ASI Research End of Year Roundup



Dear Colleague,

Welcome to our final newsletter of 2022!

We would like to extend our warmest wishes to those who are celebrating Christmas, Chanukah or Kwanzaa a happy one and those who might celebrate in other ways a joyous one.



Research Roundup

Spring / Summer Highlights

Research Strategy 2022-2024 officially launched: Our 2022-2024 Research Strategy was launched at the start of June and sets out the priorities, objectives and actions that will guide our work over the next two years.

Over the next two years we will:

Support the development of essential research infrastructure in Ireland to assert research readiness and prepare for current and future developments in the field.

Develop and support quality dementia research that is in line with The ASI's mission and values and is important to our communities of people living with dementia, family carers / supporters, staff and branches.



Dementia & Brain Health Briefing in the Dáil: The ASI was involved in a Brain Health and Dementia briefing in the AV Room of Leinster House in March, hosted by The All Party Oireachtas Group on Dementia. We heard from colleagues across the organisation, advocates and clinicians and academics on the importance of brain health.



TeamUp for Dementia Research Turns 1!



Team Up for Dementia Research (TUDR) celebrated its first anniversary on July 12th. TUDR is an Alzheimer Society of Ireland (The ASI) service connecting people with an experience of dementia with opportunities to take part in ethically approved research in Ireland.

In 2022, The ASI was delighted to offer our members more than 25 different opportunities from various institutions and organisations across Ireland.

Anyone who would like to become involved with TUDR can find more information on our website.

Autumn / Winter Highlights

ASI's Pre Budget Submission 2023: The Alzheimer Society of Ireland launched our Pre Budget Submission in July and over the summer into Autumn we were busy continuing to share our message that "Dementia Can't Wait".

One of our asks this year is for €1 million for dementia-specific research funding. As many of us in the research community are aware, dementia research continues to be poorly funded relative to its importance, and the detrimental impact of the disease at both an individual and societal level.



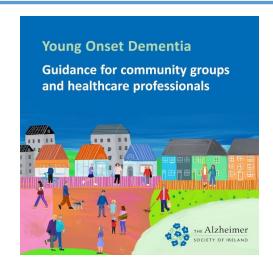
Postgraduate Research Bursaries: We launched our first postgraduate research bursary scheme which sought to support early career researchers with a bursary up to the value of €2500. Thank you to all who submitted applications. We had four successful applicants who will be revealed in January.



Young Onset Dementia Research: In late In September 2022, The ASI published a report and guidance for community groups and healthcare professionals on the topic of young onset dementia.

This work was carried out by a team of researchers (Drs Caroline Kilty, Siobhan Fox and Catriona Curtin) to develop guidelines on how dementia service providers and community groups can support people you younger onset dementia (YOD) living in their communities.

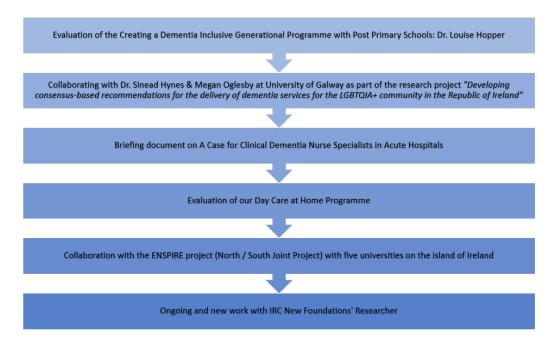
The project was wrapped up in late summer with team presenting their findings to ASI staff in October. Links for this guidance document and report can be found on our website.



Funding & Collaborations

We were delighted to be able to fund a number of projects this year, and continue work in collaboration with researchers on the IRC's New Foundations programme. We partnered with universities and organisations to strengthen the work that we do collectively and produce high quality, dementia research.

A number of these include:



We worked with our Research Review Committee to undertake scoring of some of these applications. We would like to thank both our Professional and Public Reviewers for taking the time this year to support us in this work.

Funding & Collaborations

#TeamASI was busy this year attending Alzheimer's Disease International Conference, Alzheimer Europe Conference and Engaging Dementia Conference in 2022!



We were well represented across the board, from both members of ASI staff, advocates, and members of the Dementia Research Advisory Team.

