THE Alzheimer
SOCIETY OF IRELAND

RUNNING OUR OWN RESEARCH PROJECT

Project Report

THE DEMENTIA RESEARCH ADVISORY TEAM

Foreword

The publication of this report represents a significant leap forward in the work of the Dementia Research Advisory Team (DRAT). By leading their own research project, DRAT members have demonstrated the power of PPI-led research to explore meaningful topics with the potential to yield real, tangible outcomes. This project exemplifies how solutions led by those most affected by dementia can improve quality of life, care, and policy.

The Alzheimer Society of Ireland (ASI) is committed to advancing PPI through the DRAT, ensuring that dementia research in Ireland is relevant, engaging, and impactful for people living with dementia and their caregivers. This is a key objective of The ASI's Research Strategy and central to this mission is the provision of authentic leadership opportunities for PPI Contributors, supporting them to lead and shape research that directly addresses their needs and experiences.

When I joined The ASI in 2019, one of my first responsibilities was to set up The ASI's Research Public and Patient Involvement (PPI) initiative. The ASI, as a grassroots organisation, has always been deeply rooted in the lived experience of dementia, and advocacy groups like the Irish Dementia Working Group (IDWG) and Dementia Carers Campaign Network (DCCN) have consistently shaped and strengthened its work. Recognising the importance of formalising The ASI's commitment to PPI in research, the DRAT was established. This new endeavour built on the strong foundation laid by the IDWG and DCCN, creating a structured platform for people affected by dementia to influence research in a PPI capacity.

Since then, it has been truly inspiring to watch the DRAT grow from strength to strength. The groups progress is a testament to the dedication, patience, trust, creativity, and unwavering commitment of the members, both past and present. This achievement is also a tribute to the exceptional guidance and work of ASI Research Project Officer, Cíara O'Reilly, over the past three years.

My sincere congratulations to every member of the DRAT for this remarkable achievement. I look forward to witnessing the continued evolution of the group's work and the wonderful achievements of its members.

Laura O'Philbin

Dr. Laura O'Philbin, Research & Policy Manager
The Alzheimer Society of Ireland

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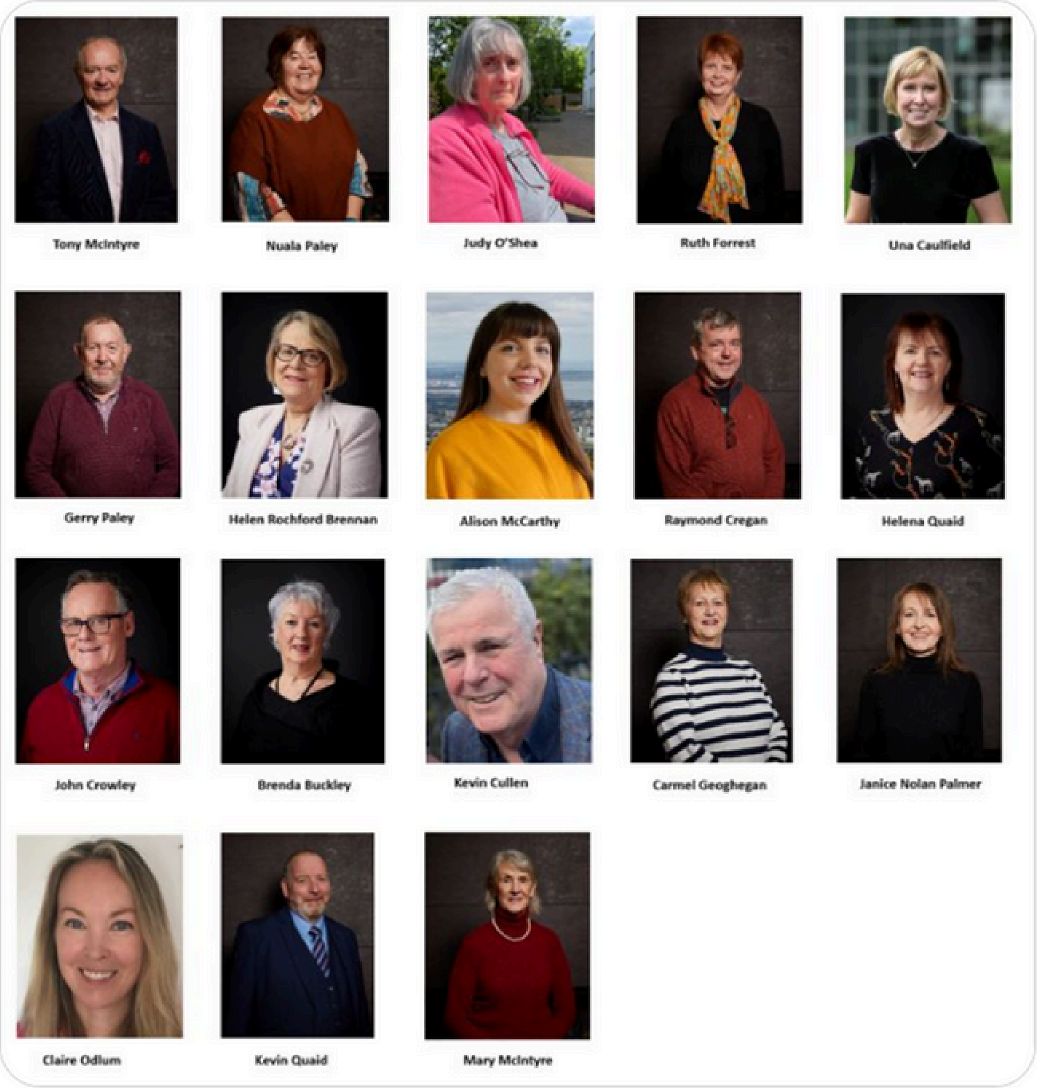
Who are the Dementia Research Team?

