



Dear Colleague,

We are delighted to welcome you along to the winter edition of your ASI Research Newsletter. Below you will find information relating to our research activities in 2021 as well as updates on the work of our Dementia Research Advisory Team and The ASI's newest service - TeamUp for Dementia Research.

Dementia Research Advisory Team Christmas Catch-up



The members of our **Dementia Research Advisory Team** met for their 2nd annual virtual Christmas catch-up earlier this month. We discussed the ample work the team has accomplished throughout the year despite lockdowns and restrictions and began to put our plans in place for 2022.

The Dementia Research Advisory Team is a group of people living with dementia and carers/supporters who are involved in dementia research as co-researchers. Throughout 2021 the members used their insights and expertise to collaborate on **7 ongoing projects** across a variety of universities, they **spoke at conferences** both nationally and internationally, they **reviewed tender documents and funding applications** and even welcomed **4 new members** to the team.

If you are a person living with dementia or a family carer / supporter who has a passion for having their voice heard in research and would like to join the **Dementia Research Advisory Team**, please get in touch with **Cíara** on **085 8709671** or email ciara.oreilly@alzheimer.ie.

Information for potential members is also available [here](#). We welcome members from all communities and there is no experience necessary.

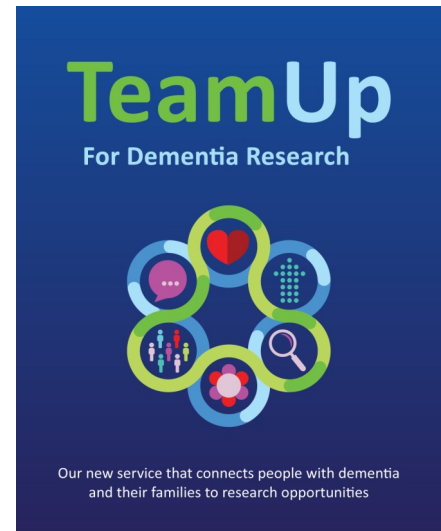
TeamUp for Dementia Research

Launched in July 2021, **TeamUp for Dementia Research** is The ASI's newest service. It connects people living with dementia, care givers and family members with researchers conducting studies across all areas of dementia.

A clear passion for dementia research is reflected not only in the number of people signing up to the service but also in the variety of projects offered to the TeamUp members. We have been delighted to bring 12 different research studies from a host of institutions nationwide to our TeamUp members. Some of these included:

- an online survey looking at the future care needs of older LGBTQI+ adults
- focus groups relating to Young Onset Dementia
- interviews relating to Pet Robots
- data collection in relation to stroke healthcare and dementia in Ireland

We look forward to ongoing success as we continue to grow this important service in 2022!



If you are not already signed up and would like to get some further information, please contact Cíara at teamup@alzheimer.ie or click [here](#) to sign up.

Working with the Dementia Research Advisory Group - Researcher Perspective

Study: Exploring autonomy from the perspectives of people with dementia

"I feel strongly that involving people living with dementia and their families as contributors in the research process, adds to the richness, strength and relevancy of the study.

As a novice researcher I was unsure how to make this happen but speaking to Cíara and Laura from the Dementia Research Advisory Team helped signpost me as to the next steps. I completed the application form and was introduced to the team who had kindly agreed to collaborate with me on the study.

I felt a mixture of nervousness and excitement at our first meeting but the team were so supportive that I quickly forgot about the nerves and we all got to work. The team were so insightful, adding comments and discussing changes that would support the participants to engage more fully and meaningfully in the study, ensuring their voices are heard. I am so grateful for the teams input and look forward with excitement to us working together in the future as the study progresses."



Susan O'Reilly

Advanced Nurse Practitioner- Memory Clinic, Connolly Hospital
PHD student in DCU

International Research News - Aducanumab

Today, the European Medicines Agency (EMA) decided not to authorise a new treatment called aducanumab for Alzheimer's Disease.

This decision would have been closely watched by the European dementia community and a lot of people living with Alzheimer's and their families will be disappointed by this news.

Granted conditional approval in the United States, the medicine will continue to be administered there.

It is important to note that there are other medications currently being tested for Alzheimer's disease and further information is available [here](#).

More information on the aducanumab decision is available [here](#).

Research Strategy Development

Thank you to everyone who took time to share their invaluable insights to The ASI's recent review of its research strategy. We look forward to bringing you the results in 2022.

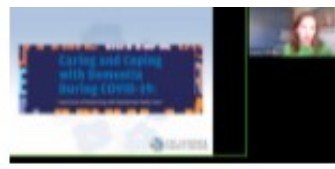
31st Alzheimer Europe Conference



The 31st Alzheimer Europe Conference was held from the 29th November to the 1st December. The theme of the conference this year was "Resilience in dementia: Moving beyond the COVID-19 pandemic."