There were in-person presentations and posters, as well as virtual posters and presentations across all conferences.





And finally...

We would like to wish all our extended research collaborators and partners a very Happy New Year!

We hope to continue to engage and work together in 2023!

ASI Research Newsletter Autumn Edition



Dear Colleague,

Welcome to our Autumn research newsletter!

We've all had the great opportunity to take some leave over the summer but we have been kept busy over the last few months and want to share some of our exciting work and upcoming events with you.

Invitation to Tender (Policy): A Case for Clinical Dementia Nurse Specialists in acute hospitals



The Alzheimer Society of Ireland is seeking tenders from suitably qualified individuals or organisations to create a short briefing document on a Case for Clinical Dementia Nurse Specialists in acute hospitals.

The overall aim is to produce a short briefing document that explores the case for further investment in Clinical Dementia Nurse Specialist roles to provide The ASI with evidence and information to inform future advocacy activities.

Cost: This project has a maximum budget including VAT of €10,000 (Excluding VAT is €7,700).

How to apply: This process will be managed by The ASI's Procurement Team via https://www.etenders.gov.ie/. Any queries should be submitted via etenders.

Deadline: 23rd September 2022

Upcoming Launch of Young Onset Dementia Research

We will soon launch a guidance document which was developed by Dr. Caroline Kilty & Dr. Siobhan Fox and their team in UCC, "Harnessing community information and support for people with young onset dementia and their families: Guidance for community groups and healthcare professionals."

This work was commissioned earlier this year by ASI to develop guidance for dementia service providers and community groups on how to best support people living with young onset dementia.

This guidance document will be officially launched on World Alzheimer Day, September 21st 2022. Keep an eye on our social media channels for publication and a briefing to follow.

ASI's Pre Budget Submission 2023



The Alzheimer Society of Ireland launched our Pre Budget Submission on July 7th and we have been busy over the summer months continuing to share our message that "Dementia Can't Wait" amongst our colleagues, politicians and wider community.

One of our asks this year is for €1 million for dementia-specific research funding. As many of us in the research community are aware, dementia research continues to be poorly funded relative to its importance, and the detrimental impact of the disease at both an individual and societal level.

We wait in anticipation of September 27th for Budget Day.

TeamUp for Dementia Research 1st Birthday Celebration







Team Up for Dementia Research (TUDR) celebrated its first anniversary on July 12th. TUDR is an Alzheimer Society of Ireland (The ASI) service connecting people with an experience of dementia with opportunities to take part in ethically approved research in Ireland. TUDR supports the research community in reaching prospective research participants that they might not be able to access otherwise. It is managed by The Alzheimer Society of Ireland in collaboration with Dementia Research Network Ireland.

We shared some lovely stories and videos across our social media channels in July about how the TUDR service has helped so many, including Agnes.

"I would encourage everybody to join TeamUp for Dementia Research! It's fun! It's not all serious, there's lots of learning but there's so much fun in it aswell! And the fact that you know your voice is being heard is so important!" Agnes, a TeamUp member.

Make sure to check out our social media channels and our research blog to stay up to date with up and coming events. Here is just a summary of some of the things we are looking forward to over the Autumn into early Winter.

- ASI Memory Walk: 18th September
- World Alzheimer's Day: 21st September
- **Budget Day:** 27th September
- <u>Dementia Trials Ireland Ireland Event</u>: 27th September
- National PPI Festival Launch: 10th October
- Alzheimer Europe Conference: 17-19th October
- Engaging Dementia Research Conference: 15th -16th November

Continue to check out our regularly updated research blog HERE.

We now also have a Plain Language Summaries section to our website HERE.

ASI Summer Research Update



Dear Colleague,

Welcome to our summer research newsletter!

We have been kept extremely busy over the last few months but want to share some of our exciting work and upcoming events with you.



The Alzheimer Society of Ireland's Research Strategy (2022-2024) officially launched



Click **HERE** to read our Research Strategy.

Our 2022-2024 Research Strategy was launched at the start of June and sets out the priorities, objectives and actions that will guide our work over the next two years. It is a result of almost 300 consultations with ASI Staff, volunteers, people with dementia, family carers/supporters, and the research and clinical communities.