The Dementia Research Advisory Team (DRAT) is a group of people living with dementia and family carers / supporters who draw on their personal expertise as people affected by dementia to work alongside members of the research community as co-researchers and collaborators. Established in 2019 with just 11 individuals, the team now boasts 20 members, each bringing invaluable insights shaped by their own experiences of dementia.

The members of the DRAT contribute to dementia research in a Person Public Involvement (PPI) capacity. At its core, the purpose of their work is to enshrine the lived experience of dementia throughout the research process. This is evidenced through active and meaningful collaboration with the research community; from devising research questions to presenting findings at conferences.

The Dementia Research Advisory Team is supported by The Alzheimer Society of Ireland (ASI) who ensures that the ethos of PPI is integrated into all research activities. The ASI empowers the members with tailored training opportunities, enabling them to shape ASI's Research Strategy, contribute to funding decisions, and influence impactful research outcomes.



Running Our Own Research Project

Background to the project

The Dementia Research Advisory Team (DRAT) have collaborated on a great variety of projects with external research professionals. In addition to their lived experience, members have developed skills to support their work in the dementia research space. In a unique undertaking, the members decided to pool their knowledge and research skills to demonstrate the benefits of PPI-led research and undertake a new challenge; running their own research project. By maintaining complete ownership of the project throughout all stages, this novel work ensured the research outcomes would be meaningful to the members of the DRAT and additionally, could be impactful to all people affected by dementia and the research community.

How the Dementia Research Advisory Team Ran their Own Research Project

To ensure the work carried out was informed and impactful, the DRAT members undertook the below steps:

Step 1. Learning from the experts

Members of the DRAT sought out the advice of their UK counterparts, the Dementia Enquirers, to learn about their experience of PPI-led research. The Dementia Enquirers programme has supported over 20 groups of people living with dementia to conduct their own small-scale research projects.

Through an engaging and informative online meeting, the Dementia Enquirers shared their insights and advice, highlighting a number of key points which they felt were fundamental to the success of their work. These included drawing on the strengths and abilities of the members when dividing tasks and breaking down each element of the project into small, manageable pieces.

Step 2. Selecting a research topic

Members of the DRAT took a democratic approach in deciding their research area. Each member was invited to suggest research topics for this initiative, with a vote to determine the outcome. Ultimately, both the members living with dementia and the family caregivers chose to investigate *The Impact on the Carer: How a diagnosis of dementia changes the life not just of the person receiving it but their family members or carers also.*

Step 3. Hiring staff

To support the academic element of the project, the DRAT members hired a Research Assistant (RA). A key role of the RA was to conduct a literature review on the members' chosen topic to provide a complete background to the topic and support the relevancy and credibility of the project. This information was presented to the members and used to inform the project.

Step 4. Deciding on methodology

Following in-depth discussions on the merits of various data collection methods, the DRAT deliberated on what was achievable with their collective skills. The members were keen to ensure that people living with dementia and family caregivers had the same opportunity to participate in this research and felt a mixed methods approach of focus groups, surveys and interviews would offer the most accessibility.