CEO Pat O'Loughlin spoke on lessons learned from the Covid-19 pandemic, Dementia Research Advisory Team member & author **Kevin Quaid** gave a powerful and much lauded keynote address, Interim Research and Policy Manager **Dr. Laura O'Philbin** presented the findings of our [A Year of Caring & Coping with Dementia in COVID-19](#) Report and Research Project Officer **Cíara O'Reilly** presented on her Masters project in the Intergenerational Dementia Care section.

With over 600 attendees from 38 countries, The Alzheimer Society of Ireland was certainly well represented at the online event.





Thanks for helping us to support people living with dementia, their family carers and supporters in 2021.

Painting by Marguerite Keating, Member of our Irish Dementia Working Group (IDWG)



THE ALZHEIMER SOCIETY of IRELAND



1800 341 341

For anyone needing support during the festive period please reach out to our National Helpline.



Dear Colleague,

Welcome to the Autumn edition of your ASI Research Newsletter. Below you will find information relating to our new Research Team, an update on our Dementia Research Advisory Team, an overview of the launch of our new TeamUp for Dementia Research service and some highlights of upcoming events.

Meet the Research Team



Dr. Laura O'Philbin

Interim Research & Policy Manager

Laura has a PhD from the Dementia Services Development Centre Wales and brings her distinguished experience to leading the new Research & Policy team at the Alzheimer Society of Ireland.

She can be contacted [here](#)

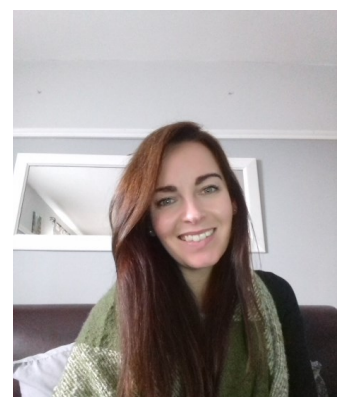


Dr. Diane O'Doherty

Research Officer

Diane is responsible for supporting internal and external research and policy activities. She has a PhD in the area of public health and has engaged with health research over the last several years.

She can be contacted [here](#)



Cíara O'Reilly

Research Project Officer

Cíara will be working closely with the members of the Dementia Research Advisory Team. She will also be the point of contact for all queries relating to our new TeamUp for Dementia Research service.

She can be contacted [here](#)

TeamUp for Dementia Research

Launched in July 2021, TeamUp for Dementia Research is a new service connecting people with an experience of dementia with research opportunities in the dementia field.

We have been delighted to support projects relating to Pet Robots, Young Onset Dementia, Virtual Reality technology and future care needs for older LGBTQI+ adults.

If you are not already signed up and would like to get some further information, please contact Cíara at teamup@alzheimer.ie or click on the sign up button [here](#).



A Word from our Dementia Research Advisory Team Members



We were delighted to meet with the members of our [Dementia Research Advisory Team](#) and present them with the exciting new engagement opportunities available to them. From reviewing research applications to writing Blog posts to Running their own Research Project, it will be a busy few months!

The Dementia Research Advisory Team is a group of people living with dementia and carers/supporters who are involved in dementia-research as co-researchers. These Experts by Experience influence, advise, and work with researchers across Ireland.

If you are a person living with dementia or a family carer / supporter who would like to learn more about joining the Dementia Research Advisory Team, please get in touch with Cíara on 085 8709671 or email ciara.oreilly@alzheimer.ie

Upcoming events

The Alzheimer Society of Ireland is delighted to announce that Interim Research and Policy Manager **Dr. Laura O'Phibin** will be presenting at the 31st Annual Conference of Alzheimer Europe in November. She will be speaking on the powerful findings of our **A Year of Caring & Coping with Dementia in COVID-19** Report.



Dementia Research Advisory Team member and author **Kevin Quaid** will also be one of the Key Note Speakers at the conference. What an amazing achievement, well done Kevin!

ASI Research Roundup

May 2021



THE ALZHEIMER
SOCIETY *of* IRELAND

Dear Colleague,

Welcome to the second Research Roundup of 2021. We are excited to tell you about a new research initiative coming to The Alzheimer Society of Ireland - TeamUp For Dementia Research.

Register for TeamUp For Dementia Research

TeamUp For Dementia Research is a brand new service from The ASI Research Team that will help people living with dementia and their families find and take part in dementia-related research projects across Ireland.

Research is essential to help understand what causes dementia, develop effective treatments, improve care, create new interventions and even one day find a cure.

The goals of TeamUp For Dementia Research are:

- To make research participation is more accessible to people living with dementia and their families.
- To improve dementia research in Ireland.
- To ensure that people living with dementia and their families have their voices heard in research.

If you wish to learn more about TeamUp For Dementia Research visit www.teamupfordementia.ie



Click [HERE](#) to register

Benefits of Taking Part in Research

Taking part in research not only helps others, but it can have benefits for you too. Many people find being involved in research a rewarding and enjoyable experience that is of benefit to them. By signing up to TeamUp For Dementia Research, you increase your chances of taking part in ethically approved dementia research that may benefit you and others in the future.



The Alzheimer Society of Ireland Supporting Research

Last year, The ASI endorsed three applications for the Irish Research Council's New Foundations Scheme. We were delighted that all applicants were successful and look forward to working on these important projects. Congratulations to all.

