

February 2023: Engagement in Research on Dementia

This document provides a presentation summary on the experience of people with lived experience of dementia and their engagement with a National Research Consortium.

Key Presentation Points

- Engagement of people with lived experience of dementia (ELED) is a cross-cutting national program established in 2020 by the Canadian Consortium on Neurodegeneration in Ageing (CCNA) and funded by the Alzheimer's Society of Canada.
- Currently, there are 16 ELED advisory group members that include current and former caregiver partners and individuals living with dementia. ELED recruited members through a role profile which outlines the expectations and commitments of participants, self-selected application form and interview.
- Members are engaged in CCNA as presenters at public and scientific events, co-applicants and co-investigators on projects, and co-authors on papers.
- ELED members and CCNA researchers hope to advance patient engagement in research methods, as well as pursue goals such as dementia education, information, and support for people living with dementia, caregivers, essential workers, and the public.

What did we discuss?

- **Commitment:** The annual commitment of ELED members is participation in video/tele-conferences. During these events, CCNA researchers ask ELED members to engage on key activities including:
 - Provide input on research questions and study design
 - Review of study documents
 - Interpret and contextualize results
 - Knowledge translation and dissemination
- **Providing support:** ELED members are provided with opportunities for orientation and training on health research and compensated for their time and related travel expenses.
- **Building relationships and flexibility with ELED members and research teams has been critical:** Engagement has involved acknowledging power imbalances within the different roles.
- **There can be differing expectations and priorities of researchers and patient partners:** Researchers work on timelines in years, and milestones in grants and publications whereas patient partners want change. It is important to recognize people are the reason the research is taking place and they are not just study subjects.

Relevant Resources on Patient Engagement in Research

- [ELED website](#): A website with engagement tools, resources, and information related to the engagement of people with lived experience of dementia.
- [Reflections](#): A commentary with reflections and learnings from the first year of the ELED program.