

Dementia Research Consensus Forum Report

10th April 2018

Contents

Section	Page No
1.0 Introduction	3
2.0 Executive Summary	4
3.0 The Need for Research Priorities	6
4.0 Top Priorities for Dementia Research	7
5.0 Group Discussion Feedback	11
<i>Q1 What are the challenges and gaps in dementia research in Ireland?</i>	<i>11</i>
<i>Q2 What areas of dementia should be prioritised and why?</i>	<i>17</i>
<i>Q3 How can we enhance the relevance and impact of dementia research?</i>	<i>21</i>
6.0 Next Steps	24
Appendix 1 – Forum Participants	25

1.0 Introduction

A Research Consensus Forum was jointly hosted by the Alzheimer Society of Ireland and the Dementia & Neurodegeneration Network Ireland (DNNI) on 10th April 2018 in the Radisson Hotel, Dublin. This research forum sought to bring together a wide range of stakeholders representing the views of researchers, practitioners and clinicians to collectively explore priorities for dementia research. The aim of the forum was to provide a platform to capture feedback from participants in relation to areas of dementia research that should be prioritised.

The forum commenced with a presentation by Pat McLoughlin, CEO of the Alzheimer Society of Ireland (ASI), who provided an outline of ASI's research plans and its funding commitments. Further presentations followed on the dementia research landscape by Prof Brian Lawlor, Dr Patricia McParland and Prof Cora O'Neill. The presenters addressed diagnosis, treatment and care, challenges in relation to underfunding of research, the absence of and need for an overarching research strategy or vision, the lack of a secure career pathway for researchers and the need for more clinicians to be involved in dementia research.

An overview of the dementia funding landscape was presented by Dr Anne Cody, Head of Pre-Award at the Health Research Board (HRB) and Dr Lisa Keating, Scientific Programme Manager of Science Foundation Ireland.

Subsequently, a research prioritisation exercise was facilitated for one hour through roundtable group discussion, focussing on three key questions. Forty-four participants took part in the exercise, with eight to nine participants at each table, and there was excellent engagement in all groups. Each table included a facilitator and a note-taker who also took part in the discussion. Participants were asked to address the following questions:

1. What are the challenges and gaps in dementia research in Ireland?
2. What areas of dementia research should be prioritised and why?
3. How can we enhance the relevance and impact of dementia research?

Each facilitator provided a summary of the topics that arose during the discussion at their table. Notes were collected from the designated note-takers in order to complete this report.

The purpose of the research forum was to act as a first step in reaching consensus on dementia research priorities and the output of this forum has been to convene an initial group of stakeholders to advance research prioritisation in the Autumn. A working group will be established and a formal methodology applied in order to complete the consensus process. The Working Group will also ensure that the identified research priorities are appropriately addressed. The outcome will be a list of priorities that are considered to be of key importance for dementia research, which offer a framework for all interested in dementia research and care to consider how directly to improve the quality of life for people affected by dementia.

2.0 Executive Summary

Many important issues pertaining to dementia research were highlighted by participants at the forum. There is a need for a suitable funding model for dementia research, which creates a framework and culture of hope, and ensures that best-practice evidence becomes embedded in policy and strategy. Currently there is a lack of a secure pathway for researchers due to the funding shortage in this area, resulting in a high attrition rate. The need for political will, strategic planning of research and high impact champions for dementia research was highlighted.

The need for research networks and for multidisciplinary collaboration was emphasised, in order to avoid researchers working in silos. Participants felt that competition for funding drives people to collaborate internationally rather than nationally. It was also felt that greater transparency is needed so that stakeholders such as the public/patients, clinicians and researchers can see what research is taking place.

Participants felt that Patient and Public Involvement (PPI) in research is important and that there is a need for mechanisms to be in place to involve people. The idea of a research ready cohort of individuals was suggested, for example a system similar to 'Join Dementia Research' (UK) in Ireland. Feedback on the ethics process for dementia research highlighted that ethics committees do not appear to be set up to take account of this patient group. The question of enabling decision-making and how this is best done was raised. The need for a dementia registry was highlighted and both a participatory register and a clinician controlled register were discussed.

There is a need for post-diagnostic supports for both patients and carers as well as a need to better understand the individual experience of receiving a diagnosis. Currently there is a lack of appropriate services for individuals with young onset dementia. It was felt that the public needs to be better informed about dementia, dementia prevention and resources available post-diagnosis. Dementia prevention is deemed a very important area with the focus on modifiable risk factors and early identification of at-risk individuals, so that early markers can be targeted. By working with public health professionals, dementia can be incorporated into the public health model in relation to prevention and reduction strategies.

The issue of the limited consultation time that GPs have with dementia patients was raised as well as concern about possible differing standards between diagnoses made through GPs versus memory clinics. The need for more memory clinics in Ireland (at least five) was highlighted. With regard to clinician involvement in research, this was seen as a challenge due to workloads and the question of how we encourage the HSE to support research was posed.

There is a need to translate research into practice as early as possible and to take into account the impact on people's lives. Evaluative criteria should be built into projects more formally and evaluation should be carried out throughout the project and not just once the research project is completed.

