

## Research Strategy

### Table of Contents

Introduction	Page 2
Dementia Research Landscape in Ireland	Page 2
Stakeholder Perceptions of ASI	Page 4
Developments in Dementia Research in Ireland	Page 6
Challenges for Dementia Research	Page 6
Gaps in Dementia Research in Ireland	Page 8
Potential Research Role for ASI	Page 11
Research Review Sub-Committee	Page 15
Copy of ASI Survey for Stakeholders	Page 16

## Introduction

### Objectives & Context

This consultation seeks to inform ASI's research strategy for 2018-2021. It draws on the views of a range of relevant stakeholders in order to map and understand the dementia research landscape in Ireland and identify needs, gaps and discrepancies in relation to dementia research. This consultation process will contribute significantly to identifying the potential research role that ASI can adopt and will be instrumental in re-defining and developing ASI's research strategy.

ASI is developing its research strategy within a specific context, that of an ageing population and increasing numbers of people with dementia. A further important contextual factor is a need for strong evidence-base. We cannot adequately plan, create policy or financial estimates for the specific needs of Irish people with dementia and those of their families without data. While the 2016 report, 'A National Dementia Registry for Ireland: A Feasibility Report' (DCU/ASI) and the HSE/ASI Mapping project, due to be published in 2017, offer leadership in filling the data gaps, both need to be further developed and explored. Of vital importance is that there is now a more in-depth understanding of the needs of carers arising from the ASI/TCD/HRB three year De-Stress study, which set out to gather information about the health and wellbeing of more than 200 family members who care for people with dementia, the largest study undertaken of people caring for their spouse with dementia. A further context to be considered is the recent national awareness campaign, that will inevitably further people's knowledge, awareness and understanding of dementia.

### Dementia Research Landscape in Ireland

In developing a research strategy for the future, it is crucial to understand and identify the key players in the dementia research landscape in Ireland, and the role that ASI has played in this landscape. A review of dementia research highlights a number of key stakeholders:

1. Centre for Economic and Social Research into Dementia, NUIG,
2. Elevator Programme, DCU,
3. Neuro Enhancement for Independent Lives, and Global Brain Health Institute, Trinity College,
4. Dementia Services Information and Development Centre, St James's Hospital
5. Genio,
6. Dementia Pathways and Prepared Project,
7. Centre for Gerontology and Rehabilitation, UCC,
8. Dementia and Neurodegeneration Network of Ireland,
9. National Dementia Office.

ASI's role in relation to research, 2008 – Present, has been largely collaborative, focusing on the following research themes:

### Role and needs of Carer

- De-Stress: A Study to Assess the Health and Wellbeing of Spousal Carers (2017)
- Resilience in Family Caregiving for People with Dementia (ongoing)

### **Planning and mapping of services**

- Mapping of Dementia Services (2017)
- A National Dementia Registry for Ireland (2016)
- Resource Allocation, Priority-Setting and Consensus in Dementia Care in Ireland (2017)
- Promoting Assisted Decision Making in Acute Care Settings (Proposed)
- Research investigating the Young Onset Dementia (Proposed)

### **Risk and prevention factors**

- Risk Reduction Project (Ongoing)
- Risk Factors, Risk Reduction – Consensus Study (2017)

### **Person and professional involvement**

- Collaborative Doctoral Awards (2017)
- Fitness to Drive (Ongoing)
- PPI Ignite (Ongoing)

Earlier research projects have addressed palliative care in Opening Conversations (2009), The Social Club Model of Dementia Care (2008) and experiences of transition to nursing home in Continuing to Care for People with Dementia (2010), Implementing Policy for Dementia Care in Ireland (2007).

In the past ASI has focused attention on supporting early career researchers; recognising that nurturing upcoming research talent can make a huge contribution to the dementia research landscape. ASI has financially supported two Trinity College based students through the Irish Research Council's (IRC) Employment Based Scheme and the IRC's Enterprise Partnership PhD fellowship. These programmes have enable ASI to engage people in a career in dementia research while producing high quality evidence to add to existing knowledge, supporting the development of evidence-based policy and practice.

Nonetheless, whilst ASI's research portfolio is valuable, it has lacked direction and strategy in the past. Its research involvement has been largely unplanned and ad-hoc, merely reacting and responding to external research requests; hence the need for a strategy and planned research strategy.

