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Help Improve Dementia Research:
Become A Research Partner



Introduction

People living with dementia and care partners can help to improve research outcomes by working together with researchers.

This resource has been created by people living with dementia and family care partners. It aims to provide information about what it means to be a “research partner” and will hopefully encourage people living with dementia and care partners to consider becoming a partner in research.

“By being involved in research and with researchers, I am able to participate and find out what other people are doing. Hopefully some of what they’re doing will also benefit me.”

- Person living with dementia

What is research?

Research is used to discover new information, solve problems or increase knowledge on a topic. Some examples of research about dementia include:

- Understanding how dementia affects the well-being or daily life of people living with dementia or care partners
- Clinical trials that test treatments for dementia
- Studying a new approach to improve quality of life

What is a research partner?

Being a research partner is different from being a research participant. Research “partners” are members of the research team, who use their skills and experience to contribute to a research study. How a person is involved as a research partner may differ from study to study. This is something that is decided on together with the researcher. For example, a research partner may provide advice on what research questions to study, review research documents, and help share results. In contrast, a research participant takes part in a research study and information (or data) is collected from them to help answer a research question.

A research partner:

- ✓ Adds value to research by sharing their knowledge, skills, and experience
- ✓ Does not need to have experience or training in research
- ✓ Works together with the research team based on a relationship of trust and mutual respect

“It is knowing that the research project actually, when it’s concluded, will be a benefit.”

- Care partner

Why are research partners important? What are the benefits?

Benefits for people living with dementia and care partners

By becoming a research partner, you may:

- ✓ Meet new people and connect with others who may have similar experiences
- ✓ Share your experience and expertise with researchers, trainees and students
- ✓ Learn new skills
- ✓ Contribute to the development of new research and ideas
- ✓ Feel good about what you have contributed
- ✓ Share your story or the story of your partner (if you wish)
- ✓ Use your voice to be an advocate for yourself or others

Benefits to research

People living with dementia and care partners are experts on dementia and what it is like to live with dementia. This knowledge and experience will add value and ensure that the research conducted is relevant to people living with dementia and care partners. Including research partners with different experiences (including age, culture, type of dementia) can help to ensure that the research findings are meaningful to a wider group of people with dementia and care partners.

By becoming a research partner:

- ✓ The outcomes of the research will be more relevant to people living with dementia and care partners
- ✓ You may help to reduce stigma and create awareness about what people living with dementia can contribute
- ✓ You may be able to help improve care services and influence policy
- ✓ You may help produce relevant resources that can help others

Ways that people with dementia and care partners can be involved as a research partner

Some different ways you can be involved in research are:

- ✓ Help to identify gaps and needs in dementia research
- ✓ Help to design and test services, programs or supports to improve quality of life
- ✓ Help to develop surveys or questionnaires
- ✓ Help to write and review documents to ensure they are easy to understand and use dementia friendly language
- ✓ Assist with interviewing research participants
- ✓ Help to review research data
- ✓ Help to develop resources such as educational pamphlets or programs
- ✓ Sharing and/or presenting findings at events

To hear stories from research partners, check out the Schlegel-UW Research Institute for Aging (RIA) Youtube channel: @SchlegelUWRIA

“Our job is to review all the documents that are being produced. To ensure that they are understandable from someone other than a researcher... [We] point out the areas that are not at the level that they want it to be for the group.”

- Care partner



What questions should I ask before becoming a research partner?

To help you decide whether you want to become a research partner, meet with the researcher to learn more about them and the research study.

Here are some questions you can ask the researcher:

If you prefer to have written information, ask the researcher to provide information in writing about the study and your role.

- ✓ What is the study about? What do you hope to achieve?
- ✓ How will I be involved? What will I be expected to do?
- ✓ Is the role paid or voluntary? Will there be expenses and will these be covered (e.g., travel, meals, other costs required to be involved)?
- ✓ When, how often and how long are the meetings?
- ✓ Where are the meetings held? Will meetings be in-person or virtual? What time of the day are the meetings held?
- ✓ When does the project end? Can I opt in or out when I need to? How do I do that?
- ✓ How will the final product or results of the project be shared with me?
- ✓ How will I benefit from partnering on the project?

After you have met with the researcher, consider the following questions:

- ✓ Did I feel comfortable with the researcher(s)? Was I respected, listened to and appreciated?
- ✓ Am I interested in the research topic?
- ✓ Do my skills fit with the needs of the project and the researcher?

“It’s a win-win because I walk away learning something each time.” -Person living with dementia

How do I find out about opportunities to be a research partner?

Here are some ways you can learn about opportunities to be a research partner:

- Ask others living with dementia and care partners about whether they are involved in research
- Speak to your local Alzheimer Society staff, health care professionals or others in your network of contacts

Alzheimer Society of Canada: alzheimer.ca or 1-800-616-881

Engagement of People with Lived Experience of Dementia:
epled.ca

Schlegel-UW Research Institute for Aging: the-ria.ca or info@the-ria.ca

- Attend lectures and conferences
- Follow dementia organizations on social media

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