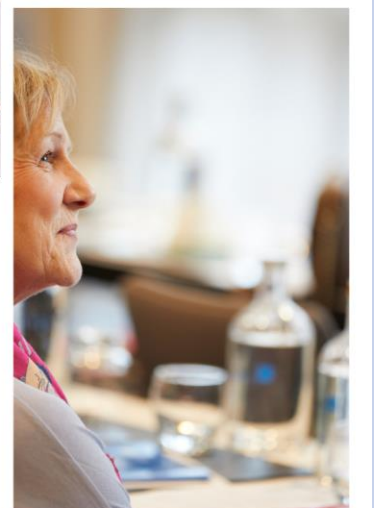


Barriers and Solutions to putting Research into Practice
A report from a Research Knowledge Exchange Seminar
co-hosted by The Alzheimer Society of Ireland and Dementia Research Network Ireland.



THE **Alzheimer**
SOCIETY OF IRELAND

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**DEMENTIA RESEARCH
NETWORK IRELAND**
Prevention, Cure & Care for
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1. Background

More than 64,000 people in Ireland are living with dementia¹ and approximately 180,000 people are family carers. The prevalence of dementia is growing, with this number expected to more than double by 2045. Dementia research must provide a tangible benefit to those currently affected by the disease and/or those who will develop it in the future.

There is international concern that health research and evidence is not translated into practice in a timely fashion^{2 3}. In fact, it is estimated that there is a 17-year time lag in research translation⁴. In 2022, The Alzheimer Society of Ireland (ASI) undertook consultations with 250 people living with dementia, family carers, clinicians and researchers to develop a new research strategy⁵. In these consultations, research translation was cited as a key challenge for the research community. Similarly, a perceived lack of research translation and outputs ‘sitting on a shelf’ is an ongoing source of frustration for people with dementia and their families. Research indicates, that, up to 85% of health research is lost but this is avoidable⁶. It is essential to translate research into policy and practice to ensure maximum impact and limit waste.

In an initial step to explore this challenge further and identify potential solutions, The ASI, with the support of Dementia Research Network Ireland (DRNI) and members of the Dementia Research Advisory Team hosted a seminar focused on research translation in February 2023.

2. Person & Public Involvement

The ASI and DRNI convened an Event Advisory Panel consisting of representatives from each of the target audience cohorts (i.e., people living with dementia, family carers, experienced researchers and early career researchers). Panel members co-developed all aspects of the event including event logistics, the agenda for the day, discussion group topics, and dissemination plans. This helped ensure the event space was inclusive while the content of the event was useful and accessible to all invited.

Specific event objectives were agreed upon:

¹ National Dementia Office (2020). Dementia Prevalence Figures 2020, <http://dementiopathways.ie/permacache/fdd/cf3/792/e223695cf65ee173882bdc394de3a8fc.pdf>.

² Fineout-Overholt E, Melnyk BM, Schultz A. Transforming health care from the inside out: advancing evidence-based practice in the 21st century. *J Prof Nurs.* 2005;21(6):335–44.

³ Westfall JM, Mold J, Fagnan L. Practice-based research—“blue highways” on the NIH roadmap. *JAMA.* 2007;297(4):403–6.

⁴ Morris ZS, Wooding S, Grant J. The answer is 17 years, what is the question: understanding time lags in translational research. *J R Soc Med.* 2011;104(12):510–20.

⁵ The Alzheimer Society of Ireland (2022). Research Strategy 2022-2024. <https://alzheimer.ie/wp-content/uploads/2022/05/ASI-Research-Strategy-2022-2024.pdf>

⁶ Chalmers, I & Glasziou, P (2009) Avoidable waste in the production and reporting of research evidence, <https://pubmed.ncbi.nlm.nih.gov/19525005/>

- To build understanding and awareness of how to plan and design dementia research so outputs can be mobilised and ready for implementation.
- To demonstrate good practice in research translation through case studies, group work and expert advice.
- To foster networking and collaboration opportunities between the research community, healthcare professionals, people living with dementia and informal carers/supporters.
- To grow understanding between people affected by dementia and the research community of research translation challenges and opportunities.
- To raise awareness of the importance of research knowledge translation and build competency in how to effectively influence policy and practice through research.