The World Health Organisation's 2017 'Global Plan of Action on the Public Health Response to Dementia 2017- 2025' was unanimously adopted by 194 countries. The plan supports the urgent message that countries need to develop practical and ambitious national strategies regarding dementia. Alzheimer Europe and people living with dementia were consulted on the development of the plan, which includes a set of seven global targets, including 'Dementia research and innovation'. Recognising that dementia is a major cause of disability and dependency among older people world-wide and is expected to increase further, the plan calls on all governments to meet these targets. This serves as a further impetus for ASI to develop its research strategy.

### Consultation Stakeholders

This Consultation draws on the perspectives and insights of a broad array of stakeholders involved in dementia care and research in Ireland over a 3 month timeframe from June-August 2017. It included both external and internal ASI parties comprising 3 regional meetings with ASI staff and managers, 30 surveys and 8 1:1 meetings with the following stakeholders:

- ASI Medical and Scientific Advisory Panel
- Irish Dementia Working Group (IDWG)
- Dementia Carers Campaign Network (DCCN)
- Members of Dementia Neuro Degeneration Network (DNNI)
- Internal ASI regional managers in Sligo, Carlow and Blanchardstown
- ASI Branch Chairs
- ASI's Senior Management Team
- Dementia Pathways Researchers
- Centre for Economic and Social Research into Dementia
- National Dementia Office
- Institute of Neuroscience, Trinity College
- Prof Mary McCarron, Trinity Centre for Ageing and Intellectual Disability
- DCU Elevator programme
- Medical Research Charities Group
- Health Research Board
- Family Carers Ireland
- Care Alliance Ireland
- All Ireland of Institute of Hospice and Palliative Care
- RCSI researchers and practitioners
- Former CEO, Maurice O'Connell

Stakeholders were asked about their views of ASI research activities and the role that ASI plays in research, their understanding of the dementia research landscape in Ireland, specifically the challenges therein, existing gaps in relation to areas of research, and their views of the potential role that ASI could play to address research gaps and needs.

## Stakeholder Perceptions of ASI

Participants offered a varied understanding of ASI’s research role:



**Collaborative:** Stakeholders largely perceive ASI’s role as collaborative, working with significant research institutions on both small and large scale projects, involved in research design and participant recruitment, and supporting ongoing research and researchers:

*“The ASI has collaborated in some research projects, but in others they have assumed more of a stakeholder role. The ASI has also enabled patient involvement through IDWG”.*

**Advisory:** ASI is described as having an advisory role in relation to the needs of people with dementia:

*“ASI can sit on the advisory board of many different research projects in a capacity to ensure that the views of needs of people affected by dementia are represented in research, and that research priorities are set in line with actual needs of this group of people”.*

**Person-Centred:** ASI’s role in research is perceived as keenly focused on person involvement, “ASI puts the patient’s well-being first, which is very important”.

ASI’s research role is defined as person-centred, with several respondents noting that ASI has the capacity to be a strong influencer in this regard:

*“The success of the work done so far has been that it was person focused and collaborative. I do think there is a role for ASI to remind others in the research community that a holistic and integrated approach within the medical and social research is very important.”*

**Commissioning:** It is recognised by stakeholders that ASI plays a role in commissioning research and has been involved in projects as research partner. ASI’s role is also understood as identifying important research questions and gaps based on their experience working directly with people with

dementia and family carers. This includes identifying areas which warrant further investigation and commissioning relevant pieces of research to fill these gaps.

**Reactive:** In relation to research, ASI's role is also described as lacking in focus and reactive to requests for participation and the needs of organisations, rather than being pro-active in setting its own goals. ASI does not have preferred themes or identified areas of research, and is viewed by research organisations and universities as a likely source of access to patients with dementia.

When asked about the significance of the role that ASI plays in research, over 70% of stakeholders stated that it is a "*fairly significant*" role, while those involved in medical research tend to describe ASI's role as "not very significant". It is noteworthy that the majority of stakeholders, such as members of the DNNI and Scientific and Medical Advisory Panel, do not feel very informed about the research activities of ASI and its current research role. Several observe that ASI's research activities are not apparent even on its website. It is only stakeholders with whom ASI has a particularly close working relationship, such as the NDO and CESRD, that demonstrate awareness of ASI's research activities, such as relevant reports that have informed policy and service development of dementia in Ireland.