Some of the research topics that participants would like to see prioritised included; (1) systems of care and ethos of care for people with dementia living in care homes (2) supporting independence in residential care; (3) the environment in acute settings and the need for more flexible and dementia-specific services; (4) the healthcare system in Ireland; (5) the use of antipsychotic medication (6) facilitating people's independence to stay in their own home as opposed to long-term care facilities; (7) the "true" cost of care, including informal care giving; (8) the lived experience of dementia and caregiver stress; (9) including people with dementia who have an intellectual disability, particularly Down Syndrome, in research given their increased genetic risk; (10) dementia in the travelling community and ethnic minority groups. Participants mentioned innovative research areas that they feel should be prioritised, including predictive analytics, databasing, AI (artificial intelligence) for

mapping, provision of care supported by technology and the use of untapped community assets (e.g. green space movement).

Bench research is perceived as important. Participants mentioned that we have a homogenous population in Ireland, making it a good place to do clinical trials, which should be further encouraged and supported.

Summary of Priorities

❖ A suitable funding model and strategic planning of dementia research required. Need political will and high impact champions for dementia research.	❖ Differing standards between GP vs memory clinic diagnosis. The need for more memory clinics in Ireland.
❖ Need research networks and multidisciplinary collaboration	❖ Need more clinicians involved in research
❖ Greater transparency needed so that stakeholders can see what research is taking place	❖ Need to translate research into practice as early as possible and to take into account the impact on people's lives.
❖ PPI important and need mechanisms in place to involve people e.g. 'Join Dementia Research' (UK) model	❖ Build evaluative criteria into projects and evaluate throughout the project
❖ Investigate ethics process for dementia research and best practice for enabling decision-making .	❖ Investigate systems of care and ethos of care in care homes, supporting independence in the community and residential care and the environment in acute settings. Need more research on the healthcare system in Ireland.
❖ Need a dementia registry	❖ Investigate the use of antipsychotic medication
❖ Need for post-diagnostic supports for patients & carers and better understanding of the individual experience of receiving a diagnosis	❖ Research needed on the "true" cost of care, including informal care giving;
❖ Tackle lack of appropriate services for individuals with young onset dementia	❖ Investigate the lived experience of dementia and caregiver stress
❖ Need a better informed public re. dementia and dementia prevention	❖ Include people with dementia who have an intellectual disability, particularly Down Syndrome, in research and investigate dementia in the travelling community and ethnic minority groups
❖ Focus on dementia prevention including modifiable risk factors and early identification of at-risk individuals. Link with public health model.	❖ Bench research important. Ireland a good place to do clinical trials - should be encouraged and supported.

3.0 The Need for Research Priorities

There are an estimated 55,000 people living with dementia in Ireland. The biggest risk factor for dementia is age and current increases in life-expectancy mean that dementia is becoming increasingly more common in the population. Ireland has one of the fastest growing ageing populations where approximately 1.5 million people will be over 60 years of age by 2020 (National Research Prioritisation (NRP) report, 2012). It is predicted that the number of people living with dementia will double in the next 20 years in the absence of preventative interventions, representing a growing health crisis.

Dementia poses a major societal challenge due to the significant personal and economic burden of the condition. The total health and social care costs for dementia exceed stroke, cancer and heart disease combined, making it Ireland's most expensive disease. Regarding Alzheimer's, the total direct and informal care costs are presently estimated at €2 billion per annum in Ireland. Despite this, funding for research in dementia has been disproportionately low when compared with the burden of disease. Given limited funding resources and ever-increasing demands on these finite resources, it is vital that funding is allocated effectively to achieve the desired outcomes, impacts and benefits. There is a need for research to explore areas of care, treatment, diagnosis and prevention as well as the causes and mechanisms of the disease. The aim of such research is to alleviate the impact and burden of dementia and improve the quality of life for people affected by the condition.

Currently, funding for dementia research is provided by various funding bodies and organisations including the Health Research Board, Science Foundation Ireland, the Irish Research Council, the EU, Enterprise Ireland, the Wellcome Trust, the Higher Education Authority, the Alzheimer Society of Ireland, the HSE, the Medical Research Charities Group and Genio. Atlantic Philanthropies has provided a significant amount of funding to Ireland in the area of dementia research over the past number of years, however this funding stream has now ceased. Research prioritisation has many benefits, including providing a framework for those involved in dementia research which helps guide research activity. Prioritisation highlights where there are gaps in knowledge and this can guide research funding to close these gaps.

Funding bodies are faced with the challenge of prioritising funding for many different disease areas and therefore if disease-specific networks have carried out their own prioritisation exercise, this can provide reassurance to funders that funds are being allocated to the areas of highest need or greatest impact for a particular disease. Research prioritisation also ensures a more democratic approach to funding allocation, allowing everyone's voices to be heard and ensuring a level playing field.

4.0 Top Priorities for Dementia Research

During this research forum a total of fifteen themes emerged from the roundtable discussion with stakeholders, and these are detailed below:

Theme 1 - Research Funding & Capacity Building

Concern was expressed about the lack of funding for dementia research and that funding grants are needed for the whole trajectory of the disease from pre-clinical to palliative care. Participants felt that it was important to develop researchers at all stages of their career and to align funding and research capacity. It was felt that research careers were precarious and there was a high attrition rate.

The need for a new funding model was highlighted and the need to understand best practice in relation to research funding models.

Theme 2 - Research Strategy

The need for political will and high impact champions for dementia research was highlighted. It was felt that there is an absence of strategic planning for dementia research in Ireland and that more strategic oversight was important to avoid duplication of research. Participants felt that research should be seen as an investment rather than a cost.

