italy and the Netherlands. Three of the work strands of the joint action effectively involve administration and process, and Scotland and Spain will manage those. They will ensure that we get the deliverables of the joint action, but they will also manage the process, the money and the communications. The four substantive areas of the joint action are in respect of:

1. diagnosis and post-diagnostic support, led by the French
2. crisis and care coordination, led by the Italians but with the strong involvement of the Dutch government
3. quality of care in residential settings, led by the Norwegians

4. dementia-friendly communities, led by the Department of Health, Scotland.

Diagnosis and post-diagnostic support

In the area of diagnosis and post-diagnostic support, under the leadership of the French but also with the involvement of Bulgaria and Poland, the process was to test three different propositions. The first was around addressing stigma and discrimination in respect of people with dementia. The second was around whether we could improve diagnosis through better collaboration between general practitioners (GPs) and hospital-based nursing staff. And the third was around the use of telemedicine to increase the support being offered in residential care settings and nursing homes.

Our aim was to understand the impact of each of these areas. Therefore, our French, Polish and Bulgarian colleagues identified within their respective countries locations where they could take this work forward. When we began the process, people said, 'Unless you've got money to fund these projects, nobody will do them.' However, we ended up with somewhere between 25 and 30 individual tests of change going on across Europe, with a lot of activity, because people saw the value of taking the work forward locally and also because they were able to take it forward under the broad heading of the EU. We have relatively small amounts of resource from the EU to manage these projects and deliver the programmes, but the resource that's been added to the process has been more significant.

The broad takeaway from the second proposition is that GPs find it helpful to move away from being given an understanding of dementia as an illness to being assisted in how they can actually work with people living with dementia. So, in this area, because through these programmes GPs could begin to focus on better understanding the needs of people living with dementia, there was a good uptake and a good response. The research and its outcomes suggested that people gained a lot of value from this work. One reason could have been that these projects tapped into a broader idea that we often see within primary care: that healthcare professionals' primary objective is to help people, and knowing things doesn't always help people. So this was a positive outcome. There was a good uptake, and we achieved the benefits that we were seeking.

We also looked to recruit GPs and nurses within secondary care settings, to improve the diagnostic support being given to general practice and thereby assist with diagnosis. One of the things that came out in early conversations was that there are different approaches across Europe to where diagnosis takes place and, in France, there is a general lack of diagnosis taking place within primary care centres. This came out of a particular challenge experienced by the French, who had significant difficulty in recruiting GPs to become involved in this work. When we looked at why this was the case, there were a range of factors. Many didn't see it (the diagnosis of dementia) as their role, and many thought that if they took on this work that it would bring other work. Therefore, what we saw here is that even though historically this kind of diagnostic work has been done in primary care settings, which suggests that it has value, in practice the system is not very welcoming of it as an approach.

Comparison with Italy is interesting, because the Italians carried out the same piece of work and got a better uptake. This shows that it is important to understand what is going on within your own locality, take into account how your broader structure of health and care works, and think about what is most likely to have value within your system.

The third proposition we tested was around telemedicine. There is good evidence for holding telemedicine consultations between specialist settings and residential settings. However, the French researchers spent

nine months trying to get regulatory approval to talk to somebody over video conferencing. This problem had not been anticipated and led to a discussion about whether or not telemedicine is a medical intervention and whether it needs to be subject to additional regulation. This meant that, in France, almost none of the intended work took place. I believe that in Poland there were no similar regulatory problems, even though in France we were told that the problem was related to EU regulation. This shows that understanding that there may be unanticipated barriers to your implementation process is quite important.

Crisis and care coordination

A further work package is around crisis and care coordination. During the first phase, the Italian investigators produced a strong literature review. This document identified very good evidence that care coordination in many cases was having a bigger clinical impact than clinical interventions. Care coordination has often been seen as a 'hygiene' issue, or an issue that is about quality or about the patient experience. However, in practical terms, when the researchers took measurements and looked at the evidence, they identified that, for many people, care coordination was actually producing bigger clinical outcomes than other types of intervention.

This was a really interesting bit of learning. It was not something that we expected to see, and it suggests that we need to pay more attention to ideas around social care integration and how the system actually works as a whole, bearing in mind that it's not just about convenience. Social care integration actually makes people's lives better, and I think that's important to remember.