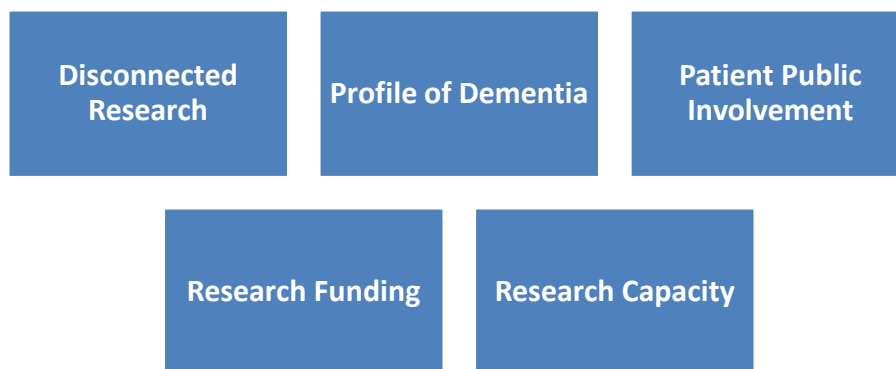
### **Developments in Dementia Research in Ireland**

When asked what is going well in terms of dementia research in Ireland, specific areas were identified as having received significant attention:

- Respondents observed that over the last four years there is strong and growing focus on dementia research, and this can have a positive effect in encouraging the public to discuss dementia.
- There is greater understanding of the importance of patient public involvement and quality of life research involving people with dementia and carers.
- Several respondents feel that healthy living, brain health, dementia prevention and risk, delay of cognitive decline and prevention are being increasingly profiled, but are nonetheless limited regarding interventions and treatments for people with dementia. It was noted that such research needs to be grounded in collaboration with relevant organisations.
- A good body of research is being developed on palliative and end of life care, community based services for people with dementia, best practice home and community care approaches, dementia education but nonetheless there is still further research needed.
- Research is increasingly addressing the economics of dementia care and care-giver burden.
- In addition to biomarker and biochemical mechanisms of dementia, there have been a number of successful dementia projects in Ireland that have examined a range of dementia-related policies and interventions, such as Genio. The difficulty is that they are available in very limited areas, and despite favourable evaluations and outcomes, are not being rolled out nationally.

### **Challenges for Dementia Research**

Various stakeholders identified several obstacles to furthering dementia research in Ireland:



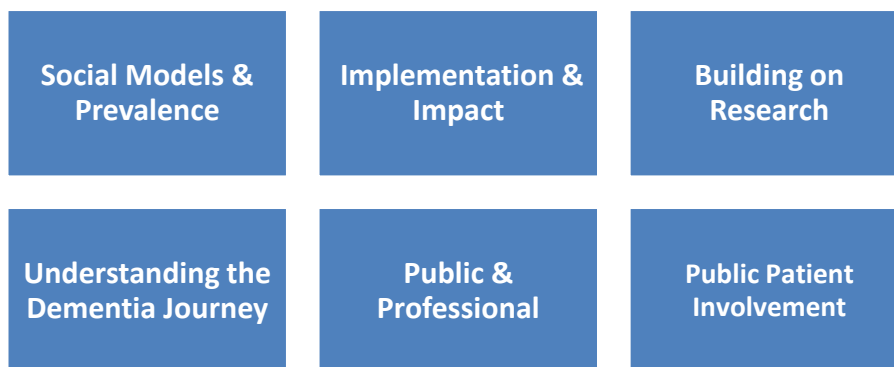
1. **Disconnected Research:** The dementia research agenda is highly political with significant competition among researchers for available funding. While this can lead to innovation and new ideas, it can be problematic when it leads to division and insular research practices. Researchers tend to work in silos and there is an absence of a joined-up plan. Research agendas tend to be driven by a need for professional recognition rather than the needs and priorities of people with dementia and their carers, although this is changing very gradually. There needs to be more collaborative and effective partnerships. It is essential that dementia research is inter-disciplinary and all efforts should be made to move in this direction.
2. **Profile of Dementia:** Dementia research competes with other areas of health research and may not be perceived as a priority in the way that illnesses such as cancer might be. Dementia researchers should work together to address the disparity between funding allocated to dementia in comparison to that allocated to other diseases. They should also explore the potential to collaborate with researchers in chronic illness management and other related fields.
3. **Patient Public Involvement:** Research participants can benefit from being involved in research, yet it can be challenging for potential participants to aware of and become involved in research. Similarly, for researchers gaining access to people with lived experiences of dementia can be challenging and cumbersome. A very homogeneous group of people with dementia tends to be over-represented in ASI related research (e.g. younger onset, mild dementia). Ensuring people with more advanced dementia are included as research subjects can entail practical challenges such as oral expression, which need to be addressed. Nonetheless PPI is a process ASI could facilitate through direct communication with people with dementia. A platform such as Join Dementia Research UK could potentially be expanded to Ireland and this would allow all researchers to present their research questions to interested people with dementia, family and professional caregivers, and give potential participants the power to choose research studies that they would like to join. This takes the power from gatekeepers and passes it to those directly impacted by the condition.
4. **Funding:** Respondents largely believe that dementia research is very poorly funded relative to the importance of dementia, and there is a need to develop funding opportunities that

