

Information Letter for Neighbourhood Steering Team Participants

Study Name: Creation of a Dementia-Capable Neighbourhood from Person to Policy: A Participatory Action Research Approach

What is this study about?

The purpose of the Dementia Capable Communities project is to identify specific actions that are needed at different levels (individuals, programs, buildings, community, policy) to create dementia-capable communities. We will do this using a method called 'Participatory Action Research'. Participatory Action Research is a way of doing research that involves participants living with dementia and their communities in all stages of the research with an end goal of creating 'action' to bring about change. As part of one of the Neighbourhood Steering Teams, your contributions, reflections, decisions, and actions will inherently be part of the Participatory Action Research process.

In addition to the Participatory Action Research within the Neighbourhood Steering Teams, there are additional phases that are planned for the study. Note that these plans may change or evolve within our participatory process:

Phase 1: Engagement of the Research Team and Participatory Action Research (throughout the study)

Phase 2: Engagement of the Neighbourhood Steering Teams to guide neighbourhood level decisions

Phase 3: Data Collection to understand barriers and support to inclusion in each neighbourhood

Phase 4: Co-creation of actions and a framework for the development of dementia-inclusive neighbourhoods

What does involvement in a Neighbourhood Steering Team involve?

We value the expertise and experiences of each steering team member. As a member of one of three Neighbourhood Steering Teams, you will help us plan actions and research in your neighbourhood throughout all phases of this project. During this process, we will ask for your ideas feedback, and collaboration.

Our three target neighbourhoods are downtown Kitchener (urban), North-West Waterloo (suburban), **and** Woolwich (rural). Within each neighbourhood, we aim to bring together about 10-12 people, which may include:

- Persons living with dementia
- Care partners
- Health care providers
- Neighbourhood associations
- Cultural centres
- Religious organizations
- Educators
- Community program or service providers
- Local business representatives
- Transit representatives
- Accessibility coordinators
- Urban planners
- Researchers

Together, we aim to identify the actions needed to create dementia-inclusive communities in the Region of Waterloo.

Each Neighbourhood Steering Team as a collective group, is expected to listen to, and value, the perspectives, and experiences of all members. Members have the right to express and present themselves in the way best aligns with their physical and mental ability, religion, culture, ethnicity, sexual orientation, and gender identity. To promote inclusivity, all members will refrain from making assumptions about, or labelling others. Instead, all members will appreciate and adapt to each individual's unique capabilities. Through these actions, the Neighbourhood Steering Team and Research Team members commit to respectfully interacting with each other in order to maintain trust, confidentiality, and an authentic partnership.

With your consent, we will be asking each steering team member to fill out a demographic questionnaire – with the choice of online or over the phone - to gain insight into group dynamics and processes for collective action (e.g., Who are the individuals on the steering team? What works well about bringing different community members together? What challenges or tensions existed between group members and why might this have been?).

You may also be asked to participate in an interview or focus group once the project is complete, so that we can gain an understanding your experiences throughout this project.

What is the time commitment for this role?

- Neighbourhood Steering Team meetings are expected to take place over the next year or so.
- Neighbourhood Steering Team meetings are expected to happen one to two times a month, though the timing and frequency of the meetings will be decided based on the **preferences of team members**, and the stage of the project.

Honoraria:

People living with dementia and care partners will receive an honorarium of \$25 per meeting to recognize their time and contributions. The amount received is taxable. It is your responsibility to report this amount for income tax purposes.

Where will this project take place?

- Due to the challenges of COVID-19, all initial meetings with the Neighbourhood Steering Teams will occur on-line over Zoom until further notice.
 - We can provide a tablet to team members where needed. We will also provide training for how to use Zoom.

- Your safety is important to us! Decisions about when to shift from meeting on-line to in-person will be decided by the members of each Neighbourhood Steering Team when safe to do so.

Will my information be kept confidential?

We will document the processes used by the Neighbourhood Steering Teams in various ways, including meeting agenda and associated items, audio and/or video recordings, and meeting minutes. These records will be used to document our processes for the purpose of presentations and papers. All study documents will be stored on an encrypted University of Waterloo server for at least 7 years.

- Identifying information will be removed from the data that is collected and will be stored separately. Identifiable features, such as faces, will be visible in the video recordings, however, these recordings will be encrypted and then once transcription and analysis notes are complete, the audio and video files will be deleted. If you do not wish to be identified in project results, your name will not appear in any paper or publication resulting from this project, however, with your permission quotations may be used with a pseudonym in place of your real name. Alternatively, you may decide to be identified by name and have your quotations directly attributed to you in study results.
- Note that meeting minutes will not be de-identified, as it would make it difficult to understand decision processes.
- Collected data will be securely stored for a minimum of 7 years on an encrypted University of Waterloo server.
- We will ask all Neighbourhood Steering Team members to keep in confidence information that identifies or could potentially identify another member and/or their comments, however we cannot guarantee that everyone will honour this request.

What are the potential benefits of your participation?

You may benefit from your participation in a Neighbourhood Steering Team and the Participatory Action Research processes by building relationships with other members and learning from each person's experiences and perspectives. The work of the steering teams may also improve the inclusion of persons living with dementia, locally at first but perhaps with broader long-term impact.

What are the potential risks of your participation?

There are some risks. We may discuss issues of a sensitive nature that may make you feel upset or anxious. We will always check back with Neighbourhood Steering Team members to see if there are ways our processes and discussions can be improved. Please also feel free to reach out with feedback or suggestions at any time.

Also, please note that whenever information is transmitted over the internet privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g., government agencies, hackers). In addition, this risk is also associated with any internet use (e.g. e-mails etc.). University of Waterloo researchers will not collect or use internet protocol (IP) addresses or other information which could link your participation to your computer or electronic device without first informing you.

Is participation in this project voluntary?

Your involvement on a Neighbourhood Steering Team is voluntary. While we hope to have all members for the full project, we understand that situations and interests change and that involvement with a Neighbourhood Steering Team may change over time (e.g., members may not be available for a period of time or may have to step away from the project completely). This is perfectly acceptable. We appreciate any contribution that members can make.

A few other items to note:

- You may decline to answer any of the questions asked during any video-calls or in-person meetings throughout this research project.
- You may decide to exit the video-calls or in-person meetings at any time without any consequence.
- Please note that the video-calls will be audio- and video-recorded. The audio portion will be transcribed and all recorded material (audio and video) will be used to help with project processes.
- You can withdraw your consent and request that your data be removed from the study by contacting the researchers up until the completion of the final project (~ Winter 2023). Please note that due to the group format of the conversations, it may not be possible to remove all data associated with you. Additionally, it is not possible to remove data once project results have been submitted for publication.

If you have any questions about participating on the research team, please reach out to Laura Middleton at laura.middleton@uwaterloo.ca

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB 43551). If you have questions for the Board contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or reb@uwaterloo.ca. For all other questions contact Laura Middleton at laura.middleton@uwaterloo.ca.

Thank you for your interest and considering participating in this project!

Yours sincerely, Laura Middleton & Samantha Biglieri