

## Appendix M: Data Collection Information Letter

### Information Letter for Data Collection Participants

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

#### What is this letter about?

This letter is to help you make a decision about participating in a research study, **“Creation of a Dementia-Capable Neighbourhood from Person to Policy: A Participatory Action Research Approach”**. It is entirely your choice whether to participate or not. Before you decide, it is important for you to understand what the research study involves. This letter will explain the study, the possible benefits and risks, and your rights as a research participant. If you do not understand something in the letter or have any concerns, please ask the researcher before making your decision to participate.

#### What is this study about?

The purpose of the Dementia Capable Communities project is to identify specific actions that are needed 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. The end goal of the research is to create ‘action’ to bring about change.

We would like to gather specific information about your community by talking to you before and after going on a tour through your neighbourhood. You can also choose to drive instead of walking through the neighbourhood if it is more feasible for you.

## **What does your participation involve?**

**Session 1:** We will begin with a short conversation, in a space that you are comfortable in. We will discuss your experiences living and getting around in your community. We will also work together to make a plan for going through your neighbourhood in the second session. You can tell us where you would like to go, and how long you would like the outing to be. We will request to audio-record this meeting to ensure the accurate transcription and analysis of data.

**Session 2:** We will ask you to take a researcher on a tour of your community along a route that is familiar and comfortable for you. You and the researcher will have a conversation along the way about what you are experiencing, your reactions as things happen, and your likes and dislikes. During this tour, you and the researcher can stop for refreshments or bathroom breaks whenever needed. We will encourage you to take us on a tour using their usual means of transportation (e.g., walking or public transit). However, if needed, the researchers will work with participants to explore alternative options. We will end the outing with a conversation reviewing and summarizing your experiences on the neighbourhood tour. You may feel free to bring a family member or care partner along. We will request to audio-record this meeting to ensure the accurate transcription and analysis of data.

**Session 2 Optional:** If you would like, you can take photographs while we tour around your community. If you chose this option, you will be instructed to take photographs that show the barriers and supports for getting around the community. You can use your smart phone, or we can provide you with either an instant or digital camera. If needed, we will provide training on how to use the camera. We will remind you to only take photographs when at a safe vantage point.

Session 2 **Optional:** You can choose to carry a small GPS tracker (about half the size of a deck of card) during the Go-Along interview. The tracker's data is stored on the device (it will be transferred manually to the researcher's secure computer after the interview is complete). This would help support the accurate description and analysis of our tour through the neighbourhood. It will help us align the audio-recording with where we are on the route while the conversation is taking place.

### **COVID-19 Precautions:**

Due to COVID-19, there are a number of safety measures put in place to keep you safe. You will have the option to have the first interview take place either over Zoom, by telephone, or in-person. Please know that all researchers are double vaccinated. If meeting in an indoor space, masks and social distancing measures will be required. For the outdoor Go-Along interview, masks will be optional, however, social distancing measures will still be in place. In terms of using the equipment, you can choose to have it dropped off and picked up in a contactless manner, with training over Zoom or the telephone, or you have the option of being trained on how to use the equipment at your home or at the public location of your choice. If there are any other precautions you would like us to have in place, please let one of the researchers know.

### **What is the time commitment for this role?**

- Session 1: One 30–45-minute conversation in person, over the phone, or Zoom to learn more about your experiences living in your community and to make a plan for the Go-Along interview.
- Session 2: You choose! Our day out in your community can be as short or as long as you like.

**Honoraria:**

People living with dementia and care partners will receive an honorarium of \$70 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?**

- Session 1: For this phase, you have the option to have the conversation take place over the telephone, Zoom, or in-person. If you choose to meet in-person, we can arrange to meet either in your home or a public location of your choice.
- Session 2: The Go-Along portion of the study will take place in person, outdoors, along the route of your choice in your community.

**Will my information be kept confidential?**

The audio-recordings, GPS data and photos will be kept on a secure University of Waterloo OneDrive, and will only be able to be accessed by members of the research team. Any audio-recordings will be transcribed. The recordings will be encrypted and then once transcription and analysis notes are complete, the audio files will be deleted. Once the transcriptions are complete, the audio-recordings will be deleted. (No data from these devices can be transmitted via Bluetooth or accessed in real time, which ensures the security of the data). All study documents will be stored on an encrypted University of Waterloo server for at least 7 years.

You can choose whether or not to be identified in research results. If you do not wish to be identified, your name will not appear in any paper or publication resulting from this project. Instead, quotations would be associated 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.

### **What are the potential benefits of your participation?**

We do not know if being in the study will help you directly. However, with this study, we hope to understand how your community can change to make you feel more comfortable, safe, and supported. The people in your community alongside decisions about roads and sidewalks, stores, programs, businesses, and services affect how you how you can participate and be supported in your community. Through this study, we hope to understand what could be changed about your community to make it more accessible and supportive to you as a person living with dementia. Your involvement may also improve the inclusion of persons living with dementia at a local level, and perhaps have broader long-term impact in other communities across Canada as well.

### **What are the potential risks of your participation?**

We may discuss issues of a sensitive nature that may make you feel upset or anxious. Should you find yourself feeling uncomfortable with the study at any point, please notify the researcher immediately. In addition, you will take the researcher on a tour through your community. We do not expect this to bother you. However, it is possible that you will be seen by someone you might know. If this is upsetting to you, we will stop the interview if you do not feel comfortable proceeding.

### **Is participation in this project voluntary?**

Your involvement in this research study is completely voluntary. You may choose to withdraw from the study by letting the researchers know. You can decline to participate in any part of the study without influencing your future research relationships. If you agree to participate, you will be able to talk about whatever you are comfortable with answering any questions. If there is a question you do not want to answer, you must say, "I don't want to answer that question."

A few other items to note:

- You may decline to answer any of the questions asked during any interviews throughout this research project.
- You may decide to stop the interviews at any time without any consequence.
- Please note that the interviews will be audio- and video-recorded. The audio portion will be transcribed.
- 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 data analysis (within about 2 weeks of your involvement).

If you have any questions about participating on the research team, please reach out to Laura Middleton at [laura.middleton@uwaterloo.ca](mailto: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](mailto:reb@uwaterloo.ca). For all other questions contact Laura Middleton at [laura.middleton@uwaterloo.ca](mailto:laura.middleton@uwaterloo.ca).

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

Yours sincerely, Laura Middleton & Samantha Biglieri