are indigenously to the Republic of Ireland. Numerous stakeholders have suggested that ASI should ring fence funding specifically for research, similar to Alzheimer UK.

5. **Research Capacity:** A critical issue in terms of dementia research is research capacity, and the lack of individuals at various levels (leaders, fellows, post-docs, PhD candidates etc.) with the interest and crucially the variety of skills required to carry out good quality innovative research addressing key questions around dementia service provision and policy. The cadre of trained researchers in the area tends to be limited and retaining researchers is challenging. Instead of funding single research projects, emphasis should be on investing in core research staff, invest in research teams. Research teams should interact and seek to educate and empower the wider public and those with dementia and their carers.

### Gaps in Dementia Research in Ireland

Stakeholders were asked about perceived gaps in dementia research in Ireland and their views about areas that are overlooked and in need of further research:



- **Social Models & Prevalence**

There is a need to explore and evaluate psychosocial and cognitive interventions, such as cognitive rehabilitation, cognitive stimulation therapy, the impact of these interventions and optimum models of community based care, all of which requires sustained research effort. There is a need to better understand long-term care models and outcomes for individuals and family carers. Consideration needs to be given to interventions that demonstrate efficacy and that can be rolled out on a national basis.

Stakeholders identified a need for research into secondary prevention, which seeks to delay decline in people at higher risk of dementia. There is a perceived need for research to identify feasible interventions and test whether they can delay dementia onset.

There needs to be improved national, regional and local estimates of current and future prevalence of dementia across all care settings (very importantly this includes not just those within the HSE but private and voluntary care settings as well). This is essential to identifying current care inequities and facilitating a more equitable distribution of care in the future.



- **Implementation & Impact**

There has been significant research on areas such as unmet needs of carers and persons living with dementia, dementia prevention and risk. However, it is crucial to focus on shortening the gap between a research project and the impact on the person/carer. Greater emphasis is needed on ways of translating these findings into policy and practise and implementing supports in a sustainable way by incorporating cost-effectiveness research, evaluating community-led interventions, evaluating the feasibility of delivering evidence-based treatments/supports in practice. A quantitative research study could investigate the impact of a variety of early interventions, with a view to informing the delivery of the most effective evidence-based interventions country-wide. As well as applying research, it is vital to demonstrate the impact of research, and impact is important in order to gain further funding.

- **Building on Research**

Stakeholders cited that building in a smart way on what has already been learned through research and practice is crucial. The 2017 De-Stress report highlights a number of interesting and insightful findings that should be further researched in order to enable a more in-depth understanding of carer experiences. For example, many carers can feel frustrated as a result of a lack of understanding about the side effects of various medications and perceive that an asymmetrical relationship with HCPs renders them feeling powerless. The grief, loneliness and isolation experienced by many carers, even post-caring, and the need for care pathways for carers are also areas that need further understanding. An additional potential area of research, following on from the De-Stress report, is that of elder abuse, which can be non-deliberate, such as the carer being reluctant to give the person with dementia a drink because they will need assistance using a bathroom facility. Research should focus on building on what is already evidenced, instead of re-inventing the research wheel.