As part of this work, the researchers replicated the work that had been done around GP and specialist nursing, but they looked at particular issues around care pathways. Essentially, they looked at the degree to which they could provide better coordination within this space. They got a good uptake and good responses, partially (I suspect) because they took this work forward in Medina in Italy, which has a long history of very strong work around dementia. Relatedly, they also looked at these issues in respect of behavioural and psychological symptoms of dementia, and they were able to build on a strong report in the Alcove papers about the precise approaches that can be used and the impact that good care coordination can have. In this area, we are also looking at the reduction of the use of antipsychotics, and one of the case studies below ('The prescribing of antipsychotics to nursing home residents with dementia') shows that we are able to demonstrate some impact.

All of this work was intended to look at the pathways by which people actually move through the system. This is interesting to me because it is similar to some work that we did in Scotland where we mapped care pathways for people over the age of 65 who had been hospitalised. The findings showed that it was possible to intervene with GPs to reduce inappropriate referrals that were leading to people becoming stuck in hospital; by adding additional support, it is possible to bend people's pathways through the system. I think further work is likely to be required in this area. Again, this is probably going to be a very localised issue, because your experience here in Ireland will be that people relate to different hospitals in different ways simply because of where they are within the country. Understanding this is about evidence and underlying need, but it is also about clinician and public behaviours.

Quality of care in residential settings

The Norwegians have led the area of research on the quality of residential care. This is probably the group that has had the most participants, and the focus here has been on looking at the behavioural and psychological symptoms of dementia alongside the use of antipsychotics (drugs). This is an interesting piece

of work, because we can see that different parts of Europe are at different stages in the process. The objectives here were to see how we could develop better knowledge and understanding, look at alternatives, and think differently about the quality of care. The goal was to raise awareness of the need to personalise and humanise care, and move it away from many of the problems that all of our countries have seen historically.

Bulgaria, Greece and Romania are areas where dementia services are significantly less developed. However, in terms of beginning to simply ask questions, think about the use of antipsychotics and think about other approaches, the participants in these countries were able to make good progress. They were able to begin to think differently and start to improve the quality and the nature of the care that was being offered. In contrast, in the Netherlands and Norway – countries with established evidence bases and existing traction around dementia research – the approach focused more on a general package, with the objective being to try to roll it out across multiple care homes.

Interestingly, in the Netherlands, there was almost no impact. The researchers found it very difficult to get the package taken up. When they looked into why this was, they found that the residential care settings already had a number of different ways of carrying out the processes covered by the package. So, when somebody came along and said, 'We've got this really good way you could do this,' their response was, 'Well, we're doing this, this, and this already, and we're not really sure why we would adopt your method.' The existing methods weren't necessarily dementia focused, but the new intervention effectively cut across how the residential care settings were doing other things. And that meant the take-up was a lot less than it could have been.

In Norway the experience was better, simply because it was probably going more with the grain of what the residential care settings were already looking at, and it built on some initial work that had already been done. However, again, this shows that each of these countries – and even individual institutions – have different financial and organisational structures. As a result, they end up with quite different outcomes and approaches.

Dementia-friendly communities

The final work package was led by the Department of Health, Scotland with pilot tests carried out by Greece and Bulgaria. They lent the work a great deal of energy, and their participation enabled them to begin to take additional work forward that would otherwise probably have been quite challenging. This is an example of how, through these projects, participants often began to talk about dementia and quality of care for the first time in a way that had an impact on what was actually going on.

The topic of dementia-friendly communities is an interesting one, because it was difficult to decide whether we would include it. When we were putting the joint action together, probably about five years ago, colleagues in the UK government were very keen for this to be one of the areas of joint action and were very keen to lead it. If we go back to 2013–2014, we had David Cameron travelling the world, talking about dementia as a global priority. We had significant investment from the UK government and collaboration with the governments in North America, Japan and Australia. Effectively, there was an effort to build a global alliance between the G7 countries. However, since that time, the team at the Department of Health and Social Care in London has shrunk from having around 45 people working on dementia to about three or four.

The work that's been done on dementia-friendly communities has led to a strong report authored by Diane Blood. The report argues that, too often, when we talk about dementia-friendly communities, we describe

them from the perspective of the service manager or politicians. Very rarely do we see people living with dementia actually involved in the construction or consideration of what a dementia-friendly community should be.

This notion was a real wake-up call to this agenda, as it showed that it is not always appropriate to try to systemise something. Initiatives always have to begin with people living with dementia and their families, so we began by considering how we would like to develop this idea. Stage one of this work is really strong, but stage two has almost entirely taken place in Bulgaria and Greece. There is no pilot site in England. We have done some work on this topic in Scotland, but we did not connect it to the joint action. Overall, these developments show how the political significance of dementia can move very quickly within a country and can become overly attached to particular agendas over time. This is something that we need to be in for the long haul. It needs to incorporate long-term planning, long-term thinking and ongoing commitment.