Step 5. Upskilling

An ongoing commitment from The ASI to the DRAT is to provide training and development suited to the needs of the members. These training opportunities arm members with research-related skills useful in their work as PPI Contributors. Bespoke facilitation training was provided by Michael Foley (PPI Ignite Network) and supported by The ASI to empower the members to sensitively gather insights from focus group participants. This training highlighted topics such as

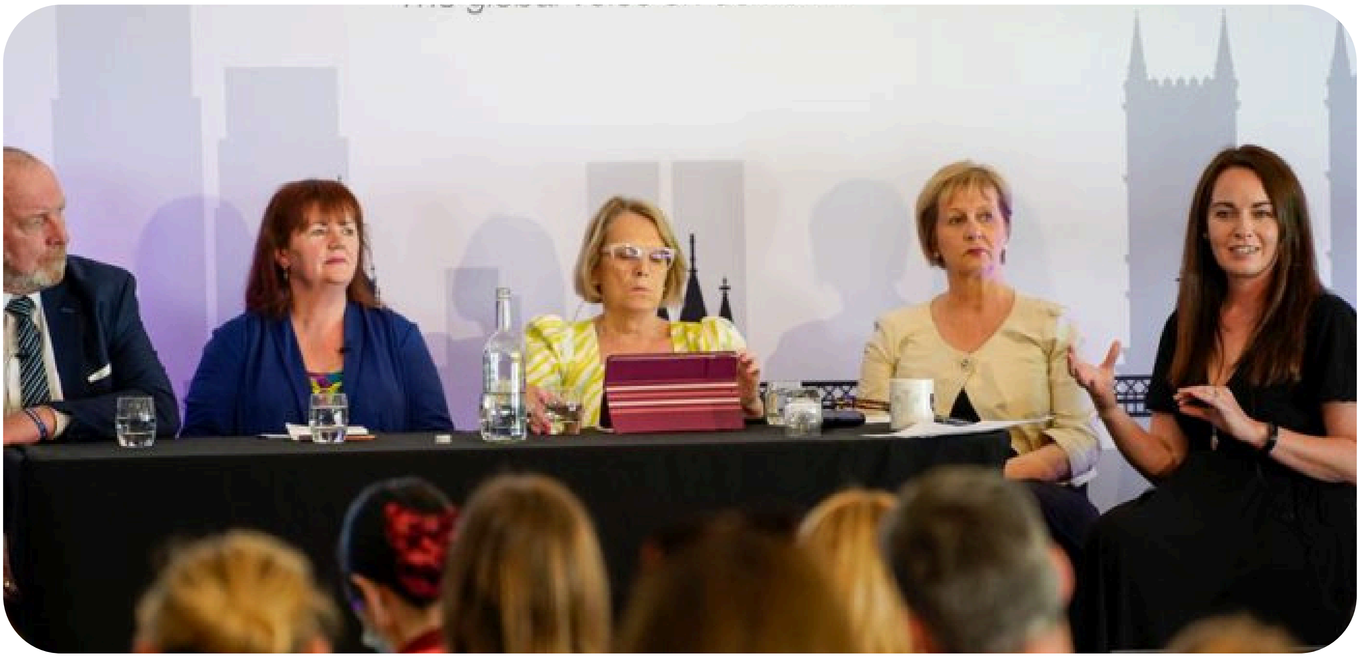
- the importance of active listening, reframing and reflection to demonstrate understanding.
- overcoming potential issues such as ensuring each participant has an opportunity to contribute to the conversation.

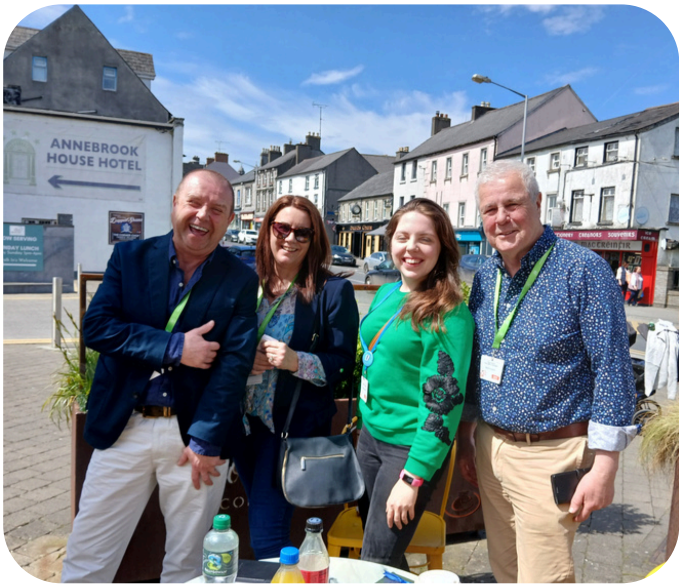
Step 6: Undertaking data collection & analysis

The members of the DRAT collaborated to create focus group and survey questions which would explore the experience of dementia. Focus groups were facilitated by members of the DRAT with the support of The ASI Research Team. Surveys were distributed via The ASI's research participation service, TeamUp for Dementia Research. Data analysis was undertaken by the Research Assistant, and supported and verified by members of the DRAT.

