

INFORMATION PAGES FOR PROXY INFORMATION PROVIDER

Title: Canadian Longitudinal Study on Aging (CLSA)

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What is the Canadian Longitudinal Study on Aging (CLSA)?

The CLSA is a Canada-wide study that looks at health and aging over a 20-year period. It is designed to collect a wide range of information about people's health as they age, including that which is relevant for their physical, emotional and social functioning, as well as the onset of health conditions and diseases. The information collected will be used by many researchers for decades to come with a goal to improve the health of Canadians.

What is the purpose of a proxy information provider?

People currently participating in the study joined when they were between the ages of 45 to 85, and are contacted to provide data every three years. With a longitudinal study there may come a time when a research study participant is no longer able to participate further on their own, usually due to physical or cognitive health reasons. Because of this, participants are asked if they would like someone to act as their CLSA information provider should they lose the capacity to provide information about themselves to the study. Those that choose this option are also asked to provide their designated proxy information provider's contact information and to identify their wishes concerning how they would like (or would not like) to continue to participate in the study if they become unable, for any reason, to take part on their own.

Who is a proxy information provider?

- A proxy information provider is someone, usually designated by the participant, who provides questionnaire-based information about the

participant to researchers, when the participant cannot (or simply may not want to) do so on their own anymore.

- A proxy information provider is someone who usually knows the participant well or sees them often, such as a family member, friend or care-giver.
- Optimally, a proxy information provider would be the person who is best able to answer questions about the participant.

What is my role as a proxy information provider?

- There are two proxy roles: 1) proxy decision maker; and 2) proxy information provider. You may be named as both the proxy decision maker and the proxy information provider, or you may be named as the proxy information provider only.
- As the proxy information provider, you will be contacted and asked to answer study questions about the participant by telephone, once every three years.
- If you are the proxy information provider only, please be aware that decisions to remain in the study are made by the proxy decision maker.

Is there any guidance for me as a proxy information provider for the participant?

- Continue to consult with the participant as much as possible.
- Consult as needed and appropriate with family members and professionals who likely have knowledge of the ongoing health, history and living

conditions of the participant.

- The CLSA understands that you can only provide information about the participant to the best of your ability and knowledge.

How can I get more information about the CLSA?

- You can choose to be sent regular updates about the study progress through electronic or mailed newsletters.
- Information about the CLSA's ongoing research, the research team and general study results are available on the CLSA website (www.clsa-elcv.ca).

Is there any way I can be replaced as a proxy information provider?

- You can choose to withdraw from your role as proxy information provider at any time. Withdrawal from this role does not mean that the participant will be withdrawn from the CLSA.
- The CLSA will contact you at least every three years to complete the CLSA proxy interview. Additional attempts to contact may be made at certain time points (at 18 months between interviews, for example), to maintain contact.
- If the CLSA is unable to reach you after three attempts using the contact information we have on file for you (telephone, email address, and mailing address), we will consider that you have withdrawn from your role as proxy information provider. In that case, a replacement proxy information provider may be contacted. This replacement will be named by the acting



proxy decision maker.

- It is important that you keep the CLSA up-to-date about any changes to your contact information, so that we can be sure to reach you.

How do I contact the CLSA?

Any time you have questions about the study you may write, call the CLSA toll-free number or send us an e-mail message:

For Residents of British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Prince Edward Island, or Nova Scotia

PLEASE CALL:

Toll-free: 1-866-999-8303

French and English

e-mail: info@clsa-elcv.ca

mailing address:

McMaster University-CLSA

1280 Main Street West

Hamilton ON L8S 4K1

For Residents of Newfoundland or Labrador PLEASE CALL:

English Toll-free: 1-888-908-4988

French Toll-free: 1-866-999-8303

(Dr. Zhiwei Gao, Site Investigator, Memorial University)



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