- **Understanding the Dementia Journey**

There is a need to research the whole dementia process from diagnosis through to day care attendance, hospital stay and support post-caring. There are numerous gaps and complexities that require in-depth understanding. Research into various stages of the dementia journey should be based on the experiences and preferences of the person with dementia in relation to the type of support they require now and in the future. It should be focused on the person with dementia, the community and the relationships that have sustained the person, including the impact of supports, services and NGOs.

Our limited and patchy understanding of various cohorts needs to be addressed, such as the lived experiences of dementia among people with intellectual disabilities and those with young onset dementia, in terms of how they cope with the diagnosis, family life and employment. There is a need to understand the experiences of people who are newly-diagnosed with dementia to address the anxiety and fear that often follows diagnosis. Research should explore how to reduce anxiety for people with dementia using non pharmacotherapy supports. Michelle Kelly's research with ASI showed that applying some of Linda Clare's methods to goal-setting/rehabilitation for these patients produced very significant improvements. But these interventions are currently not funded or facilitated and should be followed up.

As those with dementia increase in age, people are presenting with complex medical needs. An increasing ageing population means that people with dementia are presenting with an additional illness or condition. In this consultation, stakeholders noted that regarding hospital visits, patients with dementia should be fast-tracked. The butterfly scheme is an example of how this can work well in the hospital environment, and an example of a pocket of good practice that could potentially be further explored and developed.

There is limited understanding about how to best support the person with dementia/carer on transition from home and community to nursing home/hospital/hospice setting, and care issues in the advanced stages of dementia, directed towards both the person living with dementia and their family carer. This includes ethical decision-making, evidence to enable/support people with dementia around decision-making and to support professionals/carers in relation to decision-making particularly at end of life.

There is an acute gap in terms of research and understanding of experiences of people with dementia in nursing homes. Concern has been expressed among carers that family members in nursing homes who exhibit what are perceived as challenging symptoms of dementia are being requested to leave the nursing home and are unable to access services under the Nursing Home Support Scheme Act 2009. Within nursing homes, those with dementia often experience a high turnover in carers and this can lead to stress and confusion for the person with dementia who needs consistency. It takes time for the carer to understand the need of the person with dementia, their background and personality, and changing carers can be immensely frustrating for the person with dementia and their family. Concern has also been expressed in relation to pain assessment and how levels of pain are assessed and managed in people with dementia, given that they are sometimes unable to verbalise and express their needs.

- **Professional & Public**

This consultation identified a need for research into professional practice in relation to caring for people with dementia. Stakeholders perceive that GPs can be reluctant to share information with family members about the person with dementia, and as a result, the family/carer are uncertain about the types of medication the person is taking, side effects and how they can best support the person with dementia. Stakeholders pointed to a need for intervention studies to improve attitudes and behaviours of HCP in relation to dementia and their carers. There is a need to continue raising awareness and developing educational materials about dementia. Advocacy work is crucial to empower people to speak out and affect change.

- **Public & Patient Involvement in Research**

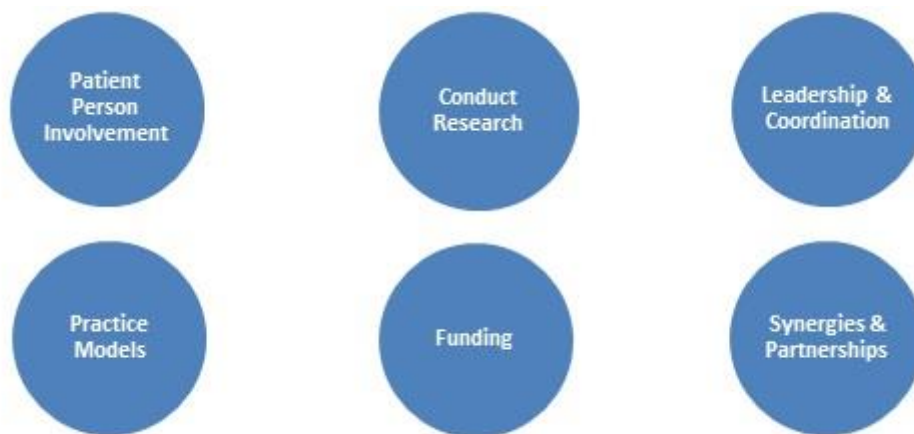
The needs and preferences of people with dementia and their carers should underpin research, policy and service design. There is a need for a more robust mechanism to hear the voices of as diverse a group of people with dementia/carers as possible and more evidence about how to meaningfully involve people with dementia in the design and conduct of research, priority setting and dissemination activities.

