

Société Alzheimer Society

Engagement of People with Lived Experience

The vision of the Alzheimer Society of Canada is “A world without Alzheimer’s disease and other dementias”. The Society funds the best and brightest minds in dementia research and is strongly encouraging researchers across all streams to involve people with lived experience (PWLE) in their research projects.

People With Lived Experience is used to describe people living with dementia and/or their caregivers. They include people from diverse communities, including 2SLGBTQIA+, Indigenous peoples, people of colour and other racialized communities. Collectively, they strive for autonomy and for their voices to be heard. Knowledge gained from lived experience is invaluable to research and is critical to the work of the Alzheimer Society of Canada.

Engaging PWLE in research gives researchers a truly authentic perspective on priorities that are important to patients, insight into unmet needs and an awareness of problems and issues that they encounter.

The aim of this collaboration is to identify research priorities that are more focused and responsive to the needs of PLWE.

PWLE can be involved at any stage of the research project, some examples include:

- As collaborators or co-investigators
- In design (to ensure methods are feasible and sensitive to the needs of potential research participants)
- As participants
- In data analysis (to get a diverse perspective)
- In obtaining protocol feedback
- Through advisory boards and workshops
- In knowledge, translation, and exchange efforts (e.g., outreach, education)
- As co-authors in manuscripts and publications

Ethics approval may be required to engage PWLE in health research. Different provinces and territories across Canada may have different requirements.