3. Event Proceedings

The event agenda included:

- Guest speakers with direct experience and examples of translating research into practice providing tangible outputs
- Small, mixed discussion groups to brainstorm the barriers and solutions for translating research into practice (and provide networking opportunities)
- Informal networking breaks over refreshments



Guest speakers included;

- Mr Andy Heffernan (CEO of The Alzheimer Society of Ireland)
- Dr Avril Kennan (CEO of Health Research Charities Ireland)
- Prof Mary McCarron (Professor of Ageing and Intellectual Disability, Director of the Trinity Centre for Ageing and Intellectual Disability)
- Mr Tony McIntyre and Mrs Brenda Buckley (Dementia Research Advisory Team members)
- Dr Siobhan Fox (Lecturer & Senior Postdoctoral Researcher, Centre for Gerontology and Rehabilitation, University College Cork)
- Prof Sean Kennelly (Clinical Associate Professor Trinity College Dublin, Consultant Physician in Geriatric and Stroke Medicine, Tallaght University Hospital)

4. Barriers & Solutions: Small group discussion findings

Each discussion group was assigned a facilitator/notetaker. Groups were asked to draft their top three barriers for putting research into practice. To enhance interest and engagement, each group gave their list to another group, and in turn, received another group's list of barriers. Each group was then asked to develop three solutions to the barriers in front of them.



The barriers and solutions identified by each group were recorded by the facilitator/note taker. These are combined and sorted into broad themes in Table 1 below.

Barriers	Solutions
<ul style="list-style-type: none"> ● Culture of Scarcity 	<ul style="list-style-type: none"> ● Culture of Plenty
<ul style="list-style-type: none"> ● Access to Collaborators 	<ul style="list-style-type: none"> ● Collaboration & Knowledge Sharing
<ul style="list-style-type: none"> ● Limited Person/Public Involvement 	<ul style="list-style-type: none"> ● Research Partnerships
<ul style="list-style-type: none"> ● Accessibility of Research 	<ul style="list-style-type: none"> ● Better Communication of Research
<ul style="list-style-type: none"> ● Lack of Awareness of Dementia 	<ul style="list-style-type: none"> ● Awareness raising of Dementia

Table 1: Broad themes as described by discussion groups as part of the Research Event

Theme 1

i) Barrier: Culture of Scarcity

The most prominent barrier highlighted by almost every discussion group was lack of funding for dementia research in Ireland. Where funding is available, participants commented that this is generally limited, in a once-off capacity, with little scope for long-term research projects. Funding was also directly linked with the issue of time, with many participants noting that current funding streams often do not allow the necessary time required for researchers to implement their findings in real life. Participants noted that there can often be a lag between research completion and implementation. Some participants stated their frustrations with how the current research environment and higher education institute culture is limiting their implementation of research, with structural issues around funding, contracting of researchers etc., as key issues and barriers. Moreover, the use of specific purpose contracts and funding being utilised to complete projects was discussed. This does not support embedding research into practice. It may take several months or years to see research findings implemented, and in this time teams and groups may have moved on to other projects and do not see this stage of the process to completion.

Note:

It should be noted that dementia research in Ireland is significantly underfunded relative to the scale of its prevalence and costs⁷, even though it is one of six priority areas under the Irish National

⁷ JPND Research (2012) Tackling the challenge of Alzheimer's Disease and other neurodegenerative diseases in Europe, <http://www.neurodegenerationresearch.eu/>

Dementia Strategy (2014)⁸. The Sláintecare Implementation Strategy (2018)⁹ states that “health research in Ireland needs to be positioned to make its greatest contribution for patients, the health system and the economy”. The Model of Care for Dementia in Ireland (2023)¹⁰ also highlights the importance of active citizenship in relation to dementia, a central activity of ensuring participation and inclusion in care, research and governance.

ii) Solution: Culture of Plenty

The most cited solution for putting research into practice was increased funding (both in value and frequency) and more time for translation of research findings/recommendations into practice following an initial research study. It was felt that funding should be made available for the implementation component of dementia research as this would allow more impactful and high-quality research to be undertaken. This could take the form of additional funding or ring-fenced funding that takes into consideration the implementation stage, for example, allocating a time frame within the funding specifically to implementation after the research is complete. In addition, it can be difficult for researchers to know the right avenue for research implementation as they may not have the skills or experience to do so. The lack of dedicated training in this regard is an area which could be improved in the higher education environment.



Several researchers identified a shift in research culture as a solution for putting research into practice. As mentioned, research contracts can often be precarious, limited in time for projects and limited in funding of specific work packages. If we are striving for dementia research to be optimised for policy or practical implementation, there needs to be appropriate funding and contracts in place to support this. Providing training and having suitably skilled staff can facilitate research being put into practice, serving those living with dementia and their families, carers and supporters.

The ASI has specifically requested enhanced funding for dementia research in our Annual Pre Budget Submission (2022, 2023 and 2024).