Within this context, a number of phenomena have arisen that in other jurisdictions we might describe as 'social inclusion', 'anti-stigmatisation' and strongly dementia-friendly community approaches that are focused on engagement with and involvement of people living with dementia. But this is just one perspective. Other perspectives we are seeing relate to accessibility, non-discrimination and the degree to which the fabric of our environment enables us to actually engage in the work (hospitals are really interesting in that space).

What we take from this, what we see in both Bulgaria and Greece, are very strong civic movements. It is interesting to look back seven or eight years to when dementia was at the forefront of the agenda in the UK and globally. At this time, when we went to visit a dementia-friendly community in Kyoto (for example), it would have been led by the mayor, who would have personally decided to set the initiative in motion. The mayor would have shown political leadership in taking it forward. And this is what we've seen in both Bulgaria and Greece, and it goes well with the work that both countries have done in respect of residential care. It also connects to some of the work these countries, such as Bulgaria, have done around discrimination, the Bulgarians in respect of work package four. But it is important to remember that how a society thinks about dementia depends on where the country is on this journey. What we are seeing here is Southeastern European nations waking up to this as a challenge and engaging with it. And we are probably not seeing the other jurisdictions – the Western European jurisdictions – moving on. They are not considering what comes next or how to improve the quality of services.

Concluding thoughts

We are now about five or six months away from the end of the programme. It has been extended to October of this year. The various teams in each of the work packages are currently writing up reports on the outcomes of their research. We are meeting in June in The Hague to work through the process of signing off and finalising those reports. And there will be a conference in The Hague in October (combined with the Alzheimer Europe conference) at which we will draw a line under the whole process. We are continuing to promote the work as we go through the process, through opportunities like this but also through our website, which includes a lot of rich material (increasingly incorporating video and other media) to show what's happening on the ground.

We have also worked with Alzheimer Europe, colleagues in Italy and colleagues in Holland to maintain and re-establish the EU expert group on dementia. The EU, for reasons we don't always understand, effectively removed all of its behavioural health expert groups about 18 months ago, and there was a real sense of loss,

both in the mental health area and in the dementia area (these are two separate groups). So we've agreed to reinstate the expert group, which will no longer be funded or managed by the EU. One of the advantages of this is that the group can now have non-EU members, so it can bring in other countries across Europe that would not previously have been able to be involved. The second meeting of the new expert group will take place in June of this year, and I hope that colleagues from Ireland will be well represented as they were at the last meeting.

So that's where we are. Thank you for your attention.

Speaker biography: Geoff Huggins

Geoff Huggins was appointed Director of Health and Social Care Integration at the Scottish government in April 2014. Prior to this, Geoff was Head of the Mental Health and Protection of Rights Division. He has worked across a variety of roles covering housing and education policy in Scotland and politics and security with the Northern Ireland Office. He is also the leader of the Second EU Joint Action on Dementia. Since July 2018, he has also been Director of the NHS Education for Scotland Digital Service, which is tasked with building a data platform for health and care in Scotland.

Case studies

Case study 1: Connected Health Sustaining Home Stay in Dementia (CHESS)

HRB award: Applied Research Projects in Dementia (a three-year award due to finish in November 2019))
Co-authors: C. Blake*, L. Mackey, F. Curran, B. Caulfield, D. Power, P.A. Silva, Diarmuid O'Shea, R. Doyle, J. Duggan, S. Cosgrave

The problem addressed by the research

There are challenges in living at home for people with dementia and their caregivers, but it is difficult to capture day-to-day fluctuations in health, function and wellbeing. Communication and monitoring of health, wellbeing, behaviours and quality of life of people with dementia and their carers is ad hoc, sporadic and generally limited to subjective reports at formal health and social care consultations. Valuable information that can guide clinical and social care decisions is being missed. There is an untapped opportunity to empower people with dementia and their carers to contribute to self-monitoring and to link them with health and social care providers.

The solution identified by the research

Connected health is a technology-enabled model of healthcare that utilises technologies including mobile broadband, smartphones, applications (apps), wireless monitoring and activity trackers. By linking such devices to a user input platform, it is possible to collate objective and subjective indices of habitual activity, sleep, vital signs, mood, stress and wellbeing to provide a multidimensional profile of the person with dementia and their carer. This information can be shared by the data owners with multiple stakeholders, connecting patients, carers, consultants, general practitioners, public health nurses and other health and social care professionals in the care team. It also permits communication of care plans to all stakeholders.