In relation to scalability, the suggestion of a national institute was made which should be multidisciplinary and another suggestion was made with regard to having centres of excellence.

Theme 3 - Collaboration/ Competition & Knowledge Exchange

The need for research networks and for multidisciplinary collaboration was highlighted, including working with companies who are willing to work collaboratively. Some participants felt that researchers work in silos and only very limited collaboration takes place. Competition for funding drives people to collaborate internationally rather than nationally. For some this was viewed positively and they felt that international collaboration was important. Comments were made that “we’re too small to compete with each other” and “we should exploit our small size”. Competition for funding can also result in duplication and a lack of cohesiveness amongst researchers. Intersectionality was also considered important. The need for a Dementia Ireland Conference was highlighted with the suggestion that DNNI could host it.

A need for more transparency was highlighted and the fact that it should be easier to see who is conducting what research in Ireland. It should also be easier for patients to see what clinical trials are taking place so that they can offer to participate. It was also felt that there should be a mechanism in place for healthcare workers to find out about research being conducted which they might be able to help with.

It was felt that there is a need for input from health economists from the outset of a project to address financial sustainability.

A question was asked about whether we can learn from prioritisation exercises carried out in other countries.

Theme 4 - PPI and Ethics Process

It was felt that Patient and Public Involvement (PPI) in research is important and that community level interaction is a major issue. There is a need for mechanisms to be in place to involve people

and it needs to be representative of people across the spectrum. The idea of a research ready cohort of individuals was suggested and having a system similar to 'Join Dementia UK' in Ireland. It was also felt that people with dementia should be involved in prioritisation to ensure there is an endpoint for them.

Feedback on the ethics process for dementia research highlighted that ethics committees are not set up to take account of this patient group. Issues around consent can prevent participation and this was described by one participant as a form of stigmatisation. It was suggested that developing suitable ethical processes and educating ethics committees in their use would be a good goal. Participants reported that some gatekeepers are protective over who takes part in research and this makes it difficult to engage in PPI. The question of enabling decision-making and how this is best done was raised.

Theme 5 - Dementia Registry

Participants highlighted the need for a dementia registry and discussed both a participatory register and a clinician controlled register. It was felt that we could have both, for example rolling out 'Dementia Research UK' (a participatory research oriented register) in Ireland.

Theme 6 - Diagnosis and Post-Diagnostic Supports

The need for post-diagnostic supports for both patients and carers was highlighted as well as a need to better understand the individual experience of receiving a diagnosis. Participants suggested that we should investigate the best way to provide a diagnosis and support a person. The lack of appropriate services for individuals with young onset dementia was highlighted.

It was felt that the public needs to be better informed about dementia, dementia prevention (including secondary prevention) and resources available post-diagnosis. Participants felt that there is still a stigma attached to dementia and this can lead to delayed diagnosis.

The issue of the limited consultation time that GPs have with dementia patients, when compared to memory clinic appointments was highlighted. GPs are also involved in community and social issues for patients with dementia, such as driving, without adequate resources to manage these issues appropriately. Concern was raised about possible differing standards between diagnoses made through GPs versus memory clinics and the need for more memory clinics in Ireland (at least five). It was also felt that there is a lack of understanding in how to proceed before someone is clearly diagnosed, with a lack of clear "next steps". In addition, it was felt that there is a heightened perception of risk in the health service.

Theme 7 - Translation of Research into Practice/ Research Outcomes

The need to translate research into practice was highlighted. It was felt that it is important to look at how research is translated while being carried out as well as on completion. The question of impact on people's lives was considered important.

It was felt that there is a need for better outcome measures but there is little work going on to establish better ones.

In relation to HIQA standards, it was felt that measurement of outcomes in care home facilities should not be restricted to issues such as medication issued etc. It was felt that staff may be more open to research if extended to other outcome measures, however it was acknowledged that there are restrictions on staff because of the processes in place.

Theme 8 - Evaluation of Research

It was felt that evaluative criteria should be built into projects more formally and information shared more quickly upon completion of research. It was suggested that evaluation should be carried out throughout the project and not just once the research project is completed.

Theme 9 - Dementia-friendly Infrastructure

Access to dementia-friendly infrastructure is seen as an issue, with structures and planning of towns and cities varying throughout Ireland.

Theme 10 - Research Topics

Participants indicated that there is a dearth of research in the area of care and people with dementia living in care homes, and a need to explore systems of care and ethos of care. There is very little knowledge about the 20,000 people with dementia living in long-stay care. A need for improvements in residential care to support independence was also raised.

With regard to acute care, it was felt that best practice needs to be explored with regard to the environment in acute settings and the need for more flexible and dementia-specific services.

Participants expressed a desire to see more research conducted in relation to the healthcare system in Ireland. It was felt that the health system is service-oriented and should be based on responsiveness to people's needs. Participants suggested that the use of antipsychotic medication needs to be addressed. There was also a desire to see research carried out into how we can facilitate people's independence to stay in their own home as opposed to long-term care facilities. In relation to the cost of care, there is a gap in knowledge of the "true" cost of care, including informal care giving.

With regard to clinician involvement in research, this was seen as a challenge due to workloads and the question of how we encourage the HSE to support research was posed.

Participants felt that the lived experience of dementia as well as caregiver stress were priorities for research. The importance of enhancing the visibility of dementia through individuals such as former Justice Minister Nora Owen, whose husband has been diagnosed with dementia, was highlighted.