⁸ Department of Health (2014) The National Dementia Strategy, <https://www.gov.ie/pdf/?file=https://assets.gov.ie/10870/3276adf5273f4a9aa67e7f3a970d9cb1.pdf#page=null>

⁹ Department of Health (2018) Sláintecare Implementation, Strategy <https://www.gov.ie/pdf/?file=https://assets.gov.ie/9914/3b6c2faf7ba34bb1a0e854cfa3f9b5ea.pdf#page=null>

¹⁰ Health Service Executive (2023) Model of Care for Dementia in Ireland, <https://www.hse.ie/eng/services/publications/olderpeople/model-of-care-for-dementia-in-ireland.pdf>

Theme 2

i) Barrier: Access to Collaborators

Early-career and established researchers noted that a lack of access or poor access to research collaborators is a barrier to research translation. They felt this was part of a systemic issue in Higher Education Institutes (HEIs) and a larger structural problem that could not be easily addressed. Researchers often work in silos but if people are to collectively advocate for dementia-related change, active collaboration between research teams, labs and groups needs to be facilitated. This lack of, or poor, collaboration can lead to research waste, duplication and lack of implementing findings into practice.



ii) Solution: Collaboration & Knowledge Sharing

Participants described how active research collaboration between researchers with a shared mutual vision can build capacity for knowledge sharing and eliminate research waste. This can be supported by running research seminars and events that provide spaces for networking and collaboration. Participants

suggested that joined-up thinking enhances collaboration, with the potential to develop forums of people with expertise. Continued funding and support for DRNI is important as this network (funded by the HRB), supports and facilitates such collaborative and interdisciplinary research across all research areas in dementia and neurodegeneration. There is a clear role for DRNI, The ASI and other organisations to facilitate collaboration and networking. The ASI also supports active collaboration between the research community and those with an experience of dementia through the [Dementia Research Advisory Team](#), a PPI group of people living with dementia and current and former family carers who bring their lived experience and expertise to dementia research in Ireland. Similarly, The ASI provides the [TeamUp for Dementia Research](#) service in collaboration with DRNI. This is a database of people affected by dementia who want to participate in dementia research with the goal of addressing the longstanding issue of participant recruitment.

Theme 3

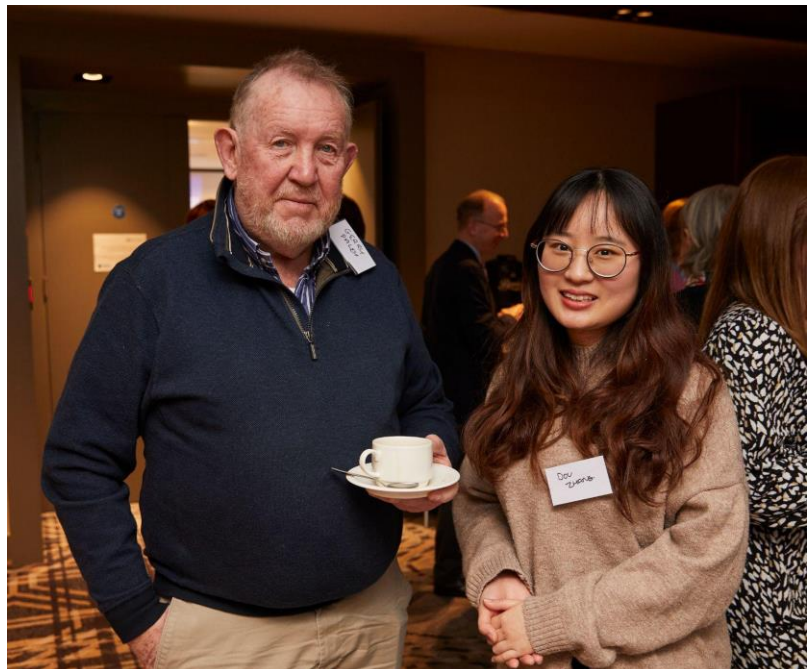
i) Barrier: Limited Person / Public Involvement

Discussion groups highlighted the limited incorporation of PPI into research as a barrier to putting that research into practice. Where a research team has not been able to include a person living with dementia or a family carer in a meaningful way, this has the potential to negatively impact the implementation and utilisation of the work for such groups. PPI contributors are experts by experience, lending their authentic voices and perspectives to projects. A key challenge is considering PPI in the development of research applications as there is limited or no funding available for this 'pre-funding stage'. PPI is considered best practice in research, and research teams want to involve PPI contributors but this requires dedicated resources which are not always available.

ii) Solution: Research Partnerships

Facilitating active partnerships between researchers/clinicians and PPI contributors where all stakeholders' perspectives are valued and incorporated were viewed as a solution. An example of an authentic PPI partnership is The ASI's Dementia Research Advisory Team and PPI Ignite Network. Here, the long-standing, bi-directional relationship ensures continuity, integrity, respect and authenticity. This is achieved through supporting the members of the Dementia Research Advisory Team to engage with multiple researchers across a variety of sites. Successful PPI is therefore not reliant on one individual partnership, but rather, the ethos is embedded through ongoing collaborations across ventures and research groups. For this to work, it is essential that all members of research teams, including the most senior staff, engage in the relationship.