How this research makes a difference to policy or practice

This research is tracking two groups of people with dementia and their carers over a 12-month period: one group who are adopters and the second who are non-adopters of a connected health platform. Key outcomes include vital signs, physical activity, sleep, mood and quality of life of the person with dementia, along with subjective burden, sleep interference and psychological indicators in caregivers. Quantitative analysis is exploring longitudinal trends, relationships and interactions between the different measures. Qualitative methods are examining acceptability and adherence to different aspects of the connected health platform from the perspectives of people with dementia, carers and health professionals. Implementation barriers, costs and benefits are being considered.

**Presenter: Catherine Blake is Associate Professor and Deputy Head of the University College Dublin School of Public Health, Physiotherapy and Sport Science (<https://people.ucd.ie/c.blake>). She initially worked as a physiotherapist in the UK, Australia and Ireland. Her research focus is on positive ageing, lifestyle medicine, health measurement and technologies for connected health.*

Case study 2: Dementia-friendly Irish hospitals: opportunities, barriers, costs and solutions

HRB award: Applied Research Projects in Dementia (a two-year award that finished in March 2018)

Co-authors: D. O'Neill*, T. Grey, D. Xidous, S. Kennelly, P. de Freine, A de Siún, N. Murphy, S. Mahon, V. Mannion.

The problem addressed by the research

For many patients and their families, the hospital is a challenging setting due to the busy, unfamiliar and stressful nature of the environment. For a person living with dementia, the hospital experience can be exacerbated by cognitive impairment and can therefore prove to be a frightening, distressing and disorientating place. This research looked at how the physical hospital environment can provide a better experience for people with dementia, and how hospitals can be designed to enable family members and carers to provide support for the person with dementia throughout their visit to the hospital.

The solution identified by the research

The solution identified was to develop and provide guidelines for design, reconfiguration and redevelopment of existing facilities using original research and extensive consultation, and drawing on best international practice. With a perspective starting at the approaches to the hospital, seven principles provide a framework for a dementia-supportive hospital environment: engagement and participation; providing a people-centred environment; supporting patient safety, health and wellbeing; balancing sensory stimulation; supporting orientation and navigation; adequate space to support the needs of a person with dementia; and appropriate use of technology.

How this research makes a difference to policy or practice

Through collaboration with HSE Estates and the National Dementia Office, these guidelines are now incorporated into the fabric of the main provider of hospitals in Ireland. The guidelines also incorporate a new environmental audit tool to be used in the second iteration of the Irish National Audit of Dementia Care in 2019. In addition, the guidelines are accompanied by a video of the key elements and have helped to promote interest in dementia-supportive healthcare architecture among architects. The work has also engaged stakeholders previously unrecognised in dementia-supportive design, such as facilities and technical managers. From an international perspective, through papers in journals such as *The Lancet*, the project has contributed to a growing movement on engaging clinicians with building design.

**Presenter: Professor Desmond O'Neill is Professor of Medical Gerontology at Trinity College Dublin and Consultant Geriatrician at Tallaght University Hospital (<http://people.tcd.ie/Profile?Username=doneill>). Professor O'Neill's research interests centre on ageing and the neurosciences, with over 350 peer-reviewed papers. He has worked collaboratively with a wide range of disciplines, including artists, scholars in the humanities, ethicists, architects and musicians.*

Case study 3: Validation of the Profile for Communication Abilities in Dementia (P-CAD)

HRB award: Applied Research Projects in Dementia (a two-year award that finished in December 2017)

Co-authors: M. Walshe*, S. Dooley, R. Doyle, D. O' Neill.

The problem addressed by the research

Communication difficulty is an integral part of dementia. People with dementia can have the following communication difficulties: difficulty finding words; difficulty using and understanding complex language forms (idioms, metaphors and similes), and difficulty reading and writing. This causes misunderstanding, increased frustration (leading to problem behaviours) and increased caregiver stress. Clinicians have few options for standardised assessment of cognitive communication skills in people with dementia. Many of the available assessments focus on the impairment rather than maximising the abilities of people with dementia.

The solution identified by the research

The aim of the research was to improve the management of communication impairment and increase the quality of the speech and language therapy services provided to people with dementia and their families. The objectives were to:

1. validate a new assessment – the Profile for Communication Abilities in Dementia (P-CAD) – to provide clinicians with a much-needed, psychometrically sound assessment for individuals with dementia
2. determine the efficacy of specific interventions using a valid outcome measure such as the P-CAD.

