

What is *Building Capacity for Meaningful Participation by People Living With Dementia*?

This is a collaborative community-based research project, with funding from the Public Health Agency of Canada for 2019-2023. Its primary goal is to develop community capacity that fosters meaningful participation by people living with dementia in a wide range of activities.

After four years, we want more PLWD being active and participating in their community in a variety of ways. More importantly, we want increased capacity in the community so this kind of active participation can

- be normalized
- continue to grow and flourish
- change perceptions of dementia as a diagnosis that signals withdrawal from community participation.

How will the collaboration work?

We will be enabling PLWD to reinvest in a new life after a dementia diagnosis and be encouraging them to live well with the condition. In doing so, we will aim to lessen the stigma currently associated with dementia.

The following guiding principles for *Building Capacity* were formulated by Hub Partners in Fall 2018:

1. Listen to the Persons Living with Dementia (PLWD), their caregivers and their families and respond to their needs.
2. Keep any project “do-able” and within the community, respecting neighbourhood assets.
3. Respect the diversity and capacity of the Partners to develop appropriate activities.
4. Include the expertise of organizations, such as Alzheimer Society, Paul’s Club, Health Authority
5. Recognize there is a need for ongoing services; therefore any project would need to be scalable.
6. Carefully consider accessibility of programs to participants, namely location and transportation.
7. Support Partners through funding for leadership training and program support.

Community Partners’ Responsibilities

Project support for the community partners could include:

- access to information and communication resources
- remuneration for staff leadership
- special event funding
- logistical coordination with project secretariat
- volunteer training

UBC Research Secretariat Responsibilities in conjunction with Lakehead University

Responsibilities could include:

- overall coordination among research groups and community partners
- conducting surveys and facilitating focus groups
- assembling and analyzing data
- coordinating project reporting
- overseeing website development