

STUDY INFORMATION PACKAGE

Title: Canadian Longitudinal Study on Aging (CLSA)

Lead Principal Investigator:

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Memorial University of
Newfoundland

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University of Victoria

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What is the purpose of the CLSA?

The CLSA is a Canada-wide study that looks at health and aging over a 20-year period. People who are between the ages of 45 and 85 are being invited to take part. We will collect a wide range of information about people's health as they age, such as physical, emotional and social health and functioning, as well as the onset of health conditions and diseases. The information collected as part of the CLSA will be used by many researchers over the next four to five decades.

With your help, researchers will be able to answer a wide range of questions, such as:

- What are the things that affect how adults age?
- Why do some people stay healthy as they get older and other people develop health problems?
- What life changing events do people face as they get older and how to they cope with them?



What will I be asked to do if I volunteer to be part of the CLSA?

You will be asked to:

- Have a CLSA interviewer contact you by telephone at your convenience, to ask questions about yourself and your physical, emotional and social health functioning. This interview will be repeated every 3 years (70 minutes).
- Be called on the phone by a CLSA interviewer mid-way between each 3-year interview to maintain contact and answer a few more questions about your health and well-being (35 minutes).
- We will also ask you to provide your Health Card Number to enhance the quality of this research project. However, you can refuse this part of data collection and still participate in the study.
- Over 20 years this adds up to about 2-3 days of your time.



Why am I being asked to give the CLSA my Health Card Number?

- Your provincial healthcare records will be linked to data collected by the CLSA to study patterns of health and health care over time. For example, Ministries of Health in each province keep records about your visits to doctors and hospitals, medicines you fill a prescription for, and what people die from.
- Linking will occur from the date you agree to participate in the CLSA onward.
- The Ministries of Health will have no access to the data collected by the CLSA.

How will my information be managed and kept safe?

- As with all studies that collect personal information, there is a remote possibility that third parties, such as an insurance company or employer could get your personal information without permission of the CLSA.
- Many levels of safeguards have been put in place to reduce this risk.



Your name, address, and phone number will be kept in a secure database with a unique study number at McMaster University and will only be used to contact you.

- The rest of the study information, without your contact information, will also be stored in a secure database at McMaster University.
- Your study information, without your contact information, will also be stored on a secure computer at McGill University for analyses by researchers.
- All CLSA staff will sign an agreement to protect your privacy and confidentiality.

CLSA has a privacy policy which includes the above information. You can read this policy on the CLSA website at www.clsa-elcv.ca. If you would like a copy, call **toll-free: 1-866-999-8303**.

Who will have access to my data?

- The CLSA Data and Sample Access Committee must approve requests from researchers from Canada and other countries to use your data.



- Researchers from other countries will not be able to use your linked healthcare records.
- Researchers from private businesses will not have direct access to your data, but may be part of a research team.
- Your study information will NOT be released by the CLSA to a third party (other than an approved researcher) unless ordered to do so by a court order or by law.

Will I be told about research projects using CLSA data?

- The CLSA will keep a list of the projects using the CLSA data on its website.
- You will be able to see the names of researchers, a description of the project and a summary of the results (once the project is completed).
- You can also get this information by calling the CLSA, **toll-free: 1-866-999-8303.**

Will there be changes in the study over 20 years?

- Most of the topics and items will stay the same.
- New topics and tests, however, may come to light over the 20-year period as science moves forward. If this means the



way you take part in the study is different, you will be asked to provide a new consent.

- All changes will be approved by a Research Ethics Board.

How long will the CLSA keep information about me?

- The CLSA is enrolling people to take part in the study from 2011-2014.
- When the CLSA stops collecting new information from people, your contact information (name, address, phone number) will be destroyed.
- Information will be collected from you over the next 20 years.
- Data will be kept and used for research for another 25 years. Data may be destroyed after this time based on the advice of an ethics board.
- The CLSA is designed to exist until 2059.



What happens if I move while I am a part of the CLSA?

- We will do our very best to follow you to where you move.
- You can contact the CLSA by mail, phone or e-mail to tell us that you are moving.
- At the first interview we will also ask you for the name of a person who would know of your whereabouts if you move.