Step 7: Reporting the findings

This brief project report was prepared to highlight the process of PPI-led research. Key findings were drawn from the data analysis and used to create a set of recommendations for Medical Practitioners when disclosing a dementia diagnosis. The practical work of the project and its outputs have been presented at a variety of national and international research conferences and events.




ANNEBROOK HOUSE HOTEL

The Research Cycle

Introduction and literature review

The aim of this project was to design and develop a research study which explored the impact that a diagnosis of dementia has on the person who becomes the carer. A review of existing research and literature was carried out to gain a broad understanding of the role of caring for and supporting a person living with dementia. This was examined considering the following subheadings and is summarised below:

Diagnosis

- Delivery of diagnosis
- Knowledge and information
- Emotional response

Transition Needs

- Emotional / psychological support
- Changes in relationship and responsibilities

Interventions

- Supporting transition into caregiver role
- Support with care planning

Summary of Literature Review Findings

Studies in this area highlight motivations for caring (including feelings of love or reciprocity, spiritual fulfilment, a sense of responsibility), personal experiences (both positive and negative), the impact of caring on health, social isolation, and the transition many carers experience in moving from a family member to a carer. The review indicated the challenge carers often experience with juggling multiple caring roles, such as caring for a loved one with dementia and raising children, and maintaining careers. Finally, the review looked at the impact of receiving a dementia diagnosis on carers and the supports necessary to sustain them at this time; these included peer support, access to resources and assistance with future care planning.

Data Collection

Offering potential research participants a selection of ways to be involved in this project was important to the DRAT members. They recognised the potential benefits of interactive discussions through focus groups, and that insights shared more privately through anonymous online surveys would be important too. They worked together to devise these questions and produced a recruitment poster and topic guide. This included the participants' experience of dementia and caregiving, questions relating to diagnosis, relationships and carer supports.

Participant Recruitment

Participants were recruited through The ASI's TeamUp for Dementia Research service.

Data Collection

Data were collected in the following ways:

1. Two online focus groups with carers and supporters of people living with dementia (n=7)
2. One online interview with one person living with dementia (n=1)
3. Online survey for people living with dementia and for carers and supporters of people living with dementia (n=65)

Focus groups were facilitated by members of the Dementia Research Advisory Team alongside a member of The ASI's Research Team.

Findings and Discussion

Participants were generous in sharing their experience of dementia and caregiving, with responses echoing the literature findings across several key themes which are summarised briefly below;

1) The experience of diagnosis
2) Changes to relationships
3) The responsibilities and challenges of caring
4) Supports and resources

The experience of diagnosis

Participants described various experiences regarding the delivery of dementia diagnoses, including being present with their loved one during the diagnosis delivery, while others received the news over the phone or through a letter to the GP. Initially, many felt overwhelmed and helpless, however some found relief in finally getting answers.
"You can't change it anyway, so it's better to accept it and to get the support."

Participants also reported that the healthcare practitioners' tone during the delivery of a dementia diagnosis played a significant role in how they felt on receiving the news. While some individuals felt the approach taken had been complacent or limiting, others experienced a more gentle approach where healthcare practitioners prepared them and maintained a positive attitude.
"It was like an off-the-cuff statement,"

"She actually told us, life doesn't end here, it changes… just keep living because make the most of it from the time you have."

Changes to relationships

Participants noted that when a diagnosis of dementia comes into someone's life, change is experienced across a spectrum "financially, socially and personally."

Some respondents felt the caring role had caused a shift in their relationship, with one noting their dynamic had "changed from a father/daughter relationship" and others citing a "role reversal."

Focus group participants and survey respondents noted similar experiences of conflicting feelings as dementia caused change in their relationships, with one sharing they experienced a "greater connection" and a "fear for the future" at the same time. Another noted "we lived our lives around Mum which I'm glad we did. We lived our lives around dementia for a very long time".

The responsibilities and challenges of caring

Supporting a loved one living with dementia can be a multi-faceted experience; rewarding and challenging. Careers and family dynamics can be affected, "everything changed, our home, my career, our relationship", with some participants reporting having to move location or needing to live between two locations to be able to facilitate care. Additionally, respondents noted that they have "a lot more financial and caring responsibilities."

Participants also reported that their social circles and social lives had reduced significantly due to caring for the person in their lives living with dementia, with one respondent stating "I have no time for myself."

Even in instances where alternative care was provided, participants reported that this time was used to restore their own energy levels and they were unable to engage in social activities, "when I did get time out, I had no energy to go have the coffee… I'd be just trying to replenish my energy."

Supports and resources

While participants identified that it would be overwhelming to have all the information provided at the time of diagnosis, having some information about the diagnosis and next steps to be taken would have been helpful for them "just some information that you don't feel you have to do everything by yourself, especially in the beginning."