How this research makes a difference to policy or practice

The P-CAD is a new, valid, reliable instrument and comprises eight sections that include cognitive, linguistic and functional communication parameters. The instrument objectively evaluates cognitive communication abilities, provides support strategies and facilitates the evaluation of the functional communication abilities of individuals with dementia, with a specific focus on conversational skills. The instrument has been validated on 100 people with dementia (across a range of severities and subtypes) and their carers.

The instrument is already improving care of people with dementia and carers by directing intervention in clinical sites in Dublin and by informing 'conversational coaching' programmes for people with dementia and their families. Data collection is underway with collaborators in Edmonton, Canada. The P-CAD will be available from the publisher in late 2019.

**Presenter: Dr Margaret Walshe is an Associate Professor in the Department of Clinical Speech and Language Studies at Trinity College Dublin (<http://people.tcd.ie/Profile?Username=walshema>). She has published widely on communication and swallowing disorders. She is Vice President of the European Society for Swallowing Disorders. With colleagues at Tallaght University Hospital and University College London, she has recently published a Cochrane review on diet modification to improve swallowing in dementia.*

Case study 4: Resource allocation, priority setting and consensus in dementia care

HRB award: Applied Partnership Award (a two year award due to finish in August 2019; Principal Investigator: Eamon O’ Shea).

Co-authors: F. Keogh*, T. Pierse, E. O’Shea

The problem addressed by the research

Resource allocation decision making in dementia care in Ireland is largely implicit, provider driven, and narrowly focused on a standard set of services with no visible consensus across stakeholders on priorities. We have little insight into or knowledge of how priorities are set and addressed, and to what effect. The current narrowly focused model of resource allocation precludes the possibility of providing alternative services and supports that may be more appropriate for people with dementia. In addition, the absence of people with dementia (and carers) from the decision-making process undermines personhood, which is a key principle of the National Dementia Strategy. As a result, dementia service provision is not as responsive, person centred, transparent and cost-effective as it could be.

The solution identified by the research

This study is currently underway. It set out to identify optimality in resource allocation decision making for dementia care. This multi-stakeholder study is obtaining different perspectives on the decision making in the resource allocation process, including the perspectives of people with dementia, their carers, and health and social care professionals. Irish data sets were analysed to develop six dementia case types and vignettes. The quantitative exercise will identify the components of optimal care for people with different needs, identify priorities and help to make decision making explicit. The qualitative data will aid understanding of the information used to make resource allocation decisions.

How this research makes a difference to policy or practice

We have found the Applied Partnership Award to be a useful model for promoting closer relationships leading to greater engagement and collaboration with policy makers and decision makers on service provision. This creates the conditions for applying research results directly to policy. The applied exercise in the workshop methodology has built the capacity of participants in terms of understanding the resource allocation process and the challenges facing decision makers. The outputs will include costed optimal care packages for people at different stages of dementia that can be used to develop resource allocation methodologies.

**Presenter: Dr Fiona Keogh, is a Senior Research Fellow at the Centre for Economic and Social Research in Dementia in the National University of Ireland, Galway. Her work there includes research into psychosocial interventions for people with dementia, decision making on resource allocation for dementia services, and evaluating intensive home care packages for people with dementia. Fiona has over 25 years’ experience conducting health services research and policy analysis in the areas of dementia, mental health and disability.*

Case study 5: The prescribing of antipsychotics to nursing home residents with dementia

HRB award: SPHeRE scholar (2014-2018) funded under the HRB–Atlantic Philanthropies dementia research funding initiative

Co-authors: K. Walsh*; S. Timmons, S. Byrne, J. Browne, J. Mc Sharry

The problem addressed by the research

Antipsychotics are commonly prescribed to people with dementia, especially in nursing homes, despite limited benefits and significant harms. It has been estimated that for every 100 people with dementia treated with an antipsychotic, 80 will not gain any benefit and 1 of these is likely to die or have a stroke. There have been calls to better understand the reasons why antipsychotics continue to be inappropriately prescribed to people with dementia and to develop sustainable interventions.

This research was based on systematic reviews, primary qualitative research and a Delphi consensus study, all of which incorporated theory and evidence, with the aim of developing a suitable intervention. At the core of the intervention development process was an advisory group composed of people living with dementia and family carers.