Over the next two years we will:

- Support the development of essential research infrastructure in Ireland to assert research readiness and prepare for current and future developments in the field.
- Develop and support quality dementia research that is in line with The ASI's mission and values and is important to our communities of people living with dementia, family carers / supporters, staff and branches.
- Translate and disseminate evidence-based research to promote public awareness of dementia research.

Alzheimer's Disease International Conference 2022



#TeamASI were a force to be reckoned with in London this June!

We were delighted to attend the ADI Conference in London which took place June 9th -11th.

The Alzheimer Society of Ireland was well represented, supported by our Interim Advocacy, Research and Public Affairs Interim Manager Cormac Cahill, Advocacy Manager Clodagh Whelan and Interim Research & Policy Manager Dr. Laura O'Philbin (not pictured here).

You can read about what we got up to at ADI below as part of our latest research blog.





Dr. Sinéad Hynes & Megan Oglesby from NUI Galway recently gave staff at The Alzheimer Society of Ireland a wonderful presentation on their work "Developing consensus-based recommendations for the delivery of dementia services for the LGBTQIA+ community in the Republic of Ireland".

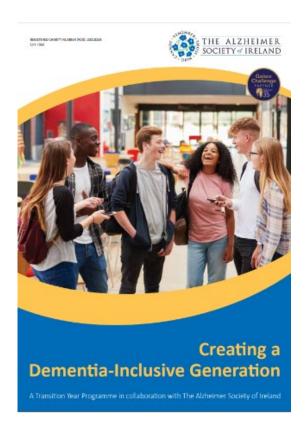
This research identifies the future needs that older LGTBQIA+ people and their care partners living in Ireland have in relation to dementia care service delivery, and 2) develops consensus-based recommendations for dementia service provision in Ireland. You can read the full article by clicking the button below.

This research is extremely timely and has been showcased as part of RTE's Brainstorm. You can read below the 5 things older LGBT+ people need you to know.

Read 5 things old LGBT+ people need you to know HERE.

Read the full article HERE.

Closed Invitations



Thank you to those who expressed an interest in our e-tender to conduct an evaluation of the Creating a Dementia Inclusive Generation Programme.

We are in the process of evaluating applications with the hope for this evaluation to take place starting September 2022.



Thank you to everyone who contacted us also regarding the Irish Research Council's New Foundations Scheme for 2023.

We had a lot of inquiries and unfortunately were unable to endorse all applications. We hope that you think of us as a potential partner for next years' application.

Up and coming events...





TeamUp for Dementia Turns 1!

July 12th sees the TeamUp for Dementia Research service turn one year old.

We've been quite busy the last year. We have 170 members engaged with the service with more than 20 projects currently being offered to members.

TeamUp for Dementia Research is a service where people living with dementia and their families can register their interest in participating in dementia research. It connects people living with dementia and their carers/supports with researchers like you who are conducting studies in the area of dementia (e.g. prevention, diagnosis, treatment, care, cure).

We have some exciting things planned for this 1st birthday so keep an eye on our social media channels!

The Alzheimer Society of Ireland's Pre-Budget Submission Launch Event



We will officially launch our Pre-Budget Submission on July 7th. This submission has been informed by consultations with different stakeholder groups and highlights our growing need for continued investment across several areas from the Government.

One of our asks this year is for €1 million euro for dementia-specific research funding. As many of the research community are aware, dementia research continues to be poorly funded relative to its importance, and the detrimental impact of the disease at both an individual and societal level.

Stay up to date with our Pre-Budget Submission Asks on July 7th through our social media!

Make sure to check out our social media channels and our research blog to stay up to date with up and coming events. Here is just a summary of some of the things we are looking forward to over the summer into the early Autumn.

Carers Week: 13-19th June 2022

Engaging Dementia Research Conference: 4-6th October

Alzheimer Europe Conference: 17-19th October

Continue to check out our regularly updated research blog HERE.

ASI Research Newsletter

Spring 2021







Dear Alzheimers,

Welcome to our Spring Newsletter of 2022!

We at the Research & Policy team have been busy since January planning for our new Research Strategy that will be published in the very near future.