Additionally, participants noted that "a follow appointment where strategies of support can be explained" would be helpful for future care planning but of equal importance would be insights into what to expect in the short-to-medium term, "follow up appointment with GP to explain the diagnosis in simple terms and lay out what might change in short term - driving assessment/inform insurance etc" would be beneficial.

Positive Mission Creep

The traditional research experience often includes unexpected insights throughout the lifecycle of a project, detours which typically enrich the work. This element of unpredictability presented itself in this project. Despite setting out to investigate the impact a diagnosis of dementia has on the person who becomes the family carer / supporter, the perspectives and experiences shared during the data collection phase inspired the DRAT members to craft a set of guidelines for healthcare practitioners to consider when delivering a diagnosis of dementia. This demonstration of flexibility and openness whilst already innovating is a testament to the members' passion for creating impactful research.

Project Outputs

Research must influence practice. This research resulted in the production of some simple leaflets that include basic recommendations for health and social care professionals to consider when disclosing a dementia diagnosis, alongside contact information for The Alzheimer Society of Ireland.

Checklist for Health and Social Care Professionals when delivering a diagnosis of dementia

While most health and social care professionals put tremendous time, thought and care into delivering a dementia diagnosis, research and anecdotal evidence show that there are instances where a diagnosis has been communicated poorly.

This checklist has been developed through research conducted by members of the Dementia Research Advisory Team to support health and social care professionals when preparing to communicate a diagnosis of dementia. Please note this research was conducted before the publication of the Model of Care for Dementia in Ireland, which should also be consulted when considering how to communicate a diagnosis of dementia.

- The disclosure of diagnosis should take place, where possible, in person, in a quiet room with extra time allotted so the person receiving the diagnosis does not feel rushed and has adequate time to ask questions.

- The person should be encouraged to have a support person with them during the diagnosis such as a spouse / partner, family member or friend.

- The communication of a diagnosis can impact the person's own attitude to the diagnosis. Therefore, placing emphasis on the diagnosis being life-changing rather than life-ending is recommended.

- A follow-up appointment should be scheduled within ten days, where possible.

- Where possible, establish links to a Multi-Disciplinary Team with a direct point of contact to whom the person receiving the diagnosis of dementia may reach out.

- Local services and supports for both the person receiving the diagnosis and supporter / carer should be signposted, including The Alzheimer Society of Ireland's Helpline and contact details for the local Dementia Advisor. The clinic should have a supply of written information leaflets and documents available.

The Dementia Research Advisory Team (DRAT) is a group of people living with dementia and family caregivers who are actively involved in dementia research as co-researchers. Members of the Dementia Research Advisory Team have created and conducted their own research project with the support of a research assistant. These guidelines are a direct result of this research and included consultation with GPs.

*The Alzheimer Society of Ireland's Helpline is a confidential information and support service for people with dementia and their families. It provides accurate, up-to-date, accessible and relevant information and emotional support to our service users. Helpline Advisors and Volunteers can be contacted on 1800 341 341.

Dissemination of Running Our Own Research Project

Opportunities to hone and develop new research skills are vital to the growth of PPI Contributors in general and the DRAT specifically. In addition to drawing on the expertise of external research partners, The ASI provides bespoke in-house workshops. Over the course of this project, the DRAT members broadened their skills-base through facilitation training, one-to-one presentation-support sessions and academic poster design collaborations.

Members were encouraged to volunteer for tasks that matched their strengths and to explore new challenges in a supported manner. This equal-opportunity approach allowed the members to attend and contribute to research conferences, providing invaluable bidirectional learning and networking whilst promoting their work to an audience of their peers.

Specific examples of communicating the results of this project include:

- Oral Presentation at the 2024 Alzheimer Europe Conference, Geneva (Lead Presenter: Claire Odlum).
- Virtual Oral Presentation at the 2024 Alzheimer Disease International (ADI) Conference (Lead Presenters: Kevin Cullen and Claire Odlum).
- Oral Presentation at the Liverpool Dementia & Ageing Research Conference 2023 (Lead Presenter: Tony McIntyre).
- Poster Presentation at the 2023 Alzheimer Europe Conference, Helsinki (Lead Presenters: Carmel Geoghegan, Helena Quaid, Kevin Quaid, and Helen Rochford Brennan).
- Oral Presentation at the 2023 ASI/DRNI Knowledge Exchange Research Seminar, Dublin (Lead Presenters: Brenda Buckley and Tony McIntyre).
- Virtual Oral Presentation at the 2022 Alzheimer Europe Conference.
- Poster Presentation at the 2022 Alzheimer Disease International Conference, London.