The solution identified by the research

Based on the findings of this research, the Rationalising Antipsychotic Prescribing in Dementia (RAPID) complex intervention was developed, consisting of academic detailing with general practitioners, education and training with nursing home staff, and an assessment tool.

How this research makes a difference to policy or practice

The RAPID complex intervention was feasibility tested in one public nursing home over a three-month period. The intervention was found to be broadly feasible and acceptable and saw a reduction of antipsychotic prescribing from a stable level pre-intervention of 44% to 36% post-intervention, along with reductions in 'as required' psychotropic medication administration. However, caution is required when interpreting these findings due to the lack of a control group and the single-site nature of the feasibility study. Larger-scale evaluations of this intervention are required.

In terms of policy, the findings of this research have informed the development of the forthcoming *National Clinical Guideline on Appropriate Prescribing of Psychotropic Medication for Non-cognitive Symptoms in People with Dementia*.

***Presenter:** Dr Kieran Walsh completed his PhD at University College Cork in 2018. The title of his thesis was 'Rationalising Antipsychotic Prescribing in Dementia: A Mixed-Methods Investigation'. Dr Walsh is a pharmacist by background and is currently working in the Evidence for Policy team within the Health Technology Assessment directorate of the Health Information and Quality Authority. Dr Walsh is a guideline development group member of the forthcoming *National Clinical Guideline on Appropriate Prescribing of Psychotropic Medication for Non-cognitive Symptoms in People with Dementia*.

Case study 6: The Model for Dementia Palliative Care Project: enabling implementation of national policy

HRB award: Investigator Led Project (a three-year award due to finish in September 2020)

Co-authors: S. Timmons*, J. Drennan, S. Guerin, G. Kernohan, A. Murphy, N. O'Connor, S. Fox.

The problem addressed by the research

Dementia is a life-limiting illness; median survival post-diagnosis is 4.5 years. There is currently no cure, so all treatment is essentially palliative. People with advanced dementia have equal palliative care needs to people with metastatic cancer. However, many people with dementia in Ireland are not routinely provided with palliative care. A national interdisciplinary research workshop prioritised research into the organisation and provision of palliative care for people with dementia and their families, particularly regarding how to best integrate palliative and dementia care across disciplines and sectors.

The solution identified by the research

This research is evaluating existing services that provide palliative care for people with dementia in the community in Ireland, Northern Ireland, England, Scotland and Wales. It will describe the programme models underlying selected services. It will explore whether service activities are effective, evidence based, feasible to adopt, and acceptable to healthcare workers and potential service users in the Irish healthcare system, using multiple methodologies (literature review, expert input and the service evaluations). Ultimately, a service model for use in Ireland will be iteratively developed, with input from healthcare providers and key stakeholders. User preferences and user-determined value will strongly inform the final model.

How this research makes a difference to policy or practice

The Irish National Dementia Strategy (2014) had a strong focus on palliative care for people with dementia and their families. However, there were no specific actions relating to palliative care in the subsequent implementation plan. Through close collaboration with the National Dementia Office and the National Clinical Programme for Palliative Care, the model for dementia palliative care developed from this research will form part of an overall post-diagnostic support framework for dementia in Ireland. This research thus enables policy (the strategy) to be implemented (via the national framework). The economic analysis embedded in the project will support future business cases to pilot and then roll out this model nationally.

**Presenter: Dr Suzanne Timmons is a geriatrician, Senior Lecturer at University College Cork, and Clinical Lead for the National Dementia Office (<http://research.ucc.ie/profiles/C101/stimmons>). She has a particular interest in dementia and delirium, and in health service research, with research incorporating service evaluation, quality improvement, implementation science and audit methodologies.*

Panel discussion

Addressing the evidence gaps: the future of dementia research

Panel discussion

Panel Chair: Professor Eamon O'Shea; Participants: Mr Geoff Huggins, Professor Sean Kennelly, Dr Emer Begley, Dr Kathleen MacLellan and Dr Bernadette Rock

The presentations were followed by a panel discussion chaired by Professor Eamon O'Shea, Personal Professor in the School of Business & Economics and Director of the National Centre for Social Research on Dementia at the National University of Ireland, Galway. The panel members were Geoff Huggins, Director of Health and Social Care Integration for the Scottish government and Director of the NHS Education for Scotland Digital Service; Professor Sean Kennelly, Dementia and Neurodegeneration Network Ireland; Dr Emer Begley, National Dementia Office; and Dr Bernadette Rock, Alzheimer Society of Ireland; Dr Kathleen MacLellan, Assistant Secretary, Department of Health]The participants were asked to consider a number of specific questions prior to the discussion, including regarding major practice and policy changes arising from Irish and international research, strengths and weaknesses of dementia research in Ireland, issues arising in respect of knowledge exchange, and public and patient involvement. Throughout the discussion, consideration was given to the development of future research agendas around dementia research.

