

Clarifying the work and positions of the groups supported by the ASI Advocacy & Research Teams

The Alzheimer Society of Ireland advocates as a strategic priority for the rights and resources for people living with dementia, family carers and their communities.

The organisation grounds its work in the lived experience of dementia and ensures that research and advocacy work across Ireland reflects that experience.

This document seeks to provide clear delineation between the groups involved in this work, their function and support structure. Groups/initiatives supported by The ASI include

1. The Irish Dementia Working Group
2. The Dementia Carers Campaign Network
3. The Dementia Research Advisory Team
4. TeamUp For Dementia Research

1. The Irish Dementia Working Group (Advocacy)

The Irish Dementia Working Group (IDWG) are an advocacy group of people who have been diagnosed with dementia who meet to share experiences and highlight issues which are important to them.

Members work to destigmatise dementia and raise awareness by speaking publicly in the media and at conferences and amplify the lived experience of dementia. They wish to improve supports for all people living with dementia and are engaged in local and national political advocacy. They sit on Steering Groups to influence policy and monitor the implementation of the National Dementia Strategy.

Coordinator: Saoirse Kelly

Contact: saoirse.kelly@alzheimer.ie

Examples of relevant work

- Policy Steering Groups
- Media engagements regarding the lived experience of dementia
- Speaking engagements
- Awareness raising and campaigns
- Political Advocacy
- Development of guidance documents
- Engagement/education of health care professionals
- Supporting the other ASI departments (eg fundraising)



Outside the scope of IDWG

- Research Participation
- Research Involvement (eg PPI) and Research Steering Groups

Requirements to engage with IDWG

- Completion of the [Request for Engagement Form](#)
- Provide follow up information if required eg; clarity around dementia inclusive approach, steps to ensure advocate wellbeing, support to participate
- Be within the scope of the IDWG Work plan as set out by members and agreed by the Steering Group.

For more information about The Irish Dementia Working Group please see [HERE](#).

2. Dementia Carers Campaign Network (Advocacy)

The Dementia Carers Campaign Network (DCCN) are a group of people who have experience caring for a loved one with dementia. They aim to be a voice of and for dementia carers in Ireland and raise awareness of issues affecting families living with dementia.

Coordinator: Judy Williams

Contact: judy.williams@alzheimer.ie

Examples of relevant work for the DCCN

- Policy Steering Groups
- Media engagements regarding the lived experience of dementia
- Speaking engagements
- Awareness raising and campaigns
- Political Advocacy
- Development of guidance documents
- Engagement/education of health care professionals
- Supporting the other ASI departments (eg fundraising)

Outside the scope of DCCN

- Research Participation
- Research Involvement (eg PPI)
- Research Steering Groups



Requirements to engage with DCCN

- If you are interested in joining the DCCN please email judy.williams@alzheimer.ie
- If you or your organisation is interested in working with the DCCN on a piece of work, please complete this [Engagement Request Form](#) and return it to judy.williams@alzheimer.ie

For more information about the Dementia Carers Campaign Network please see [HERE](#).

3. The Dementia Research Advisory Team (Research; Person & Public Involvement)

The Dementia Research Advisory Team is a group of people living with dementia and family carers / supporters who are involved in dementia research as co-researchers. These Experts by Experience influence, advise, and work with researchers across Ireland. Their work is defined as [Person Public Involvement \(PPI\)](#) whereby team members work in partnership with researchers from the outset of a project right through to disseminating findings. DRAT members work alongside researchers to set the research question rather than answering the research question as a participant.

Coordinator: Cíara O'Reilly

Contact: ciara.oreilly@alzheimer.ie

Examples of relevant work

- Sitting on steering group of a research project
- Co-applicant/Collaborator on a research grant
- Advisory position at the outset and throughout a research project
- Co-researcher on research projects

Outside the scope of DRAT

- Research participation (eg completing a survey, answering research questions)
- One-off consultations (unless developing research grant application)
- Advocacy work

Requirements to engage with DRAT

- Completion of the [DRAT Involvement Form](#)
- Provide follow up information if required eg; clarity around dementia inclusive approach, steps to ensure advocate wellbeing, support to participate
- Planned authentic involvement
- Read [DRAT Guidelines for Engagement](#)

For more information about the Dementia Research Advisory Team please see [HERE](#).

4. TeamUp for Dementia Research

TeamUp for Dementia Research was launched in July 2021. It is an empowering 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 / family members with researchers who are conducting studies in the area of dementia (e.g. prevention, diagnosis, treatment, care, cure).

This group is solely about research participation. Anyone interested in signing up as a research participant can fill in the [online form](#) or can be walked through this process over the phone by requesting a call back through our National Helpline.

Coordinator: Cíara O'Reilly

Contact: ciara.oreilly@alzheimer.ie

Examples of relevant work for members of TeamUp for Dementia Research

- Participating in research projects (sole purpose)

Outside the scope of TeamUp

- Research involvement (e.g. PPI)
- Advocacy Work (e.g. media interviews, consultations etc.)

Requirements for researchers to engage with TeamUp for Dementia Research

- Completion of TeamUp Application Form (email teamup@alzheimer.ie for a copy)
- Ethical Approval from Irish Research Ethics Committee
- Study must be dementia-related
- Commitment to share results of project with participants and The ASI

For more information about TeamUp For Dementia Research please see [HERE](#).



Examples of Grey Areas

Sometimes it is not clear which group should be contacted for a particular project. Some examples are highlighted below.

Example 1.

Researcher wants to work with people living with dementia and family carers. Work involves three focus groups looking at a newly developed app and giving feedback in a focus group context. They contact the research team asking to engage with the DRAT.

What group: TeamUp for Dementia Research

Why

- Not PPI because the project is already ongoing and only scope for a small amount of input into one stage (e.g. app development). Therefore this is not authentic involvement.
- Not the IDWG because it is research participation
- It is TeamUp because it is participating in a research project (e.g. the researchers are using the focus group to collect data)

Example 2.

Researcher asks The ASI to find a person living with dementia to sit on a University Steering Group to look at a dementia curriculum.

What group: IDWG

Why

- Not PPI because it is not codesign/involvement in a research project
- Not TeamUp for Dementia Research because it is not research participation
- It is the IDWG because it is a request to represent the voice of people living with dementia



Example 3.

A research conference organiser would like a family carer to speak at a dementia conference about their wellbeing. This will complement a session about research on family carers.

What group: DCCN

Why?

- Not the IDWG because it relates to family carers
- It is not DRAT because it does not relate to ongoing involvement in a research study (the study is complete).
- It is not TeamUp for Dementia Research because it is not about participating in a research study.
- It is DCCN because
 - Even though it is a research conference, the engagement is about the voice and lived experience of family carers.

Example 4.

Researcher wants to ask a family carers advice on a research project not yet developed.

What group: DRAT

Why

- Not the DCCN because it is relates to research, co-design and involvement.
- It is not TeamUp because the project is not up and running or collecting data.
- It is the DRAT because it is a research project with scope for co-design and involvement.



Example 5.

Researcher wants to meet people with dementia to ask them about planned methodology and research questions for a grant application they are writing with researchers in the UK. There will be a one off consultation. The researcher hopes that if the UK project goes well they will apply for funding to do it in Ireland.

What group: DRAT

Why?

- Not the IDWG because it relates to research, co-design and involvement.
- It is not TeamUp because the project is not up and running or collecting data.
- It is DRAT because
 - Even though the involvement is once-off, there is potential for future involvement
 - Members can make changes to a proposed research project