What happens if I am no longer able to make decisions or answer questions as I get older?

- The CLSA would like to know about all aspects of the aging process.
- If you are aged 70 or older now (or when you reach age 70) we will ask you to provide the name of another person(s), such as a spouse, adult child, or legal guardian. This person(s) will be able to answer questions on your behalf or make decisions for you, such as withdraw you from the study.
- There will be a separate consent package for the process for identifying this person(s).



- Information already collected from you will stay as part of the CLSA records and be kept for research purposes.

What if I decide at some point that I no longer want to be part of the CLSA?

You can choose to withdraw from the study at any time.

- If you choose to withdraw from the study, the CLSA will not contact you in the future.
- You will be given choices about the use (or destruction) of your data already collected and whether you would like us to continue to link your existing data to data about you in your healthcare records.
- However, data that has already been used by researchers cannot be taken out of current or completed projects.
- You may inform the CLSA of your decision when we contact you or at any time by phone, regular post or e-mail.

What happens to information about me if I die while I am still a participant in the CLSA?

- Information collected about you up until the time of your death will remain part of the CLSA for research purposes.



Will I get any personal benefit from taking part in the CLSA?

- You will not get any direct personal benefit from taking part in the CLSA.

Will there be a cost to me to take part in this study?

- The only cost to you is the time that it takes you to take part in the CLSA.

How can I get more information about the CLSA?

- As a person taking part in the study you can choose to be sent regular updates about the study progress through electronic or mailed newsletters.
- Information about ongoing research, the research team, and general study results will be posted on the CLSA website (www.clsa-elcv.ca).



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, Nova Scotia
or PEI**

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. Gerry Mugford, Site Investigator, Memorial University)



Who do I talk to at the Research Ethics Board if I have questions about my rights as a research participant?

- Contact the Research Ethics Board that is affiliated with the telephone interviewing facility with whom you have discussed taking part in the study, or any of the three lead sites.

NEWFOUNDLAND AND LABRADOR

Memorial University
Faculty of Medicine
Health Research Ethics Authority
2nd Floor, Bonaventure Place
95 Bonaventure Avenue
St. John's NL A1B 2X5
Phone: (709) 777-6974

QUEBEC

Germain Lambert
Local Service Quality and Complaints
Commissioner
Centre de santé et des services sociaux –
Institut universitaire de gériatrie de
Sherbrooke
1036, rue Belvédère Sud
Sherbrooke QC J1H 4C4
Phone : (819) 821-1170 poste 40204
Email : glambert.csss-iugs@ssss.gouv.qc.ca

NOVA SCOTIA

Director
Office of Research Ethics
Administration
Dalhousie University
6299 South Street
2nd Floor, Suite 231
Halifax NS B3H 4H6
Phone: (902) 494-1462

Ms. Ilde Lepore
Senior Ethics Administrator
McGill Institutional Review Board
McGill University
Faculty of Medicine
McIntyre Medical Building
#633 – 3655 Promenade Sir William
Osler
Montreal QC H3G 1Y6
Phone: (514) 398-2334
Email: ilde.lepore@mcgill.ca



Who do I talk to at the Research Ethics Board if I have questions about my rights as a research participant?

ONTARIO

Office of the Chair
Hamilton Health Sciences
Faculty of Health Sciences
Research Ethics Board
293 Wellington St. N., Suite 102
Hamilton ON L8L 8E7
Phone: (905) 521-2100 ext. 42013

MANITOBA

Bannatyne Campus
Research Ethics Board
University of Manitoba
P126 Pathology Building
770 Bannatyne Avenue
Winnipeg MB R3E 0W3
Phone: (204) 789-3883

BRITISH COLUMBIA

Human Research Ethics
Office of Research Services
University of Victoria
Administrative Services Building (ASB),
Room B202
PO Box 1700 STN CSC
3800 Finnerty Road
Victoria BC V8W 2Y2
Phone: (250) 472-4545

Thank you for your time.



www.clsa-elcv.ca

Toll-free: 1-866-999-8303

