

Canadian Dementia Priority Setting Partnership

*Asking Canadians about their
priorities for dementia research*

Why is this study important?

Better ways to prevent dementia and improve the health and quality of life for people living with dementia are required. Research is vital to achieving these goals. The results of this study will help researchers and research funding organisations make sure that their work focuses on the needs of people affected by dementia.

Who should take part in this study?

- People with dementia
- Friends and family of people with dementia (sometimes called caregivers)
- Health and social care providers (including doctors, nurses, personal support workers, pharmacists, social workers and others)
- People not yet affected by dementia but who are interested in the topic

You must be Canadian or live in Canada to take part in this questionnaire.

What's involved if I take part in the study?

Participating in the study is voluntary. It involves completing this questionnaire, but you do not have to answer any question that you do not want to answer. At the end, you will be asked if you would like to participate in the second phase of the study by helping to decide which of the research topics identified from this questionnaire are most important. If you agree, you will be asked for your name and contact information. We will only contact you if you provide this information. If you do not provide this information, your participation will be anonymous and we will not contact you again.

Will my answers be kept confidential?

All personal information will remain confidential and when we release the results of this study, we will never identify any individual who took part in this questionnaire. Data will be kept at the University Health Network in Toronto and only the study team will have access to it.

Who is supporting this study?

This study is being funded by the [Alzheimer Society of Canada](#) and follows the methods of the [James Lind Alliance](#), a non-profit initiative based in England.

What will happen to the results?

The Alzheimer Society will make the final results public, and use the results to inform their research funding program and also work to promote the results with other researchers and organisations that fund dementia research.

Who can I contact for more information?

If you would like more information, please go to www.alzheimer.ca/researchpriorities or contact:

Dr. Jennifer Bethell
Toronto Rehabilitation Institute -
University Health Network
Bickle Centre, 130 Dunn Ave
Toronto, ON M6K 2R8
Email: Jennifer.bethell@uhn.ca
Telephone: (416) 597-3422 ext. 2158

or Dr. Katherine McGilton, Senior Scientist, Toronto Rehabilitation Institute, email: kathy.mcgilton@uhn.ca or telephone: (416) 597-3422 ext. 2500. If you would like more information about your rights as a participant, please contact the University Health Network Research Ethics Board at (416) 581-7849.

By completing the questionnaire, you are agreeing to participate in the study.

Thank-you for your participation!

Instructions for completing this questionnaire

STEP 1: Your questions about dementia

In step 1, we ask for your questions about dementia. When you answer, please:

- **Think about your own personal and/or professional experience with dementia.** This is what makes you the expert.
- **Provide the question(s) about dementia that are important to you.** To do this, it might be helpful to ask yourself “if it was up to me, where would I spend money on dementia research?”
- **Remember research covers a lot of ground.** Researchers study almost any aspect of dementia, from the microscopic changes that happen inside someone’s brain to the way society treats people with dementia.
- **Feel free to complete the questionnaire alone or discuss and complete it as a pair or as a member of a group.** We welcome any type of response and the questionnaire is set up for responses from individuals, pairs or groups.
- **Don’t worry about which box to write your question(s) in.** Some of the questions may seem similar or overlapping. If so, when you go to write your question(s), you can use any box and we will analyse the responses.
- **Don’t feel like you need to check if there is already research on your question(s).** We will check if there is research that has answered the questions. However, because of the way we are collecting information, we will not be able to respond to you directly with information about your question(s).

STEP 2: Your information

In step 2, we ask for some information about you so that we can understand who has responded to our questionnaire and make sure we hear from all groups.

STEP 3: Your contact information

- The next phase of the study involves putting the research topics identified from this questionnaire into order of importance.
- In step 3, we will ask if you would like to go through the list of research topics and tell us which ones you think are most important.
- If you would like to be involved in this next phase of the study, we will ask you provide your name and contact information.

Every question in every section is optional.

STEP 1: Your questions about dementia

1. What question(s) about living with dementia (or living with someone with dementia) would you like to see answered by research?

