

INFORMATION PAGES FOR PROXY DECISION MAKER

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 decision maker?

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 make certain decisions usually due to physical or cognitive health reasons. Because of this, participants are asked if they would like someone to act as their CLSA proxy decision maker should they ever lose the capacity to make decisions related to their participation in the study. Those that choose this option are also asked to provide their designated proxy decision maker'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 decision maker?

- A proxy decision maker is someone, usually designated by the participant, who makes decisions on the participant's behalf concerning all matters relevant to their participation in the study.

- A proxy decision maker is usually someone who is close to the participant, such as a spouse, family member, friend or care-giver.
- A proxy decision maker can be a person who has been named to look after a participant's affairs, such as a power of attorney.

What is my role as a proxy decision maker?

As the proxy decision maker for the participant, you will be asked to make decisions on their behalf.

- At a minimum, the proxy decision maker would decide if the participant is to remain in the study (when the participant can no longer decide this for themselves).
- If the participant loses capacity to be interviewed, the proxy decision maker would decide if they themselves or someone else (called "a proxy information provider") may be interviewed to provide information *about* the participant to the CLSA.
- Other decisions could include, whether the CLSA may link information about the participant with other health databases (if the study participant previously agreed to this).

As a proxy decision-maker, the CLSA will contact you every three years to confirm your decisions made on the participant's behalf.

Is there any guidance for me as a proxy decision maker for the participant?

- The CLSA retains a record of the participant's own decision about whether they wish to designate a proxy information provider and if so, who that person is. The CLSA also retains records of the participant's wishes about participating in each aspect of the study. If you decide to act as the participant's proxy decision maker, someone from the CLSA will discuss these decisions with you and a copy of the relevant records will be made available to you upon request.
- The participant may also have discussed their wishes (for future participation in the study) with you at the time that they designated you as their proxy decision maker
- In general, as a proxy decision maker you are encouraged to consider what the participant would have decided if they were in a position to make the decisions on their own.

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 decision maker?

- You can choose to withdraw from your role as proxy decision maker 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 confirm that the CLSA can continue with proxy data collection. Additional attempts to contact may be made at certain time points (at 18 months between interviews, for example), to maintain contact with you or ask about any new or additional research that is being proposed.
- 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 decision maker. In that case, a replacement proxy decision maker may be contacted. This replacement will be on file as an alternate, named by the participant. Not all participants will provide alternate proxy decision makers.
- 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 or your role as a proxy decision maker 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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