Liverpool Dementia and Ageing Research Forum
Liverpool Dementia and Ageing Research Forum
Our aims
Our activities
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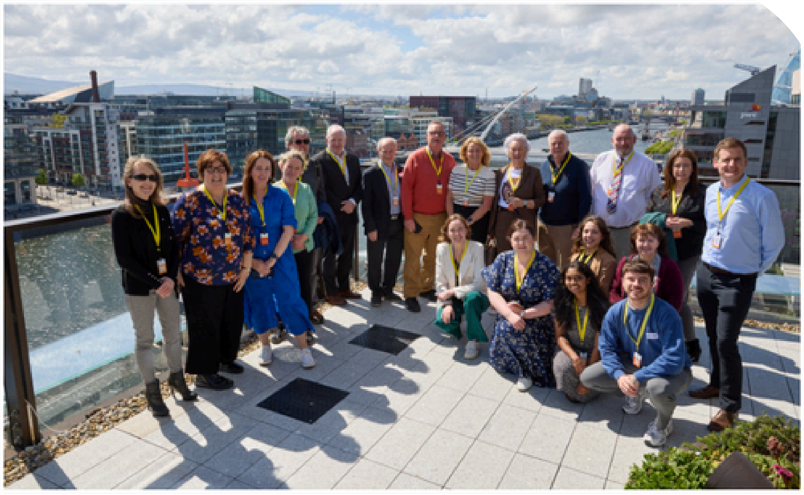
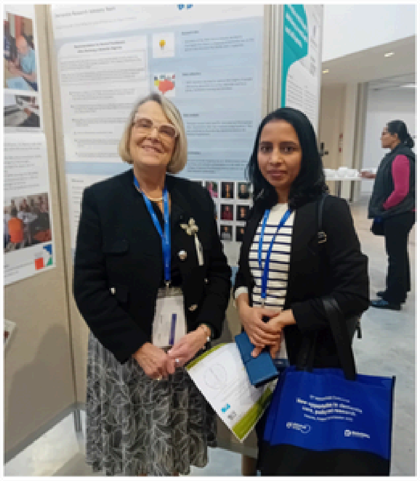
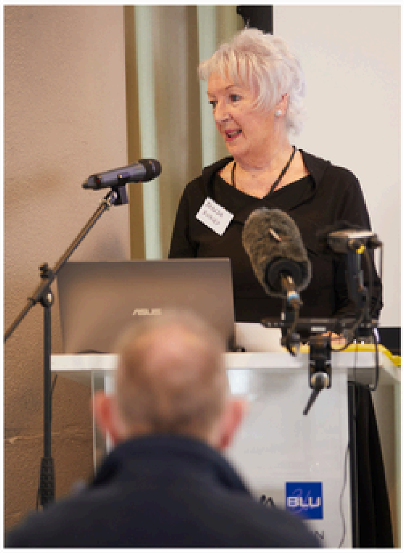
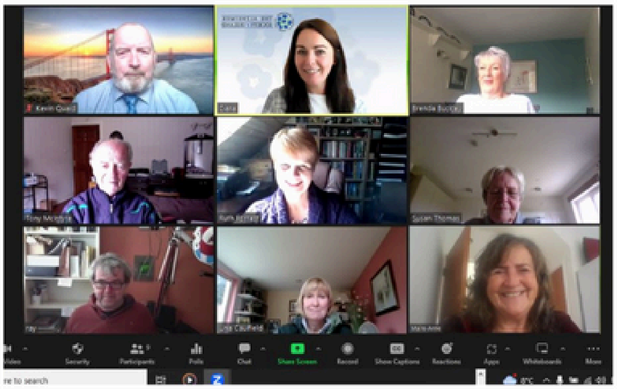







Running Our Own Research Project:
The Impact of Dementia on the Carer / Supporter
The Alzheimer Society of Ireland


Kevin Quaid
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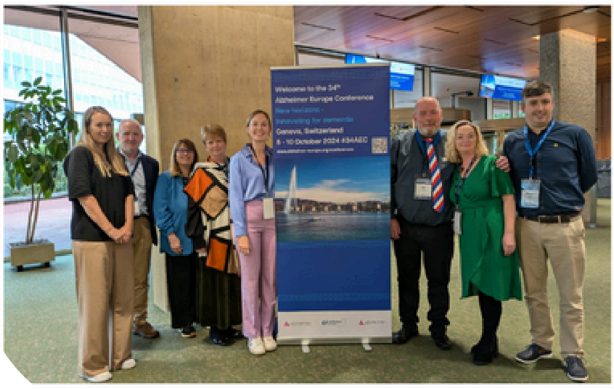
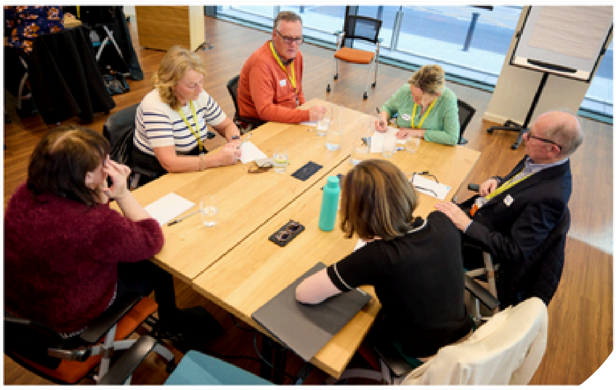