2. What question(s) about the barriers to living well with dementia would you like to see answered by research?

3. What question(s) about preventing dementia would you like to see answered by research?

STEP 1: Your questions about dementia continued

4. What question(s) about the treatments for symptoms of dementia would you like to see answered by research?

5. What question(s) about diagnosing or being diagnosed with dementia would you like to see answered by research?

STEP 2: Your information

This will help us keep track of who is completing the questionnaire and make sure we hear from all groups.

1. Are you completing this questionnaire alone or as a pair or group?

- Alone As a pair or group (more than one person)

If you answered "As a pair or group": please skip questions 6-7 but tell us how many people are in your group: _____

2. Which of the following best describes you or the members of your pair or group? Check all that apply.

- Person with dementia
 Partner/relative/friend of a person with dementia
 Caregiver/former caregiver of a person with dementia
 Health and/or social care provider, current profession:
 Nurse
 Occupational therapist
 Pharmacist
 Physician
 Physiotherapist
 Personal support worker, care aide or community health worker
 Social worker
 Other, please specify: _____
 Part of an organisation representing people with dementia
 No direct experience of dementia, but interested in it

3. Which type of dementia do you or the members of your pair or group have experience with? Check all that apply.

- | | |
|---|--|
| <input type="checkbox"/> Alzheimer's disease | <input type="checkbox"/> Creutzfeldt-Jakob disease |
| <input type="checkbox"/> Vascular dementia | <input type="checkbox"/> Fronto-temporal dementia |
| <input type="checkbox"/> Dementia with Lewy bodies | <input type="checkbox"/> Mild cognitive impairment |
| <input type="checkbox"/> Young onset dementia | <input type="checkbox"/> Dementia, but don't know which type |
| <input type="checkbox"/> Other, please specify: _____ | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> No direct experience of dementia | |

STEP 2: Your information continued

4. Which part of Canada do you or the members of your pair or group live in? Check all that apply.

- | | |
|--|---|
| <input type="checkbox"/> Alberta | <input type="checkbox"/> Nunavut |
| <input type="checkbox"/> British Columbia | <input type="checkbox"/> Ontario |
| <input type="checkbox"/> Manitoba | <input type="checkbox"/> Prince Edward Island |
| <input type="checkbox"/> New Brunswick | <input type="checkbox"/> Quebec |
| <input type="checkbox"/> Newfoundland and Labrador | <input type="checkbox"/> Saskatchewan |
| <input type="checkbox"/> Northwest Territories | <input type="checkbox"/> Yukon |
| <input type="checkbox"/> Nova Scotia | |

5. What were the ethnic or cultural origins of your ancestors? Check all that apply.

- | | |
|--|--|
| <input type="checkbox"/> North American Aboriginal | <input type="checkbox"/> Latin, Central or South American |
| <input type="checkbox"/> Other North American (e.g., Canadian or American) | <input type="checkbox"/> African |
| <input type="checkbox"/> European | <input type="checkbox"/> Oceania (e.g., Australian) |
| <input type="checkbox"/> Caribbean | <input type="checkbox"/> Asian (e.g., Middle Eastern, South, East and Southeast Asian) |
| <input type="checkbox"/> Prefer not to say | |

6. How do you identify?

- | | | | |
|-------------------------------|---------------------------------|--------------------------------|--|
| <input type="checkbox"/> Male | <input type="checkbox"/> Female | <input type="checkbox"/> Other | <input type="checkbox"/> Prefer not to say |
|-------------------------------|---------------------------------|--------------------------------|--|

7. In what year were you born? _____

- Prefer not to say

STEP 3: Your contact information

Thank you for completing this questionnaire!

The next phase of the study involves putting the research topics identified from this questionnaire into order of importance. If you would like to go through the list of research topics and tell us which ones you think are most important, please provide your contact information either on line at <https://surveys.uhnresearch.ca/index.php?sid=73463&lang=en> or by contacting the study office by telephone, email or in writing to:

Dr. Jennifer Bethell
Toronto Rehabilitation Institute -
University Health Network
Bickle Centre, 130 Dunn Ave
Toronto, ON M6K 2R8
Email: Jennifer.bethell@uhn.ca
Telephone: (416) 597-3422 ext. 2158

To maintain your confidentiality, please do not provide your contact information when returning the questionnaire.