Seminar welcomed

Professor O'Shea opened the discussion by drawing attention to the fact that the seminar was taking place in the Department of Health and noted that 'the physical act of being in the building' was very important. He also highlighted that the participants were drawn from many different disciplines and this was considered very relevant in light of new developments. The seminar was identified as being particularly timely in the context of the forthcoming home care legislation, which, it was noted, will require significant funding as well as extensive research and evaluation. It was suggested that the funding requirements will be additional to those areas already of interest, such as residential care and quality of life.

Major practice and policy changes arising from Irish and international research

Panel participants were asked to provide examples of major practice and policy changes arising from Irish and international research relating to dementia. Examples provided are presented in Figure 1. Some discussion took place around the complexity of implementing change and it was suggested that it was important to:

- identify a small number of key areas, as it was reported that any health system can only cope with two national clinical guidelines or two pieces of reforming change at a time due to the risk of 'change fatigue'
- focus on implementation from the very beginning of a project
- be aware of the complexity of change
- understand that making changes as a result of research requires time, resources and finance.

Figure 1: Examples of practice and policy changes arising from dementia research

Significant investment in Irish research over the past decade has had important impacts on policy and practice

- The research has directly influenced the wording and elements of the National Dementia Strategy.
- The research has created an evidence base around practice development.

Understanding the value of good coordination between home and professional carers has had an impact on practice

- These understandings emerged from the Second EU Joint Action on Dementia.
- While this aspect was previously reflected in national strategies, the new knowledge has been transformative in delivering care.

Emerging understandings of the need for palliative care for people with dementia have implications for policy and practice

- It was noted that people with dementia have often been an invisible population with regard to palliative care. The quantification of the proportion of people within hospitals (believed to be between 20–40% of all patients depending on context) with dementia who would benefit from palliative care has led to a greater awareness of this issue. It was noted that Ireland is ahead in this area.

Strengths and weaknesses of dementia research in Ireland

Some discussion took place around the strengths and weaknesses of dementia research within Ireland and it was suggested that there is a challenge in prioritising dementia research within a wide range of healthcare issues. Key issues arising in this discussion were as follows:

- Comparisons were drawn with those engaged in research on other areas, such as cancer. It was highlighted that for those involved in cancer research there is a very clear career pathway, and early stage researchers have many opportunities to develop their research careers. This, however, is not the case currently for those involved in dementia.
- An example was provided from Scotland, where there is a common data platform where access to data is equitable and transparent. One advantage highlighted from this is that academic institutions now compete with each other on the basis of their expertise, rather than on the basis of access to a particular data set.
- Consideration was made of the challenges arising for policy makers in prioritising dementia research within the field of dementia itself – for example, balancing the need for research with the need for more care packages or for increasing palliative care supports. It was suggested that certain types of research can be more helpful than others and examples given included research relating to home care and packages of care. It was noted that budget estimation processes generally require some consideration of the impact of proposed interventions on the budget and an estimation of the costs and benefits of particular interventions.
- There was a call for ambition to be part of the objectives of researchers and policy makers. It was suggested that, rather than weigh up one intervention against another intervention, some provision should be made for the provision of ‘long-shots and transformative interventions’ where the scale of the impact would be transformative (similar to that of the smoking ban) and the dividends potentially much

greater. One example given was to put in place a preventative programme for the midlife period that draws on all the information currently available.

Figure 2 summarises the key strengths and weaknesses.

Figure 2: Summary of key strengths and weaknesses identified

Strengths

- Relatively small research community with good potential for cross-discipline and cross-sector working
- A number of clinical leaders engaged in high-quality research
- Establishment of centres for dementia research
- Focal point and coordination role of the National Dementia Office and the Dementia Neurodegeneration Network Ireland
- Good potential for coordination between basic, clinical and social research
- Prioritisation of research within the National Dementia Strategy

Weaknesses

- Low level of funding for dementia research
- Lack of a clear pathway for researchers skilled in the dementia area and a consequent brain drain
- Potential for researchers to become siloed due to current funding mechanisms where individuals may be competitors rather than collaborators
- Challenges in engaging clinical leaders due to lack of dedicated funding for research in those posts
- Absence of key supports for an interface between those who want to participate and engage in research, on the one hand, and the research community, on the other
- Absence of a common data platform to allow researchers access to data

A number of additional issues were raised during this discussion.