The need to prioritise people with dementia who have an intellectual disability, particularly Down Syndrome, was highlighted given the increased genetic risk. It was felt that there is a need to raise awareness of the risk and further include this population in research. A need to look at dementia in the travelling community and ethnic minority groups was also highlighted.

Theme 11 - Basic & Translational Research/ Clinical Trials

Bench research is perceived as important. Participants also mentioned that we have a homogenous population in Ireland, making it a good place to do clinical trials, which should be further encouraged and supported.

Theme 12 - Regulatory Framework

With regard to HIQA standards and inspections, there is a challenge in balancing a holistic approach to caring whilst also ensuring that regulations and standards are adhered to.

Theme 13 - Innovation in Research

Participants mentioned some innovative research areas that they feel should be prioritised, including predictive analytics, databasing, AI (artificial intelligence) for mapping, provision of care supported by technology and the use of untapped community assets (e.g. green space movement).

Theme 14 - Public Health/ Prevention & Reduction Strategies

The suggestion was made that we should work with those in public health, and dementia should be incorporated into the public health model in relation to prevention and reduction strategies.

Theme 15 - Positive Narrative/ Success Stories

Participants suggested that positive research should be integrated into overall research, i.e. the “success stories” and a focus on “wellness”.

5.0 Group Discussion Feedback

This section details the comments and discussion points that arose during the roundtable discussion in relation to the following question:

Q.1 What are the Challenges and Gaps in Dementia Research in Ireland?

Research Funding and Capacity Building

Comments

- Limited funding will not address every gap, and therefore it is vital to work together to address research needs. How can this be achieved?: (1) Need networks – how to support and fund networks? (2) Future of DNNI? (3) Forums to remind stakeholders of the common goals and shared objectives (4) How to secure core funding?
- Competition for funding drives people to collaborate internationally rather than nationally. Not having dementia specific funding means competing against fields in which research funding is somewhat easier to obtain.
- Need to align funding and research capacity. Need to develop researchers at all stages of their career (early, middle and later stages).
- Early Career Researchers – how can we support their career, allow them to continue working in the field and stay in Ireland. There are no long term prospects for people working in research, this does not encourage people to stay in the field.
- How and who prioritises research in Ireland.
- Funders should collaborate more.
- Need information on what funding bodies are funding dementia research.
- Need to consider different types of research other than RCTs and systematic reviews.
- Make Ireland an attractive place to do research.

Research Strategy and Transparency

Comments:

- What is Ireland's dementia research strategy? There is an absence of strategic planning for dementia research.
- Political will and need high impact champions – like David Cameron in the UK.
- It should be easier for industry to see who is doing what research in Ireland. It should also be easier for patients to see what clinical trials are taking place so they can offer to take part.
- More strategic oversight needed regarding research that is being undertaken. What research should be Ireland-specific? We need to identify the latter and focus our efforts on it.

- Need to avoid duplication of research and it is important to know what is being carried out internationally to avoid overlap. How can we identify where we are unnecessarily overlapping? Need to aim for a synthesis culture.
- Scalability regarding expertise that researchers have. There is an argument for one national institute which should be multidisciplinary. Also there could be a hub and spoke model, as utilised by SFI to increase the number of targeted projects within an existing SFI Research Centre and to provide a mechanism to allow new industry partners and/or new academic partners to join the Research Centre.

Collaboration and Competition

Comments:

- A current challenge is that areas of research are in silos and do not work collaboratively together. The ASI and DNNI could pull together all the levels of research. We need DNNI to become stronger for the good of dementia research in Ireland.
- International collaboration is important. Post-Brexit there should be a lot more opportunities to collaborate with UK researchers. Currently there is very little cross-border collaboration in Ireland between north and south.
- Ireland can be part of a wider international team, and we do not need to be the leaders. We could focus on the Irish health service/system questions.
- If, for example, three researchers put in an application for research on informal carers, should all three researchers come together? If other research are also granted funding, there may well be duplication, and cohesiveness is missing. The All Ireland Institute of Hospice & Palliative Care is an example of a cohesive group.
- Competition and collaboration may seem mutually exclusive but are distinct and both are important. People fighting for money – less about the person and result – all about getting the grant.
- Culture of collaboration does not happen enough. We are too small to compete with each other. We should incentivise the best ideas. Collaboration also helps with career progression. Models like that are possible. A difficulty here is that the ‘lead’ needs to be shared around so that not just one person’s career is progressed - this is difficult to do in practice.
- We should exploit our small size to research. We should think about what we can do to support people best when a pharmacological intervention is so far off. Funders place people on competition in each other which prevents collaboration.
- Intersectionality is important e.g. dementia and economics etc. Different conditions affect dementia.
- Consultation with health economists is important. It is vital to build in the health economic piece from the outset of the research, instead of merely asking for such input towards the the end of the project. The question of financial sustainability is crucial.

Collaboration and Competition

- Do not underestimate how unintelligible research is to NGOs. NGOs often do not communicate well with researchers. There is an opportunity for NGOs to be better partners with researchers.

