

Canadian Frailty Priority Setting Partnership

What is frailty?

We usually associate frailty with noticeable losses in a person's physical, mental or social functioning. Frailty is a health state continuum ranging from fit to very frail, involving multiple health problems and often associated with getting older. Frailty can result from a range of diseases and conditions where even fairly minor health events can trigger major changes in a person's health status.

Why is this study important?

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 frailty.

Who should take part in this study?

- Older adults who are concerned about frailty
- Friends, family and caregivers of frail older adults
- Health and social care providers

You must live in Canada to take part.

Do I have to take part in the study?

Your participation in this study is voluntary and you have the right to refuse participation.

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

You will not receive any direct benefit from participating. Being in the study involves completing this questionnaire. You will be asked to provide questions you would like answered about frailty as well as to provide some information about yourself and asked if you would like to participate in the next phase

of the project. You do not have to answer any question that you do not want to answer.

Will my answers be kept confidential?

All information obtained during the study will be held in strict confidence. Representatives of the University Health Network Research Ethics Board may look at the study records to check that the information collected for the study is correct and to make sure the study followed proper guidelines.

Who is supporting this study?

This study is funded by the [Canadian Frailty Network](#), a non-profit network dedicated to improving care of frail older Canadians.

What will happen to the results?

The [Canadian Frailty Network](#) will make the final results public, and use the results to inform their research funding program.

Who can I contact for more information?

For more information, please contact:

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

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (REB) or the REB office number 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 frailty

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

- **Think about your own personal and/or professional experience with or knowledge of frailty.** This is what makes you the expert.
- **Provide the question(s) about frailty 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 frailty research?”
- **Remember research covers a lot of ground.** Researchers study almost any aspect of frailty, from the microscopic changes that happen inside someone’s body to the way society treats people with frailty.
- **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.

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

In step 3, we will ask if you would like to be contacted in the coming months to go through the list of research topics and tell us which ones you think are most important.

Every question in every section is optional.

Answer only the questions you feel comfortable answering.

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?

- Yes
- No
- Prefer not to say

If you answered “No”: please skip questions 5 to 8, but tell us how many people are in your group: _____

2. Which of the following best describes you? Check all that apply.

- Older adult concerned about frailty (i.e., experiencing noticeable losses in health and/or physical, mental or social functioning)
- Older adult with no direct experience of frailty, but interested in it
- Partner, relative or friend of a frail older adult
- Caregiver or former caregiver of a frail older adult
- Health and/or social care provider, current profession:
 - Nurse
 - Occupational therapist
 - Pharmacist
 - Physician
 - Physiotherapist
 - Personal support worker, care aide or community health worker
 - Recreation therapist
 - Social worker
 - Other, please specify: _____

3. Which part of Canada do you 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 | |

4. What are your ethnic or cultural origins? Check all that apply.

- North American Aboriginal
- Other North American (e.g., Canadian or American)
- European
- Caribbean
- Prefer not to say
- Latin, Central or South American
- Asian (e.g., Middle Eastern, South, East and Southeast Asian)
- Oceania (e.g., Australian)
- African

5. What is the highest certificate, diploma or degree that you have completed?

- Less than high school diploma or its equivalent
- High school diploma or a high school equivalency certificate
- Post-secondary certificate or diploma (including college, CEGEP or trades)
- University degree
- Prefer not to say

6. How do you identify?

- Male
- Female
- Other
- Prefer not to say

7. In what year were you born? _____ Prefer not to say

8. Do you receive the Guaranteed Income Supplement?

- Yes
- No
- 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 be contacted in the coming months to go through the list of research topics and tell us which ones you think are most important, please provide your contact information (your email address, mailing address or telephone number – whichever you prefer) either on line at <<insert limesurvey website link>> 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

Please note that providing your contact information does not mean you have to participate in the next phase; ongoing participation is voluntary and you can refuse to take part when we contact you.

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