Better communication and collaboration and a national strategic approach to research prioritisation is key to optimising resources that are available. Prioritisation will be needed within research

domains (e.g. prevention, care, cure) and across domains. It is also likely that different levels of PPI will be important in each case and the approach should be flexible enough to deal with this (e.g. higher PPI for care than cure, potentially).

### Potential Research Role for ASI

In this consultation stakeholders were asked about their perception of the role that ASI should and can potentially play in relation to research:



- **Conduct Research**

**Research Participants:** There is potential for ASI to carry out its own qualitative and quantitative research and publish its findings, which could have impact and influence on key policy issues. While funding for research is limited, ASI can be creative in overcoming funding challenge: ASI has a large client base, including people with dementia and their carers/families, and access to a large sample of potential participants is a significant advantage in the research process and one that ASI should utilise. ASI’s ‘Eating Well with Dementia’ study, which received considerable media coverage, is an excellent example of how ASI can have impact in terms of research through surveying its own clients.

**Exploring Research Themes:** ASI could learn from The Trinity Centre for Ageing and Intellectual Disability which supplements the Irish Longitudinal Study on Ageing with a focus on intellectual disability. The study, led by Prof Mary McCarron, addresses a series of topics such as quality of life, cognitive wellbeing, physical wellbeing, mental health, which in turn ask questions about issues including ageing perceptions, aspirations, social activity, social participation, weight and obesity etc. There may be scope for ASI to carry out a study that similarly addresses a battery of key issues affecting the lives of carers and people with dementia. There would be considerable value in carrying out surveys exploring themes addressing:

- Quality of life, coping with diagnosis of dementia,
- Carer isolation, loneliness and ability to cope,
- Cost of caring for family carers,
- Experiences of formal care and support services,
- Medicines and challenges regarding usage of medicines and side effects,
- Information needs of carers and people with dementia,
- Public perception of dementia, stigma and awareness.

Such a research survey could build on previous research including issues raised in the De-Stress study on carer well-being, such as carer isolation, and could also be an opportunity to address and explore the numerous aspects of the dementia journey that require further research, as identified in this consultation. Our understanding of various stages of the dementia journey is patchy and limited, and a survey exploring a series of dementia issues could be an effective way to address this knowledge gap.

**Longitudinal Research:** Furthermore, developing the above suggested research as a longitudinal study would capture changes in attitudes, experiences and perceptions change over time among carers and those with dementia. A longitudinal study is a type of research that is unique in that it follows a certain timeline, and identifies and measures change and patterns over time. It would enable us to measure and understand key issues and concerns that affect carers and people with dementia. This could provide a highly valuable opportunity to deepen our understanding and knowledge of the changing needs of this cohort. To date no such research project has been carried out and such a project could significantly raise ASI's research profile and credibility, as publications and media reporting on survey findings would contribute to creating public awareness. A longitudinal approach would also elicit insight into whether people perceive impact in their daily experiences arising from implementation of various aspects of the Strategy. Taking advantage of our client base would contribute to developing a cost-effective research study.

**Rights Approach:** A further example of a potential research study could centre on ASI's Charter of Rights, and could explore how ASI's services, particularly its day care centres operate through a human rights lens. This could be a significant opportunity to understand how ASI operates to meet the need of people with dementia from a rights perspective, the challenges in this approach and how ASI can seek to address these challenges.

From a global perspective, the focus on human rights in dementia care is receiving considerable attention. For example, in Australia there is emphasis on control and choice in accessing support as a way of strengthening human rights, and policy makers and practitioners insist on the need to consider the use of promoting human rights-based approaches when intervening in the lives of people with dementia. A human rights approach underpins the Northern Irish policy with a strong focus on respecting the rights of adults as individuals, treating all adults with dignity and respecting their right to choose. It involves empowering and enabling adults at risk of harm, to manage their own health and well-being and to keep themselves safe. There is a body of research indicating that the promotion of a human rights approach is crucial in the care and safeguarding of people with dementia in order to prevent discrimination and abuse, and to ensure social inclusion.

Crucially, there is a need to address attitudes to research, as there is a lack of understanding of the importance of potential of research in terms of impacting lives and informing policy. ASI clients, including both people with dementia and carers, need to be informed about the benefits of engaging in research, how it can be interesting and rewarding, and have opportunities to identify project they would like to take part in, and be supported in this process.