PPI and Research Ethics Process

Comments:

- There exists a difficulty in the recruitment of people with dementia into studies. Their voice is less heard in the research. There is a need for effective engagement for people with dementia.
- PPI needs to be developed in relation to dementia research. Community level interaction is a major issue in this regard, and knowing who wants to be involved in research is a major challenge. A programme such as 'Join Dementia UK' is needed here.
- Need mechanisms for involving people with dementia, and this cohort needs to be representative of people with dementia across the spectrum.
- Patient data should be a bigger feature of research.
- The ethics assessment is deeply cumbersome in complex real-life trials.
- Ethics presents an ongoing challenge. GDPR is also in the picture now. Developing suitable ethical processes and educating ethics committees in their use would be a constructive goal.
- The perceived label of dementia can prevent consent in many cases which is not good. Preventing consent in dementia is a stigmatisation. Dementia is a spectrum from prodromal to MCI to florid dementia, and preventing consent for all dementia patients is not right as many can consent. Patients' rights are being infringed upon and this is illustrative of a paternalistic approach.
- No carers or people with dementia are present today, and it would be ideal if they could lead these types of forums.
- From previous work with a supranuclear palsy group, their priorities for research were practical quality of life issues.

Clinician Involvement In Research

Comments:

- We need patient and clinician involvement, and this proves difficult as clinicians are too busy to take on additional workloads of research in addition to their current workload. There is also currently no means to contact relevant clinicians as a researcher.
- Research is not a realistic or supported goal as a clinician in the HSE- How do we encourage the HSE to support research?
- GPs do not have colleagues to cover for them to attend meetings like today as clinicians in

hospitals do. Therefore there are no opportunities for them to participate.

Dementia Registry

Comments:

- There is a need for a directory of people with dementia in the area for clinicians. The absence of such a directory of this makes it difficult to plan for services.
- There is a critical need for a register that covers all dementia patients who have engaged with both memory clinics and GPs clinics. Scoping work has been carried out but the HSE is majorly lacking in IT infrastructure and there is no consensus on who gathers the data.
- A participatory register may be a better option than a clinician controlled register, as anyone affected or their carers could upload data. Active participation in management interventions, such as diet, exercise or social interventions could be integrated into such a registry.
- A participatory register and a clinician controlled register are completely different with very different objectives and there is no reason why we cannot have both (e.g. Join Dementia Research UK is a participatory research oriented register). We should look at rolling it out in Ireland (already in NI).
- Participation platforms and registries are necessary, and we need more memory clinics west of the Shannon, which should adopt a model similar to that of cancer centres of excellence. More diagnostic centres would make a registry easier to create and populate.

Diagnosis and Post Diagnostic Supports/ Public Education

Comments:

- There is no competent clinician base to make dementia diagnoses. There are clear international guidelines on this however if the majority of diagnoses are made through GPs and not memory clinics, these diagnoses may not be of the same standard as those from the memory clinics. There could be other diagnoses that were not tested for as GPs do not have time or the knowledge base to competently diagnose dementia types. There are only 3 memory clinics in Ireland, and with 45,000 patients there need to be more memory clinics, at least 5 such clinics.
- GPs worry about social issues as well as the actual diagnosis, and they are less likely to tell patients they cannot drive as they do not have the resources to test them on such a task. Memory clinics can be much more absolute on issues like this and are not as involved with community or social issues..
- There is a gap in relation to what to do with people (how to proceed) before they are more clearly diagnosed and no clear “next steps”.
- Research has not cited any real “clear steps” after diagnosis for those people diagnosed with dementia, or even after initial suspicion, which is a factor leading to delayed diagnosis.
- The stigma of a dementia diagnosis is difficult, and there is a need for post-diagnostic

supports for both patients and carers.

- The public needs to be better informed of what dementia is and what resources are available post-diagnosis.
- Dementia is still a “black box” to the public, with deep gaps in public education and understanding of dementia. People need to know about dementia prevention, including secondary prevention.
- There can be a degree of stigma attached to the public perception of dementia, and this too can lead to delayed diagnosis. Public knowledge and awareness need to be addressed.
- Diagnosis in different countries varies. At an international level this affects research cohesion, structures and funding for dementia research facilities.
- Do people from different countries/backgrounds respond differently to dementia/dementia diagnosis?
 - Public perception
 - Research
 - Reaction to diagnosis
- The public do not understand the structures to avail of services.
- That the brain is not taught on any curriculum leaves the public with very little grasp of the basics of brain health.

Translation of Research Into Practice

Comments:

- Need to translate research into practice. There is a clear need for real-world research and outcomes focussed research.
- There is a need for better outcome measures. While this need is acknowledged, there is little work going on to establish better ones.

Dementia Friendly Infrastructure

Comments:

- Access to dementia-friendly infrastructure is an issue, and structures/planning of towns and cities varies and generally does not consider access for people with dementia.

Research in the areas of ‘Care’ and the ‘Healthcare System’

Comments:

- Primary care structure does not support research. It would not be appropriate to follow the blueprint of the NHS as we do not have the same primary care structure.
- Dementia services span primary care to acute care and this presents a challenge for research and we have to optimise all of these services for dementia patients.

- GPs do not feel they can deal with dementia patients, as they have a 7 minute consultation while a memory clinic appointment is 1 to 3 hours long, completely different. Same issue for Parkinson's disease, and the complexity of the condition means primary care does not currently work for dementia.
- There is a gap in knowledge/education on the cost of care - the "true" cost of care, including informal care giving is often misunderstood, or not known.
- There is a heightened perception of risk in the health service.
- There is a lack of access to the public system in various jurisdictions (countries)
 - Lack of dementia-specific or dementia-appropriate healthcare services
 - Discrimination against people with dementia, prevalent in the healthcare system
 - Depersonalisation of people with dementia, in research, in the healthcare system.

