



Guidelines for working with the Dementia Research Advisory Team

The Dementia Research Advisory Team was established in April 2019. We are a team of five people living with dementia and five caregivers who wish to contribute to research in a Person Public Involvement (PPI) Capacity. We are glad to be involved in research, and even though we are not research experts, we are experts in our own experience and can bring unique insights and add significant value to research. We will do our best to bring our experience to your research. To make this easier for us and for you, we have written these guidelines which set out some of our expectations of research teams we work with.

This guide was written by members of the Dementia Research Advisory Team, with the support of the Alzheimer Society of Ireland and PPI Ignite at Trinity College Dublin.

At all times, we must be treated with dignity and respect, and appropriate steps should be taken to maximise the potential of each person to contribute meaningfully to the research project.

Our involvement

- If our involvement is to be authentic, we should be involved from the beginning of the project. We want to have input into setting the questions and help shape the project.
- Please be aware that each of us has different strengths and challenges (e.g. literacy, ability to travel, communication). Please be respectful, empathetic and mindful of this. Ask each person what works best for them when involved in your research.

1. Meetings

1.1. Meeting times

- Where possible, meeting times/dates should be agreed with each individual team member and organised around their schedule. Sometimes this may mean that meetings need to take place outside typical working hours.
- Usually, meetings with team members who have dementia are best to take place in the morning, though it is important to be aware of the time it may take them to travel.
- Meetings should be no longer than two hours and there should be adequate time and space for questions. If the meeting needs to be longer than two hours, please factor in a break of up to one hour. The preferred break length will vary from person to person.

1.2. Meeting Venues

- Venues for PPI should be carefully selected, with careful consideration of issues such as
 - Location
 - Lighting
 - Distractions/noise levels
 - Parking
 - Signposting
 - Accessibility
- If there is a meeting or event, please meet us in Reception as we may not know where the room is.

1.3. Support Person

- Team members with dementia should be given the opportunity to be supported by a person of their choice (e.g. for practical assistance or to help them to contribute towards discussions and activities). This could be a relative, friend, volunteer or researcher.
- Reasonable expenses of this support person should also be covered by the research project.

2. Expenses

- Discussions about repaying expenses should happen before we become involved in the project, at the very beginning.
- Please explain what expenses we may claim, and how to claim expenses. An easy-to-read print out with this information would be very helpful.
- We may need your assistance with completing expense forms, so please offer to help us.
- Expenses should be paid in a timely fashion, and where possible, the research team should pay expenses up-front (e.g. booking trains/taxis on behalf of the person).

3. Communication (outside of face to face meetings)

- Please ask us about our preferred method of communication at the beginning of the project (e.g. telephone, e-mail).
- We would like regular communication/follow-up from the research team throughout the study. Even if progress has not been made since the last communication, it is still important that we know what is going on.

- Steps should be taken to help us keep track of our ongoing involvement and how this fits in with the overall research project (e.g. a short record or reminder of what we have done so far, a brief progress report at regular intervals).
- We should be offered details of a 'contact person' on the Research Team who we may contact about the project with questions or queries so we have some continuity.
- We understand that sometimes project staff might change. Please keep us informed about this.
- Please keep us informed about what happens after the research project.
 - What was learned from the project?
 - What was the impact of the project?
 - What do we still not know?
 - What are the recommendations of the project?
 - What are the next steps?
 - How will people be told about the results of the project?

4. Project Materials/Information

- Please ensure that all documentation is easy to read. Scientific jargon, acronyms and abbreviations should be avoided and removed as far as possible (also in discussions).
- Long/dense text and small print should be avoided.
- Documentation should be sent to us at least two weeks before any meetings/involvement so we have time to go through it, seek any necessary support and prepare for the task.
- Please offer to go through any research materials and provide a briefing or explanations before the meeting, either face to face or by phone or email, depending on the preferences of the individual person and the resources available.

5. Recognition and Acknowledgement

- Please consider appropriate and meaningful ways to acknowledge our contributions to your study
- We should not be the only people in the room who are not being paid.
- If reimbursement/payment is being arranged, this should be discussed and agreed with each individual person. In some cases, members may not be able to accept money and a voucher or honorarium may be more appropriate. These conversations should happen at the beginning of the project.

6. Managing Input

- Researchers should be clear about how we will be involved and how they will use our input.
- We understand that the aims/methods of a research project may change over time. It is essential that we are part of this.
- We should be given the opportunity to check through information that we have provided to see whether it has been recorded, interpreted and reported to our satisfaction.
- Team members who have contributed towards an article for publication in a journal should be acknowledged in the article (either as co-author or in the acknowledgements section, depending on the nature of their contribution) unless they prefer to remain anonymous.
- If one or more team members contributing to a research publication do not wish to have their name acknowledged, any acknowledgement should be in the name of the group (i.e. The Dementia Research Advisory Team).

7. Support

- Researchers have an ethical duty to promote the well-being of people who contribute to their study through Involvement/PPI.
- Over the course of the research, negative/upsetting issues may arise causing strong emotions and it is important to be mindful of this. Please check in with team members to check on their well-being, and follow up contact after each meeting/engagement is important.
- Research covering particularly sensitive topics may require resource allocation for professional support (e.g. a counselling or therapy session). Please have a name and number of a counsellor/therapist prepared.
- Please 'know your team', some issues are sensitive for us.
- Please be aware that we have different challenges and capacities. It is important to support us to be involved, and ask each individual what works best for them.

Thank you for reading and following these guidelines.