- **Patient Person Involvement**

There is a role for ASI to implement a framework and structure for PPI in dementia research, and ASI could be at the forefront of providing PPI involvement to researchers in academic or clinical settings. ASI could play a key role facilitating the logistics of sourcing people with dementia and carers for research studies, providing information about various research projects being proposed by academics and clinicians so that individuals can make contact with researchers, and be involved in the delivery stages through to dissemination of the research project to the public. This involves working with the Irish Dementia Working Group to increase capacity of people with dementia to engage in research and beyond being research participants. There is also a need to explore if involvement from more Irish participants can be secured on European and international clinical trials.

Concern has been expressed by stakeholders that current members of the working groups are highlighting homogeneous experiences and being over-sampled in research. There is a clear need for a broader and more varied membership, including people from rural areas, minority groups and those over the age of 70 years to reflect the more varied and differing experience of dementia.

Instead of merely responding to research requests, ASI needs to proactively develop and implement a platform, perhaps similar to Joint Research UK, to ensure people with dementia and their carers are represented across general health or wellness studies.

- **Leadership & Coordination**

Stakeholders have identified that ASI could potentially address co-ordination and leadership in relation to dementia specific research and policy work. This could be linked to ASI's role in identifying where there policy gaps lie and where there is service and support need, and evidence to support the development of these areas. This could be achieved by commissioning policy papers, encouraging themed research via links with PhD programmes and the HRB, working closely with the DNNI and by hosting seminars with stakeholders to showcase relevant research. ASI could bring a neutral stance, given the competition between universities and researchers, and bring leadership and coordination to research activities. ASI could play an important role in working with stakeholders to facilitate a process that brings key stakeholders and research groups together to define the research priorities and strategy for dementia in Ireland.

- **Synergies & Partnerships**

ASI should focus on being a strong and essential partner in research studies. ASI should invest in developing synergies and partnerships with key universities and organisations, and there may be potential to create links with organisations outside of Ireland:

**World Dementia Council:** The Research team is led by WDC member Philippe Amouyel, who works with an expert and experienced global team of WDC members and associate members. It aims to foster and promote a culture of open science and collaborative global research into dementia; a strategic approach to research across the spectrum of the disease; and research into interconnected dementia related issues, such as health and economic disparities and gender differences.

**Alzheimer Europe:** AE, a non-governmental organisation, has been involved in a number of European projects. In particular, they recently carried out a five-country survey on the "Value of Knowing" and the general public's perceptions, experience and knowledge of Alzheimer's disease. They also carried out a number of European comparative studies, helping to identify the similarities but also the vast differences which exist in the different countries' approaches to dementia. Currently, Alzheimer Europe is also exploring the ethical implications of recognising dementia as a disability.

**Alzheimer Research UK:** Alzheimer UK fund a unique Research Network of over 1,000 dementia researchers across 15 Centres in the UK. It funds a broad range of research projects to understand dementia and work towards better diagnosis, preventions and treatments. Its research tends to centre on causes, diagnosis, risk, symptoms and treatment.

**Alzheimer's Society UK:** Its researchers are investigating a wide variety of areas related to dementia, whether it is the underlying causes of the condition, how to improve diagnosis, providing the best care or searching for a cure.

In June 2017 Alzheimer's UK developed three 'Centres of Excellence'. Each centre focuses on key priorities in dementia care research, including improving quality of life, improving support after a diagnosis and maintaining independence at home. The Centres of Excellence are a groundbreaking initiative developed by Alzheimer's Society to address areas in dementia care that are in urgent need of more research. The research team held an extensive consultation with our staff, volunteers and people affected by dementia to identify the themes that people felt most needed addressing.

**Alzheimer Scotland Dementia Research Centre:** It provides a high-quality research environment for investigations into the causes and treatment of dementia, and care provided by relatives and friends. It aims to commission and build a balanced portfolio of scientific and clinical research and develop and maintain a dementia brain tissue bank.

ASI could strengthen its research position by developing synergies and partnerships with European Alzheimer organisations.

- **Practice Models**

There is potential for ASI to play a key role in capturing and identifying best practices and models in relation to dementia care, e.g., identifying social care models that are effective earlier in diagnosis, and proven models of developing choice within the community. Translating promising interventions

in dementia care settings could involve collaborating with service providers in evaluating real implementation methods, and implementing those that are efficacious more widely.