Q.2 What Areas of Dementia Research should be Prioritised and Why?

Healthcare System/Models of Care

Comments:

- Three strands of research, as mentioned earlier, diagnostics, treatment and care. Research should be weighted heavily towards diagnostics. There is a lack of research on people with dementia living in care homes with dementia. Systems of care need to be addressed, and there are good European examples: Green Care Farms, Dementia Villages etc. Safety issues/risk assessment, ethos of care should also be explored.
- There has been an increase in papers exploring acute care, long-term care, community care etc. This is usually from the point of view of healthcare professionals' attitudes and view.
- There is a need to look at the societal aspect – as a society how are we going to include marginalised groups?
- Research should address decisions regarding care, such as perceived burden and societal perceptions of care.
- Research should be specific to Ireland. There is challenge regarding holistic/caring vs managing risks, recognised also by HIQA as an issue. Genio have published a positive risk rating document, which may inform this.
- How care is paid for will determine what care is allocated. We need a new funding model, and need to understand what works and does not work in relation to funding care.
- Long-stay care is a knowledge and research gap. There are 20,000 people with dementia in long-stay care and most are at an advanced stage. There is little knowledge about this group, and there are a vulnerable group within a vulnerable group.
- There is a need to explore best practice for dementia environments in acute care, as there is an acute decline in patient behaviour with admission to acute care, and this needs to be addressed.
- How do we also improve residential care for those with dementia, especially for those with early stage dementia? This cohort need a structure that supports independence rather than having all of their independence and ability to carry out everyday tasks removed from them.
- Research should be specific to the healthcare system and to the culture of healthcare in Ireland.
- Hospitals should be more flexible, patient-specific/dementia-specific services. Needs not being fully addressed in hospitals. Primary illnesses is being targeted, rather than secondary.

Research Funding

Comments:

- Grant applications – need whole trajectory including pre-clinical/clinical/palliative.
- Funding cycle.
- Commissioned calls needed.

Innovation in Research

Comments:

- Ability of Ireland to tap into predictive analytics.
- Further in-depth use of technological and digital advances, also in developing databases.
- AI will form a significant part of mapping in the future.
- Innovative approaches to care, supported by technology.
- Innovative structures aimed at allowing people with dementia to remain in their own homes, for longer.
- Untapped community assets, such as green space movement, could be quite innovative. In the U.S., for example, a number of research projects have been carried out with cross-facilitated findings from specific areas. There could also be a modular structure in research/training/clinical that addressed the promoting of wellbeing of people living in the community.

Public Health/Prevention & Reduction Strategies

Comments:

- A disproportionate number of people in acute care have dementia. We can work with others e.g. public health, to support their needs. Can this be incorporated into a public health model?
- Prevention and reduction strategies: We need to identify high risk groups. We could also have something like the Kilkenny project, a cardiovascular social education project where people were taught about diet and exercise on the side of milk cartons. There is no screening for dementia, such as for cancer, but we already have high risk patients presenting themselves, obese, diabetics etc. Lifestyle changes in these high risk groups could prevent dementia.
- The efficacy of the above interventions may only be about 30% (Brayne paper), so would it be cost effective to utilise such a strategy? 30% of 45,000 is still a significant number.
- The nun study (the Longitudinal Study of Aging and Alzheimer's Disease in a cohort of nuns – Dr. David Snowdon, University of Kentucky) also showed pathology in those with no diagnosis - cognitive reserve may have helped those people and this has implications for promoting healthier lifestyles.

Dementia and Intellectual Disability/ Dementia and Minority Groups

Comments:

- Intellectual disability, particularly Down Syndrome needs to be prioritised. There is an increased genetic risk, by age 40, of developing neuropathology of dementia. National campaigns are needed to raise awareness of risk and this should be included in the research.
- Dementia in travelling community and in ethnic minorities. People in these cohorts need to be more aware of supports.
- Public health initiatives are not reaching all groups. We are in the midst of a debate at the moment on public health models beyond social determinants of health (e.g. developing communities, support, encouragement). We need to re-imagine what dementia means.

Lived Experience of Dementia

Comments:

- Understanding the lived experience of dementia is a priority.

Support For Carers

Comments:

- Carers need more support. Consider caregiver stress – level of support they need and services.

Keeping People with Dementia at Home/Facilitating Independence

Comments:

- There is a need to address how we can facilitate people's independence, to stay in their home as opposed to long-term care facilities.

Research Infrastructure

Comments:

- Need Centres Of Excellence to support and facilitate research.

International Perspective

Comments:

- Can we learn from prioritisation exercises and the results of other countries?
- International cooperation to developed research is important.

Dementia Diagnosis and Post-Diagnostic Supports

Comments:

- There is a need for better understanding of the experience involved for the individual receiving the diagnosis. Research should be focussed on the best way to diagnose and support people.
- There is a need for more effective post-diagnostic supports, and a need to decide what parts of post-diagnostic supports are helpful and should be prioritised.
- Lack of appropriate services for individuals with young onset dementia is a concern. Services designed for the larger cohort are not always appropriate for individuals with young onset.

Public and Patient Involvement in Research (PPI)

Comments:

- Participant recruitment is important and also a key challenge.
- Having a research ready cohort of individuals would be beneficial. Panel of individuals interested in participating in research.