Additionally, if there was specific funding or bursaries for PPI at the pre-application stage, this will encourage PPI from the initial stages of a project, allowing for



meaningful contributions from the outset. Previous work led by PPI Ignite at UCD¹¹ has identified that respect, openness, reciprocity and flexibility are essential values in the pre-funding or pre-commencement stage of research.

Theme 4

i) Barrier: Accessibility of Research

Many family carers and people with dementia noted the lack of accessibility of research findings. Public dissemination is often missing or may not be appropriate when it is repurposed from professional dissemination, particularly given the nature of dementia. This issue was described in the majority of discussion groups. For members of the public, this creates the illusion that the research



does not exist, has not been completed or has been 'left on a shelf' as they do not have access to academic journals or conference presentations. The 'Ivory Tower' metaphor is often touted when speaking about research and it is essential that public dissemination is given as much resource and consideration as professional dissemination. Research teams wish to disseminate their research publicly, but their career progression is hugely dependent on scientific outputs and citations.

ii) Solution: Better Communication of Research

The communication of research and research findings is an integral component of ensuring that research is not only understood but that it reaches a wider audience. Participants felt that if there was more awareness of the responsibility to publicly communicate research, it would enhance opportunities for implementation. Participants also suggested that ideas for public dissemination could be developed and refined from the pre-application stages of research funding applications right through to the end. It was suggested that PPI contributors are best placed to advise on how to communicate research findings, through consideration of alternative methods such as videos, leaflets, social media etc.

¹¹ Ní Shé, É., Cassidy, J., Davies, C. et al. Minding the gap: identifying values to enable public and patient involvement at the pre-commencement stage of research projects. *Res Involv Engagem* 6, 46 (2020). <https://doi.org/10.1186/s40900-020-00220-7>

Public dissemination should be considered in assessing funding applications, and ideally, public dissemination should have marks for PPI contribution. Moreover, universities must consider public dissemination when considering academic staff for promotion rather than relying solely on academic outputs.

A key priority of The ASI's 2022-2024 Research Strategy is knowledge translation and dissemination to promote public awareness of dementia research. Through The ASI's Research Bursary Awards 2022, four researchers have been financially supported to actively disseminate dementia research via traditional and creative methods. Similarly, The ASI's inaugural Dementia Research Award requires applicants to outline dissemination plans for both public and professional audiences. The organisation continues to put significant resources into communicating research through social media, newsletters, web content and media work. In 2024, Dementia Research Network Ireland and The ASI will host a research event 'The Science of Dementia for the Non-Scientist' aimed specifically at breaking down barriers between academic research and public understanding.

Theme 5

i) Barrier: Lack of Awareness of Dementia

An item raised by discussion group participants was the general public's awareness of dementia as a disease, which they believe has impacted how dementia research as a whole is funded. According to an article in the Financial Times¹², approximately 4.8 million papers have been published on PubMed compared to approximately 264,000 on dementia despite similar numbers of people being affected by the disease worldwide. Researchers, people living with dementia and family carers felt that the general public was unaware of the continuum of dementia as a progressive disease, with its ability to affect people as young as in their 40s.



ii) Solution: Raising Awareness of Dementia

Many discussion group participants felt that dementia should be given the same level of attention as diseases such as cancer considering the economic and individual impact of the disease. Active

¹² <https://www.ft.com/content/28bd7d74-75c9-48d6-8505-717e9f56ca98>

awareness of the different types of dementia, the signs and symptoms, can lead to funding for dementia research, thereby opening more avenues for research implementation.

The ASI is committed to continuing to raise public awareness of dementia and highlight the importance of dementia research with public representatives through ongoing advocacy, campaigning and support of The HSE's *Dementia Understand Together* campaign. Political advocacy is a particularly important piece of the puzzle and The ASI has hosted events in Leinster House for political representatives. The media attention surrounding Disease Modifying Therapies should aid this message.

5. Potential Impact / Areas for further collaboration

Commonalities in both barriers and solutions amongst discussion groups indicate that there are some areas in which we, as a community, can seek change. Areas for improvement include strengthened partnerships and research collaborations which could be achieved, however, there are barriers such as the current research funding model and framework in Ireland that will require systemic change. The ASI and DRNI are considering the next steps while implementing small changes in the interim. For example, research dissemination bursaries, continued investment in PPI, hosting future events, and funding research where possible.

6. Conclusion

This event enabled The ASI and DRNI to bring the dementia research community and people affected by dementia together, to support the development of productive relationships and collaborations built on common ground and a shared passion; *that dementia research creates as much impact as possible for the people affected by it.*

Acknowledgements

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And finally, a special thank you to all those who attended our event. You made the day so special.

