



Dear Colleague,

September is World Alzheimer's Month making it the perfect time to welcome you along to the Autumn edition of your Alzheimer Society of Ireland Research Newsletter. Below you will find updates about developments within The ASI's research team, information relating to the recent celebration of TeamUp for Dementia Research's first birthday and some exciting new projects for the members of the Dementia Research Advisory Team. Pop on the kettle and enjoy the catch-up!

### The Dementia Research Advisory Team

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. Ensuring the lived experience of dementia is at the heart of dementia research the members influence, advise, and work with researchers across Ireland. This is known as Person Public Involvement or PPI.

The members are currently supporting 15 different research projects. They have worked with researchers to devise survey questions, develop research materials for potential participants and shared insights into the practicalities of moving a research project off the page and actually engaging with people affected by dementia.

Over the course of the coming months we look forward to the members sharing their PPI experience with audiences in UCD, Trinity and Maynooth.

To learn more about the Dementia Research Advisory Team visit <https://alzheimer.ie/creating-change/research/ppi/>.



## PPI Song Writing Workshop

In the famous words of Hans Christian Anderson; "where words fail, music speaks". Dementia Research Advisory Team members Gerry, Helen & Kevin have been involved as PPI contributors in Lisa Kelly's PhD research since October 2020. This research, supervised by Prof Hilary Moss & Prof Ita Richardson, aims to explore how telehealth music therapy may support community dwelling people with dementia and their families, particularly those who live in rural or isolated areas.

Gerry, Helen & Kevin alongside their partners and supporters Nuala, Carmel & Helena recently attended a song-writing workshop at the Irish World Academy of Music & Dance at the University of Limerick. The workshop was facilitated by established songwriter, Carl Corcoran, and co-facilitated by the lead researcher on this project, Lisa Kelly.

Lisa says "Thanks to a PhD student bursary from PPI Ignite @UL, we were able to meet in person for the first time, after having Zoom meetings for the last two years. Safe to say plenty of craic was had!"

The songwriting workshop aimed to capture the importance of PPI in dementia research in a creative, non-traditional way. The song is entitled 'Who Will We Tell'. It is hoped that once further funding is secured, the song will be professionally recorded and disseminated to the public. We can't wait to hear it!



## TeamUp for Dementia Research

On July 12th we celebrated **TeamUp for Dementia Research's** official 1st birthday!

The service has grown tremendously in the past year and we look forward to continuing to offer the members unique and exciting opportunities to engage in dementia research.

Many thanks to all of the members for their ongoing commitment to improving dementia research in Ireland.

Thank you to the many TeamUp for Dementia Research members who took the time to share their insights into the service and taking part in dementia research. We look forward to sharing further videos with you soon. You can watch some of these videos on The ASI's YouTube channel.

## News and Upcoming Events

### 32<sup>nd</sup> Alzheimer Europe Conference

Building bridges #32AEC



The Alzheimer Society of Ireland is proud to have been awarded eight presentations at the upcoming Alzheimer Europe Conference.

Bringing together members of the dementia community (people living with dementia, family carers, health and social care professionals, researchers & policy makers) from all over Europe and beyond.

The ASI will proudly support members of the Dementia Research Advisory Team to share their experiences of Running their own Research Project with their international colleagues.

**RESEARCH STUDY  
YOUNG ONSET  
DEMENTIA**

Are you living with a diagnosis of young onset dementia?  
We would love to hear from you.

We are conducting a study exploring the experiences of young onset dementia in Ireland. We aim to gather information on experiences of using community services, and suggestions for development of further community supports.

We are holding a series of focus groups with people living with younger onset dementia, and care partners.

Focus groups should last approx. one hour and will be held online. All information provided will be kept anonymous and confidential.

If you are interested, please contact Caroline to express your interest and to hear more about the study.

The Alzheimer Society of Ireland recently commissioned the development of specific guidance on how Dementia Service Providers and Community Groups can support people with Young Onset Dementia living in their communities through devising new services or adapting existing services.

With insights from an expert advisory panel and feedback from people affected by Young Onset Dementia we look forward to launching the results of this important work on Wednesday 21st September, World Alzheimer's Day.

To stay up to date with ongoing developments in the dementia research community please make sure to follow The Alzheimer Society of Ireland on their social media channels below or [click here to read our Research Blog](#).