- **Funding**

While funding for dementia research is generally limited and competitive, ASI could potentially seek to establish a research funding stream. Funding could be ring-fenced for research, including funding from local regions. The Nutricia 'Eating Well with Dementia' study is an example of how ASI can partner with an organisation and draw on its own research cohort to develop an effective and valuable piece of research that helps raise the profile of ASI. Specific projects could be identified that might be suitable for pharmaceutical companies to sponsor. An upcoming site visit with Dr Doug Brown, Director of Research and Development at the Alzheimer's Society UK, will offer insight into how a funding model could be developed to support ASI research projects. In addition, providing small bursaries to facilitate final year students in areas such as psychology, nursing, medicine who would present research at conferences, would be a good means to raising the profile of ASI.

### **Research Review Sub-Committee**

In the past committee membership has comprised a person with dementia and representation from key ASI departments in the national office, including Advocacy (Policy and Research Manager); fundraising (Fundraising Manager); from the information service (Information Manager) and a representatives from Operations (Services Manager).

In an effort to achieve greater objectivity and inclusivity, membership is being changed to instead include:

- A carer of a person with dementia, Ann Twomey, who believes she *"can offer a unique and valuable perspective representing the greater world outside the Research Community, given my role as Carer for my late husband, Noel, who lived with Vascular Dementia"*.
- A person with dementia, Fr Des, who describes his strengths as *"listening and thinking things through, then giving the necessary feedback and contributing my thoughts where appropriate"*.
- Advocacy Officer, Joanna Joyce, who has extensive experience and understanding of the needs of carers and people with dementia.
- Mary Bolger, ASI Home Care coordinator in Kildare and Wicklow, who has day-to-day experience of dementia issues.
- External researcher, Dr Betty Hilliard, who has research and academic experience in the areas of family, fatherhood, relationships. Betty does not have experience in dementia research and has no connection with ASI. Therefore, it is anticipated that she will bring an objective and fresh perspective.

The above members bring a broad range of objective, inclusive and experienced perspectives. Members will be given 10 days to submit feedback on a proposed research project by scoring the project according to numerous criteria, and will then submit the score sheet via email. The reviewer with dementia will have the opportunity to provide feedback via a phone call, in order to make the process facilitative and supportive.

Importantly, researchers will be required to give adequate time, possibly 3 weeks, to the ASI research committee to evaluate proposed projects. Projects that are submitted with unreasonably short notice, such as a few days will not be reviewed or accepted. Relevant stakeholders and researchers involved in dementia research will be notified of this revised process.

### **Copy of ASI Survey for Stakeholders**

ASI is currently re-assessing its research strategy and developing a research strategy plan for the next 3 years. As part of this process, ASI is mapping the dementia research landscape and identifying gaps and potential needs in relation to dementia research. To inform the research strategy, this survey seeks to ascertain the views and perspectives of key stakeholders involved in dementia research in Ireland. ASI appreciates your input and feedback.

#### **Perceptions of ASI**

What do you know about ASI's research activities?

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How would you describe ASI's research role? For example, collaborative, partnership-led, or focused on patient involvement.

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How significant is the role that ASI plays in research?

- Significant    
  Fairly Significant    
  Not very significant

#### **Dementia Research in Ireland**

How would you describe the dementia research landscape in Ireland?

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Who would you identify as the main stakeholders?

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What are the challenges in dementia-related research in Ireland?



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What is going well in relation to dementia research? For example, specific areas that are currently being researched.

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Can you identify gaps in research or issues that require further research?

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**Research Role of ASI**

The ASI is currently re-assessing its research role and strategy. In light of this:

How do you think the ASI could potentially contribute further to dementia research?

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Do you think ASI could play a more significant or different research role?

- Dementia research dissemination forums:  Yes  No  Don't know
- Research participation:  Yes  No  Don't know
- Research collaboration:  Yes  No  Don't know
- Patient Peron Involvement:  Yes  No  Don't know
- Research cure:  Yes  No  Don't know
- Nutrition and dementia:  Yes  No  Don't know
- Other: \_\_\_\_\_

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Do you have any additional comments or suggestions?

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Thank you for taking the time to complete this survey.