Use of Antipsychotic Medication for People With Dementia

Comments:

- Use of antipsychotic medication needs to be explored.

Basic & Translational Research

Comments:

- Bench research is important.

Q.3 How can we Enhance the Relevance and Impact of Dementia Research?

Translation of Research Into Practice

Comments:

- It is important that consideration is given to how research is translated while the research is being undertaken and after completion. We need to build a common language around this process.
- Impact on people's lives: It is important to have a tangible outcome e.g. dementia care facility operated by the Daughters of Charity, which has direct impact and relevance for people living there. Other people could visit and learn. Tangible result or physical evidence not always possible. Real action research is needed.

Evaluation of Research

Comments:

- Building evaluative criteria into projects: Evaluation should be carried out not just at the end of the project, but in parallel all the way through. It should be built in more formally and sharing information more quickly. This requires transforming the culture of research in the HSE.
- Evaluating research relates to better outcome measures. It is important to note that Dementia care is not just within the HSE, spans public and private health systems.
- By evaluating research, one is less likely to repeat the same mistakes.
- There is a need to remove fear of failure in carrying out research. Drug companies fail a lot, why should it be different for other researchers?
- Knowledge mobilisation: Through evaluation, adjacent areas may also benefit.

Multidisciplinary Collaboration & Knowledge Exchange

Comments:

- Multidisciplinary collaboration is crucial. While this happens regularly in the US and UK, where every research team has basic researchers, clinicians, imaging specialists and pathologists working together, it does not happen enough in Ireland.
- We need a Dementia Ireland conference, and DNNI and the ASI could lead on this. ARUK host a 2-day meeting every year in the UK and this would be an appropriate model to draw upon. The opportunity to interact with patients, carers, basic researchers, GPs, clinicians and industry would be greatly beneficial.
- There are a number of Irish dementia conferences but each has a slightly different focus (e.g. Sonas / care; Memory Clinic conference / diagnosis). There may be an opportunity for these events to be brought together with different sessions or streams that cover all areas that need to be addressed.

- If a GP is interested in supporting or taking part in research, how do researchers link in with them? Currently there is no structure to support this, and there is a similar challenge for health and social care professionals, including those in nursing homes.
- There is an opportunity to develop a participatory research database for health workers who would like to take part in or support dementia research. Support for conferences and registries could come from industry. We need patients, carers, researchers and industry working collaboratively on this.
- We need a sharing attitude, and the amount of industry competition makes it difficult to work with just one company in the corporate sector. We need to work with companies who are willing to work collaboratively. Sponsorship of a registry or conference could come from a company/corporate.
- There is a need for a strategic collaborative approach: Who are the stakeholders? Who are the key influencers? A collaborative mind-set and approach is crucial. People with dementia should be included and involved in prioritisation, and ensure there is an endpoint for patients.
- Knowledge networks are important.

Patient and Public Involvement in Research/ Enhancing Profile of the Illness

Comments:

- NGOs and gatekeepers e.g. HSE very protective of their constituents. This makes it difficult to engage in PPI. There is a need for researchers to communicate better and for gatekeepers to unwind a bit, and this can be a challenging balance to achieve.
- In dementia research, the people taking part in research are a small group, and are generally well educated and articulate. More diverse representation is necessary. We need to delve further to the person living in a home. We want to hear about homeless people etc.
- Accessing people with dementia: The decision should not lie with the gatekeeper but with the the person. There is a need for education around ethics. The new Assisted Decision Making Capacity Act is relevant in this regard and capacity must be assumed.
- How do you enable decision-making to take part in research? Meaningful involvement can be achieved by for example using innovative communication tools.
- Intellectual disability over the lifespan: The same principles should be used eg, communication, accessible information etc. There are processes in place that could be adapted for people with dementia.

Enhancing Profile of the Illness

Comments:

- Focus on specific persons that have enhanced profile of the illness e.g., former Justice Minister Nora Owen who husband has been diagnosed with dementia. There is a need to enhance the visibility of dementia.

Positive Narrative/ Success Stories

Comments:

- Integration of positive research into overall research through “success stories” with focus on “wellness”.

Suitability of Ireland for Clinical Trials

Comments:

- We have a homogenous population, which makes Ireland a suitable environment to carry out clinical trials and the cancer research community have taken advantage of this. We need to encourage dementia trials here.

Issues re Research in Residential Homes

Comments:

- HIQA crack the whip re expertise and standards. There are great things being done around engagement re. citizenship but it can be more difficult to demonstrate positive outcomes on paper for these initiatives. Staff may be more open to research if the outcomes being measured were more broad.

Research Careers

Comments:

- Precarious nature of work and high attrition rate is a concern.

Health System

Comments:

- Health system is service-oriented, and should be based on responsiveness to people’s needs. Ratio of service to research funding is very one-sided.

Research Strategy/ Investment

Comments:

- Strategy is key. Research should be perceived as an “investment” rather than a “cost”.
- Data-collection, rather than analysis of existing data. There is a need for up-to-date/flexible research.

6.0 Next Steps

The objective of the research forum was to act as an initial step in gaining consensus on dementia research priorities and exploring possibilities of funding. The DNNI are in agreement with the ASI that this forum is the first stage of a broader process that will involve focus on specific research priorities. Through exploration with stakeholders, this forum has produced a number of outputs that we would now like to see taken forward.