Welcome to the 34th Alzheimer Europe Conference
New horizons - Innovating for dementia
Geneva, Switzerland
8 - 10 October 2024 #34AEC



Reflections from Members of the Dementia Research Advisory Team

Brenda Buckley

Why take on a project like this?

In caring for my wonderful husband Aidan, our lives were changed dramatically by his dementia diagnosis. Prior to dementia coming into our lives, I had never heard of Person Public Involvement (PPI). But PPI showed me there is a forum to effect real change - how I could use my experience to make a difference. I recognise now the huge benefit and comfort that being a PPI Contributor can bring to people living with dementia and family carers. It gave me a voice and a way of using that voice to potentially improve the lives of people affected by dementia. I hope it comes across when presenting that I believe in this work implicitly. That my passion comes across.

Taking on the challenge of a research project (from start to finish, learning new skills on the way) has made me much more confident. The work that we do has shown me a road map of what is possible. Collaborating with researchers, engaging with healthcare professionals, has taught me how important my role is and that I can confidently represent my lived experience and advocate for change, certainly in the research space but also in other environments.

The DRAT approach

The process of selecting a research topic was important. We are people living with dementia and people with different experiences of caring. Investigating the impact a dementia diagnosis has on a person who becomes the carer is not something that had been discussed very much in our own group or throughout other research circles. This topic was chosen by a majority vote. Throughout our work, talking to people in focus groups, reading survey responses, the experience of the delivery of the diagnosis revealed itself to be an area needing more focus and change.

In working together, everyone is encouraged to speak up and contribute where we feel strongest. There is also an ability to say no. This is very important too – there is no pressure in the group for people to go outside of their comfort zone but with the right support you are empowered to take on new challenges.

Looking to the future

I see PPI growing. I believe that in the future, every piece of research and public health initiative will include insights from people beyond just the professionals. The skills I've gained in DRAT I can now extend to other groups that might benefit from my input. I see our work's relevance to broader areas of health research, especially considering the importance of our recommendations around diagnosis.

We continue to be empowered to share our findings within our networks, spreading the influence of our work. Meeting others—DRAT members, researchers, people in the dementia community—eases the journey. No one truly understands the path of dementia (or any health journey) unless they've lived it.

As a caregiver, you often lose sight of life beyond caregiving, but the social side of DRAT has helped me reconnect. Hearing focus group participants or survey respondents reflect similar experiences is deeply validating and strengthens my resolve to continue creating impactful research.

For people interested in getting involved in PPI and research, this kind of project is very do-able. People need only consider their motivations, ensure they have the right support and understand the commitment involved.

Kevin Quaid

Why take on a project like this?

Research is an opportunity to focus and think differently. Working alongside researchers has been incredibly rewarding; it's wonderful to see the increasing emphasis on working with PPI Contributors and drawing from the lived experience to enhance the quality and relevance of research. But we were glad of the opportunity to take our PPI work one step further and tackle a project of our own.

Working with the Dementia Research Advisory Team opens up your mind to new, fresh ideas. Taking on this challenge has been an opportunity for me to set my dementia aside. When you take a research project from start to finish, you get the feeling that there really isn't anything you can't do.

Our journey with dementia is unpredictable. The reason we are so invested, the reason we want this to be successful is because we are investing our greatest asset – the time we have. We take this work seriously and want our work to be done right.

The DRAT approach

In the DRAT, we bring the different perspectives of people living with dementia and family caregivers so the work we do is truly representative. When we work together, it is with respect and openness. When you go in with an open mind, you can bounce ideas off each other. And our approach is that every member of the DRAT is on the same footing, there is no room for ego in the group or the work.

We have been fortunate to take our work and showcase it at conferences. The guidelines we produced and our academic posters have been so well received. It was a delight and privilege to chat with researchers from all over the world who had either no experience of PPI or are new to it and want to learn from our approach, our advice and use it.

Looking to the future

PPI is growing constantly, I see that change in the opportunities coming to us as a team such as PPI in lab-based research. PPI-led research is an exciting new avenue in that changing landscape.