Check out what else we have been up to below and some upcoming events.

National Brain Health Awareness Week 14-20th March



March 14-20th marks National Brain Health Awareness Week 2022. The theme for this year is "Together We Are Stronger: Promoting the Value of Teams, Partnerships and Collaborations in Neurological Care and Research". The ASI is a proud brain partner with the Neurological Alliance of Ireland.

In conjunction with many of the national events taking place across the country, there will be a debate on brain health in the Seanad on March 9th.

You can watch the debate on Oireachtas tv online or here (time TBC) on March 9th. We will be sharing more details about the event on our social media in the coming days.

Dementia & Brain Health Briefing March 8th

The ASI is attending a Brain Health and Dementia Briefing hosted by The All Party Oireachtas Group on Dementia ahead of this debate in the Seanad. The Research Team has been working with our colleagues in Advocacy on this highly anticipated event.

Speakers at this briefing will include:

- Senator Fiona O'Loughlin (Chair of the APOGD)
- Prof Iracema Leroi (GBHI)
- Prof Mary McCarron (TCD)
- Kevin Quaid (Chair IDWG)
- Prof Sean Kennelly (TCD/TUH)
- Samantha Taylor (ASI)

Also you can encourage your local representative to attend by filling in a form here. This event will inform our public representatives about Brain Health and outline how policy makers and experts can work together to spread awareness.

New Research Blog!



The Research Team has been hard at work in the new year developing a Research Blog.

This blog will highlight some of our members' experiences, recognise some of the work being done by Early Career and Established Researchers, with some research specific topics too. We will dive into hot topics, shining a light on upcoming research and addressing some of the challenges and pitfalls in research.

Our first blog highlights Brenda, a member of the Dementia Research Advisory Team member and the reasons why she joined the team. You can read it here.

Upcoming Events

TeamUp for Dementia Research's 1st Birthday





In collaboration with the DRNI, The ASI launched its service, TeamUp for Dementia Research, in July 2021. TeamUp for Dementia Research connects people living with dementia and their families with researchers who are conducting studies in the area of dementia (e.g. prevention, diagnosis, treatment, care, cure).

TeamUp for Dementia Research is a service that streamlines this recruitment process, saving you as Researchers, money and valuable time. We can offer your projects to our diverse pool of participants and match you with relevant TeamUp members. By working together, we can help improve the overall quality of dementia research in Ireland.

Hear from Aishling Flynn, a researcher who has used the TeamUp for Dementia Research Service here.

We will celebrate one year of TeamUp for Dementia Research this July - watch this space!

If you would like to learn more please visit teamupfordementia.ie or contact Cíara at teamup@alzheimer.ie.

DRNI & 'Hot Topics in Dementia Research'



Dementia Research Network Ireland (DRNI) are currently hosting a webinar series on 'Hot Topics in Dementia Research'. Details of upcoming webinars in the series include:

- Parkinson's Disease Dementia (Wednesday 23rd March 11-12pm)
- Female Sex as a Risk Factor for Dementia (Monday 25th April 11-12pm)
- TeamUp For Dementia Research (May 2022 date TBC)

For more details and to register for these free webinars, click here.

To watch back previous webinars, visit the DRNI YouTube channel <u>here</u>.

Copies of speaker presentations from the series can be found on the DRNI website here.

PPI Ignite Network Events



March 10th at 1pm: Webinar - Let patients be your guide: optimizing trial design with participant input be-

fore, during, and after your study

Hosts: Dr. Paul Wicks & Dr. Noah Goodson

Click <u>here</u> to register for this event.

March 11th at 11am: PPI Workshop - Collaborative data

analysis & interpretation

Facilitators: Prof Anne MacFarlane & Prof Ailish Hannigan

Click <u>here</u> to register for the event.

Irish Research Council: New Foundations Scheme



We have been lucky over the last few years to collaborate and support a number of researchers under the New Foundations Scheme.

We will soon be looking for new research partners for this scheme so watch this space!

For more information on the New Foundations Scheme, please click here.

And last, but certainly not means least, we would like to thank everyone who took the time to contribute to our Research Strategy Development survey and follow-up consultations.

We will publish our Research Strategy in the coming weeks which will be available on our website.