The next step in the process is to develop a Working Group comprising relevant stakeholders to continue the consensus process. The Working Group will be established in early Autumn 2018. A formal methodology will be applied in order to support their work and complete the consensus process. One of the essential elements of this work will be to identify and link with the key stakeholders, actors and structures which are critical to supporting this process.

This report will be presented to the All-Party Oireachtas Group on Dementia, which seeks to build understanding, consensus and cross-party support for long term planning and increased investment to support people with dementia and their carers in Ireland. The ASI and DNNI will seek to present the forum findings and feedback to the All-Party Group during their Autumn 2018 schedule of meetings with the aim of informing member parties and advocating for their support in relation to increasing funding for dementia research.

In the medium to long-term, funding and research calls will be sought to address research gaps and priorities, and ASI will activate a leadership role in partnership with DNNI, developing a PPI panel and early researcher roles. ASI intends to bring the outputs of the Working Group to the wider stakeholder group at a research event in Spring 2019.

Appendix 1 – Forum Participants

Coordinators

Dr. Bernadette Rock, Research & Policy Manager, Alzheimer Society of Ireland
Carol Rogan, Scientific Coordinator, DNNI

Facilitators:

1. Prof. Brian Lawlor, TCD & St. James's Hospital, Chairman DNNI
2. Prof. Cora O'Neill, UCC and DNNI Management Committee Member
3. Dr. Fiona Keogh, NUI Galway and DNNI Member
4. Dr. Patricia McParland, Independent Consultant
5. Dr. Anne-Marie Brady, Head of School of Nursing & Midwifery, Trinity College Dublin

Note-Takers:

1. Carol Rogan, Scientific Coordinator, DNNI
2. Ben Meaney, Assistant to Senator Colette Kelleher, Civil Engagement Group
3. Dr. Catherine Jordan, Research Fellow, Global Brain Health Institute
4. Dr. Edel Hennessy, PhD Neuroscience
5. Dr. Maria Pierce, Research Manager, Genio

Participants

	Name	Position/Affiliation
1	Prof. Eamon O'Shea	Director of the Centre for Economic & Social Research in Dementia (CESRD), NUI Galway
2	Prof. Thilo Kroll	Assoc Dean for Research Innovation & Impact, UCD
3	Joan Brangan	Asst Prof. Occupational Therapy, TCD
4	Jennifer Lorrigan	Project Coordinator, Dublin Brain Bank, Beaumont Hospital
5	Dr. Geeske Peeters	Research Fellow at the Global Brain Health Institute
6	Michael Foley	Research & Development Officer at the Trinity Centre for Ageing and Intellectual Disability
7	Dr. Eimear McGlinchey	Research Fellow, Trinity Centre for Ageing and Intellectual Disability
8	Emer Fallon	Clinical Programme Manager, Genomics Medicine Ireland
9	Lorna Murphy	Programme Manager, Genomics Medicine Ireland
10	Dr. Sandra Higuete	Research Fellow, at the Global Brain Health Institute
11	Vivienne Nixon	Social Worker for Older Persons, HSE
12	David Kavanagh	Clinical Partnerships Leader, Genomics Medicine Ireland
13	Dr. Unai Diaz-Orueta	Lecturer in Psychology, Maynooth University
14	Dr. Laura Mackey	Postdoctoral Researcher, School of Public Health, Physiotherapy and Sports Science, UCD
15	Dr. Patricia Carney	Postdoctoral Researcher, Centre for Economic and Social Research on Dementia (CESRD), NUI Galway
16	Dr. Alejandra Guerrero	Research Fellow at the Global Brain Health Institute
17	Dr. Dominic Trépel	Asst Professor of Economics, Trinity College Dublin
18	Dr. Fiona Keogh	Senior Research Fellow, Centre for Economic and Social Research on Dementia (CESRD), NUI Galway
19	Prof. Kate Irving	Dept of Nursing & Human Sciences, DCU

20	Gillian Eggleston	Senior Speech & Language Therapist, HSE LHO Dublin North Central
21	Prof. Catherine Blake	Assoc Professor, School of Public Health, Physiotherapy and Sports Science, UCD
22	Dr. Louise Hopper	Asst Professor in Dementia Studies & Psychology, Dept of Nursing & Human Sciences, DCU
23	Catherine Gill	Programme Manager , Post Award and Evaluation, Research Strategy and Funding , HRB
24	Cormac Cahill	Communications Manager, Alzheimer Society of Ireland
25	Dr. Anne Cody	Head of Pre-Award, Research Strategy and Funding Directorate, HRB
26	Tina Leonard	Head of Advocacy and Public Affairs, Alzheimer Society of Ireland
27	Krystal Culler	Research Fellow at the Global Brain Health Institute
28	Jennifer Lorrigan	Project Coordinator for Dublin Brain Bank, RCSI
29	Brian Magennis	Advanced Nurse Practitioner candidate, Care of the Older Person, Mater Hospital
30	Dr. Francesca Farina	Postdoctoral Researcher, TCIN, Trinity College Dublin
31	Dr. Sean Kennelly	Consultant Physician in Geriatric Medicine, Tallaght Hospital and Clinical Senior Lecturer in Medical Gerontology, TCD
32	Jennifer Allen	Senior Social Worker, St Vincent's University Hospital
33	Jackie Ramakrishnan	Clinical Nurse Specialist, Mater Hospital
34	Suzanna Dooley	Senior Speech & Language Therapist, HSE