We have accomplished so much with this first project, but we are definitely only starting. We are beginning to realise that with what we have achieved already, we can accomplish so much more. We are now setting our own destiny, our own future. The benefit of our work will be felt into the future. There's a great sense that the work that we do now can change people's lives and ideas. We are leaving a legacy. Our work has the potential for people in the future to be less afraid when they are diagnosed.

I have been lucky to speak worldwide on the subject of PPI, and I can see that people are following us. They recognise that we are at the forefront of this new element of research, PPI-led research, and they are looking to us, seeing the impact we make.

The idea that a group of people affected by dementia could tackle our own research project was never even in the back of our minds. Now, seeing it come to life, we are truly speechless.

Claire Odlum

Why take on a project like this?

Being a member of the Dementia Research Advisory Team is an opportunity to draw on our personal experiences as people affected by dementia to work with and explore dementia research. Taking on a project of this scale, moving PPI one step further, it would be easy to feel lost in such a broad area. But being able to focus on one key aspect that mattered to us made it incredibly rewarding. The work gives you a sense of purpose, that you can make a valid contribution.

The DRAT approach

Leading our own project has been a truly fulfilling experience. At first, the process felt overwhelming but breaking it into smaller steps made it manageable and achievable.

Choosing a topic wasn't difficult—there's so much to explore in dementia research! However, narrowing down our focus group and survey questions was the real challenge. Thankfully, our team's democratic approach made this easier, with everyone contributing to the decision-making. There was also no pressure for members to contribute at each meeting, we were encouraged to mull things over and offer our ideas by email or phone afterwards. This was an important aspect of the way we worked because everyone was so passionate. It gives you a chance to think about things and still feel like you can get your point across and have it included.

As we progressed, the work gathered momentum, building excitement as we saw it coming together. We learned that unexpected things happen in research and you just have to navigate them as best you can. This was fine because it was a team effort from start to finish. We each contributed at different stages, but there was always a core group to keep things moving.

Looking to the future

It's something I'm proud to tell others about, and seeing people's surprised reactions to what we've achieved makes me realize just how much we've done. Our experiences are valuable to society, to people affected by dementia and to research - this work highlights that value. While deeply focused on the work, we didn't always grasp the impact. But looking back, I see the lasting change we've created.

It seems surprising that PPI as a concept is still so new. This work becomes a part of the research fabric and history. I feel privileged and thankful to have been a part of it.

As a team, this project has given us confidence and an appetite for more. We are still learning. But it has shown us there are no barriers to what we can accomplish. I feel privileged to have been part of this effort, which I believe will encourage other groups to follow our lead, add their voices, and inspire new projects of their own.

I found the recent Alzheimer Europe Conference an emotional but hopeful experience with a positive outlook for the future. I really feel a change is happening within the medical and research space, where the public / patients' voices are finally being heard. By using this collaborative approach we can formulate better research and treatment plans together. One shouldn't exist without the other.

Conclusion

Research is enriched by the contribution of members of the public working alongside researchers as collaborators and advisors. Their real-world insights improve the relevancy and efficacy of research. PPI-led research is the next step in this evolving element of the research landscape. This project highlights the meaningful impact PPI-led research can have both for individuals affected by dementia and the broader research community with a focus on innovation and empowerment.

Acknowledgements

The members of the Dementia Research Advisory Team would like to thank all of the people living with dementia and family carers who took the time to share their personal experiences and stories with them throughout this project.

We extend our thanks to Michael Foley, the PPI Ignite Network and Professor Tony Foley for their guidance and collaboration. We are grateful to the project's Research Assistant Holly Dennehy for her support and hard work.

Warm appreciation is offered to the members of the Dementia Enquirers whose generous insights further encouraged our passion for carrying out a research project of our own.

This work could not have been carried out without the support of The Alzheimer Society of Ireland’s Research & Policy Team Dr Laura O’Philbin, Dr. Diane O’Doherty and Ms. Cíara O’Reilly.

Finally, we are grateful for the contributions and insights of former Dementia Research Advisory Team members Séan Mackell, Mary Sweeney, Máire Anne Doyle, Susan Thomas, Alison McCarthy and Janice Nolan Palmer all of whom played notable roles in the success of this project and the team as a whole.

For further information on the work of the Dementia Research Advisory Team please visit https://alzheimer.ie/creating-change/research/ppi/.

THE Alzheimer
SOCIETY OF IRELAND

The Alzheimer Society of Ireland is a national service delivery and advocacy organisation. It is person centred, rights based and grassroots led with the voice of the person living with dementia and their carer at its core.

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Facebook: TheAlzheimerSocietyofIreland

Instagram: @Alzheimersocirl

The Alzheimer Society of Ireland Helpline is open six days a week Monday to Friday 10am – 5pm and Saturday 10am – 4pm Call 1800 341 341 or email helpline@alzheimer.ie

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