Dr Sinéad Hynes (NUIG) and Daithi C from the Dementia Research Advisory Team were awarded €12,000 for her project focused on diversifying dementia service delivery in Ireland. A key outcome of this project will be the development of recommendations for the future needs of older LGBTQI+ adults with dementia.

Dr Orla Dolan (NUIG) was awarded €12,000 to evaluate the outcomes of Virtual Cognitive Stimulation Therapy in clinical settings in Ireland.

Prof Iracema Leroi (TCD) was also awarded €12,000 to investigate COVID19-related loneliness and social isolation in carers of people with brain health challenges in Ireland. This project will be completed in partnership with Family Carers Ireland.



Dr Sinead Hynes NUIG



Mr Daithi C PPI Contributor



Dr Orla Dolan NUIG



Prof Iracema Leroi TCD



Maynooth University and the Alzheimer Society of Ireland need your help!

In Ireland, many people with dementia move to nursing home care. This is a significant event for both the person with dementia and their partner. If you are the partner of someone who has moved into a nursing home, we would like to talk to you about your experiences. We want to understand how the move may have impacted you at the time and over subsequent months. By understanding this experience, we hope to identify ways that people can be supported, particularly with regard to the loneliness that this move may bring.

If you:

- have had a spouse or partner with dementia move to a nursing home in the past 1-5 years,
- are willing to chat to us (via videoconferencing, or on the phone) about your experiences, particularly when it comes to loneliness,

Please either email us at:

eimile.holton@mu.ie

Or call/text Eimile at: 089 412 4099



Dear Colleague,

Welcome to the first Research Roundup of 2021. We will bring you some research updates and news throughout the year. Stay tuned for some exciting projects.

If you have any suggestions or anything you would like to hear please contact research@alzheimer.ie

The Alzheimer Society of Ireland Supporting Research

We would like to congratulate Professor Mary McCarron from Trinity College Dublin and her colleagues on being awarded €160,000 to develop best practice guidelines for post- diagnostic dementia supports for people with an intellectual disability in Ireland.

This project will be funded by the Health Research Board and The Alzheimer Society of Ireland.



Prof Mary McCarron

People with an Intellectual Disability are at greater risk of developing dementia than the general population. In particular, those with Down syndrome are the world's largest group with a genetic risk for Alzheimer's disease.

Prof McCarron and her colleagues will work with researchers, clinicians, services and people with Intellectual Disabilities to provide recommendations and guidelines on how best to provide post-diagnostic dementia supports to people with an Intellectual Disability and their families.



Your Voice Matters

We are inviting people living with dementia and family carers/supporters to take part in a five minute survey about your experiences during COVID19. It has been with us for almost one year and this research is part of our work in exploring the experiences of people living with dementia and their families during this pandemic.

If you are a family carer / supporter click [here](#).

If you are living with dementia click [here](#).

We will use these findings to publish a report and draw attention to experiences of people living with dementia and their families. We want your voices to be heard. Your input is very important because it tells us about the needs of people affected by dementia and how they can be better met.

YOUR
VOICE
MATTERS



New Irish Research

Priorities for Psychosocial Supports and Services among family carers of people with dementia

Dementia care relies heavily on family members or friends who often struggle with their own health and wellbeing.

Aine Teahan and her colleagues spoke to family carers in Dublin, Galway and Kerry to find out about their personal and social challenges and needs.



Top Rated Personal Supports (Desired)

- Day Care
- Family Care and Support Group
- Short break respite
- Long break respite
- Social activities

For more news, please click [here](#).

Research News

Biogen and Alzheimer's drug: Aducanumab

On July 8th 2020, Biogen announced that it has submitted an application to the FDA (Food & Drug Administration) for a new drug (aducanumab) as a treatment for Alzheimer's disease. The FDA has agreed to review the application and a decision is expected by June 2021.

It takes several years for drugs to get to this approval stage. If approved and effective, aducanumab could be the first treatment with the potential to meaningfully change the course of Alzheimer's disease.

However, there has been some controversy around this drug. The FDA is reviewing the application and will only approve the drug if they feel it will be safe and effective. Click [here](#) to read more for the full story



The INTenSE Project

Dr Louise Hopper from Dublin City University is looking for any of the below people to take part in her latest research project.

- People living with dementia
- Family carers or supporters who have completed some kind of dementia-related training or education
- Health and social care professionals who support people living with dementia

If you wish to learn more about taking part in this research please contact Louise at louise.hopper@dcu.ie

The INTenSE Project

Aimed at improving dementia care by building **self-experience** of dementia into carer training

We want to capture your experience in **imagining** what it is like to live with dementia

This study will support **dementia training & education** strategies across Europe

Participation will involve **small discussion groups** or **one-to-one interview** if you prefer

Please contact Dr Louise Hopper by email at louise.hopper@dcu.ie

DCU
DUBLIN CITY UNIVERSITY

Funded by the Erasmus+ Programme of the European Union