Knowledge exchange

The discussion about knowledge exchange focused on the roles of both researchers and research users. Four main issues were highlighted, as follows:

- Researchers need to present their findings in a way that is accessible to lay personnel so that their work is understandable by everyone, including people with dementia. This was reiterated in a later discussion, where it was noted that there is a research language, a citizen language, a patient language, a policy language and a service delivery language; as a result, there is a lack of a common understanding. Some consideration needs to be given to achieving a common language so that information can be presented in a way that is useful for everybody.
- Researchers, particularly early career researchers, may have a strong focus on publication because that is the only way in which they can progress. This, however, may lead to a narrow focus that may

not be very useful for policy makers. It was also highlighted that access to academic journals can be difficult for those working in the community sector.

- The exchange of knowledge should involve the researchers and the users of a service sharing ideas, expertise, outputs and evidence, and this should take place from the onset of the research. It was noted that organisations such as the Alzheimer Society of Ireland can assist in this.
- Policy makers can benefit where there are strong partnerships with researchers and research agendas that increase the availability of information and knowledge about the delivery of policies and care that citizens want. In that regard, it was highlighted that the partnerships between the Department of Health, the Health Research Board and other funding agencies have improved the situation; looking for opportunities to work closer together can help to deliver more.

Public and patient involvement

It was suggested that the simplification of research findings in the media can lead to a disconnection between what the newspaper headlines may say (e.g. 'coffee will cause dementia', 'coffee will cure dementia') and what is 'actionable'. Nevertheless, it was noted that the public are engaged with the issue of dementia and are willing to take part in research and to have their data used, but the system is insufficiently nimble to facilitate this.

An example was given of a survey that took place among people in Scotland who were living with or who had experience of dementia. It was reported that they were willing to be involved and register to take part but that these people were not followed up and this led to them feeling they were 'thwarted from being involved'. It was also suggested that 70–80% of people in Scotland would be willing to have their data used for research into dementia. It was concluded that this is an area to which people want to give and with which they want to engage, but the existing systems do not facilitate this and there are insufficient funding opportunities for people to do so.

Developing a research agenda

Throughout the course of the discussion, it was suggested that a more strategic approach to dementia research would be welcomed and a number of areas for consideration were identified. These are presented in Figure 3.

Figure 3: Areas for consideration in developing a more strategic approach to dementia research

Involving the right people

- There was agreement that it is important to ensure the right people take part in the process, including people who already have a diagnosis of dementia, researchers and public bodies. Within this, it was suggested that the Department of Health is a very important voice.

Putting in place key fundamentals

- Fundamentals that need to be considered include data assembly, recruitment of people to be involved, information governance and the process of learning how to disseminate research.

Prioritisation of key areas for research

- It was suggested that the prioritisation process is very challenging because of the multiple understandings, backgrounds and interests that can be involved. Two issues were identified as assisting in this process:
- (1) a need to develop a set of principles to underpin a prioritisation process that may include issues (e.g. using the best research methodologies, creation of data sets that can help to answer key types of questions, not having duplication)
- (2) the potential role that can be played by the Dementia and Neurodegeneration Network Ireland, which can bring together a collaborative network of clinicians, economists, people from social care backgrounds and academics to assist in that prioritisation process.

Development of accessible datasets

- There is a need to develop accessible (e.g. through a data portal) national datasets that operate in a standardised way and that are supported by investment in clinical leaders who understand the data and academic leaders who can work with the data. It was suggested that Ireland could be an international leader in this way.

Providing support for career development in dementia research

- It was suggested that there is a need to support a sustainable career path for researchers involved in dementia similar to that provided for cancer researchers. Funding needs to be sustainable over time and allow for career progression.

Understanding the needs of policy makers

- It was highlighted that there is a need to understand the requirements of policy makers, particularly where there is good evidence, where there are gaps in the evidence and where various methodologies have been used.

Concluding comments

There was some agreement that there is an appetite and need for ongoing dialogue between all stakeholders in respect of dementia research to find the best ways to work together to achieve a common goal. The seminar was viewed as having started that process and was welcomed in that regard.

The discussion concluded with Dr Maura Hiney (Head of Post-Award and Evaluation, Health Research Board), who had acted as MC throughout the proceedings, thanking Professor O'Shea, the participants in the panel, the speakers who had shared their expertise and the members of the audience for their participation.