

STUDY INFORMATION PACKAGE & SUMMARY

Title: Canadian Longitudinal Study on Aging (CLSA)

Lead Principal Investigator:

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Co-Principal Investigators (Co-PIs):

Dr. Christina Wolfson, Research Institute, McGill University Health Centre

Dr. Susan Kirkland, Departments of Community Health and Epidemiology and Medicine, Dalhousie University

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Dr. Vanessa Taler
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Dr. Debra Sheets
Dr. Lynne E. Young
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Dr. Verena Menec
University of Manitoba

Dr. Andrew Wister
Simon Fraser University

Biorepository & Bioanalysis Centre Investigator:

Dr. Cynthia Balion
McMaster University

Supported by:

Government of Canada through the Canadian Institutes of Health Research and the Canada Foundation for Innovation

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 do 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 come to your home, at your convenience, to ask you questions about yourself and your physical, emotional and social health and functioning. This interview will be repeated every 3 years (70 minutes).
- Visit a CLSA Data Collection Site in your area once every 3 years to have physical tests done such as height, weight, blood pressure and bone density (2 to 3 hours).
- Be called on the phone by a CLSA interviewer mid-way between each 3-year visit to maintain contact and answer a few more questions about your health and well-being (35 minutes).

- We will also ask you to provide blood and urine samples and 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 3-4 days of your time.

Why am I being asked to give blood and urine samples?

- Blood and urine contain many different substances that show how the body is working. For example, high glucose in your blood may be a sign of diabetes.
- Because genes are thought to play an important part in how we age, the blood samples and cells created from your blood samples will be used to learn about the role of genes in health, disease and aging.
- Results of blood and urine tests (including genetic tests) will be used for research purposes only.

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

- Your provincial health care 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.

What tests are done at the Data Collection Site?

The table below describes the tests that will be done at the Data Collection Site along with the risks associated with each test:

Type of Test	What are these tests for?	What will the test involve?	What are the possible risks?
Physical assessment (4 min)	To learn about body size and shape	Standing on a scale to measure height, weight, waist and hip size	No risk
Bone density and composition (10 min)	To learn about your bones, muscles, and fat	Lying on a flat table where an X-ray beam will scan your body	You will be exposed to a small amount of radiation that is equal to a dental X-ray
Heart function (20 min)	To learn how your heart works: blood pressure, thickness of arteries, and heart rate	Having a cuff placed around your arm and ankle Applying gel and placing a sensor on your neck Placing small patches called electrodes on your chest, arms and legs	No risk, however you may feel pressure from the inflating cuff No risk with sensor or gel No risk, however we may need to shave some hair to place the patches on your body
Strength testing (12 min)	To assess strength in your hands, arms, legs and overall body	Squeezing a device, walking a short distance, rising and sitting on a chair, standing on one leg with a spotter nearby	No risk

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Lung test (5 min)	To learn how your lungs work	Taking a deep breath and blowing hard and fast into a mouth piece	No risk, however it is possible that you may feel mildly dizzy, short of breath, or cough
Memory test (27 min)	To learn how your brain works	Counting, remembering and solving problems	No risk, however you might feel frustrated with some questions
Vision and Hearing tests (7 min)	To learn about your sight and hearing	Reading letters on a chart and allowing us to measure the pressure in your eye. Putting headphones on and listening for sounds	Checking the pressure in your eye can occasionally cause minor irritation. No risk
Blood and Urine Samples (10 min)	To learn how your body is working by testing blood and urine	Giving about 50 mL of blood (about 3 tablespoons) and giving a urine sample	You may feel mild “pin-prick” pain from the needle or have a small bruise on your arm. Some people may also feel dizzy Although very rare, infection may occur
Questionnaire (25 min)	To learn about your health and disease symptoms	Answering a series of questions using a questionnaire	You may feel some of the questions are very personal, but you can choose not to answer those questions

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 or genetic 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 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.

Blood and urine samples collected from you are:

- Labelled with a unique study number, not your name, at the time of collection.
- Stored in freezers to protect them for a long time.
- Kept in a safe place that has security 24 hours a day at McMaster University.

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 and samples?

- The CLSA Data and Sample Access Committee must approve requests from researchers from Canada and other countries to use your data and samples.
- 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 and samples, but may be a 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 and samples 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 I receive information about my tests done in the CLSA?

- Your visit to a CLSA Data Collection Site does not replace a visit to your doctor or other healthcare provider.
- Test results that will be returned to you include: (1) body mass index; (2) waist and hip circumference; (3) blood pressure; (4) hearing; (5) vision; (6) lung capacity; and (7) bone mineral density.
- If a result is outside of the normal range, it will be suggested that you visit your doctor or other healthcare provider to talk about the result.
- The CLSA will not send any results directly to your doctor or other health care provider.
- You will not receive any other test results including genetic tests. This is because many of the tests are exploratory and do not currently have a clinical use for healthcare or because it is not feasible.

Will there be changes in the study over 20 years?

- Most of the topics and tests 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 will be 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 and samples will be kept and used for research for another 25 years. They 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 your whereabouts if you move.

What happens if I am no longer able to make decisions or answer questions for myself 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 a 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 and samples already collected and whether you would like us to continue to link your existing data to data about you in your health care records.
- However, data and samples that have already been used by our 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.
- It is possible that, someday, data and samples collected by the CLSA will lead to new tests that could help society, for example, a diagnostic test. Should this be the case, you will receive no financial gain.

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.
- You will be given \$30 at each visit to the Data Collection Site to put toward expenses such as parking or child care.

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, Manitoba, Ontario, Quebec
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. 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 Data Collection Site with whom you have discussed taking part in the study.

Note: Please do not call the Ethics office for rescheduling or cancelling appointments. Please call the CLSA toll-free numbers provided on the last page of this document.

BRITISH COLUMBIA

BURNABY

Dr. Jeff Toward, Director
Office of Research Ethics
Simon Fraser University
8888 University Drive
Multi-Tenant Facility
Burnaby BC V5A 1S6
Phone: (778) 782-6593
E-mail: jtoward@sfu.ca

VANCOUVER

University of British Columbia
Office of Research Services
6190 Agronomy Road
Vancouver BC V6T 1Z3
Phone: toll free 1-877-822-8298
Phone: local (604) 822-8598

VICTORIA

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

Vancouver Island Health Authority
Research Ethics Office
1952 Bay Street
Victoria BC V8R 1J8
Phone: (250) 370-8620



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ALBERTA

CALGARY

Conjoint Health Research Ethics Board
University of Calgary
Phone: (403) 220-7990

MANITOBA

WINNIPEG

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

ONTARIO

HAMILTON

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

OTTAWA

Dr. Dorothy Kessler, Chair
Bruyère Continuing Care
Research Ethics Board
Attention: Debbie Brown
43 Bruyère Street, Room 739D
Ottawa ON K1N 5C8
Phone: (613) 562-6262 ext. 4003
E-mail: dbrown@bruyere.org



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

Note: Please do not call the Ethics office for rescheduling or cancelling appointments. Please call the CLSA toll-free numbers provided on the last page of this document.

QUEBEC

MONTREAL

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) 398-8302
E-mail: ilde.lepore@mcgill.ca

SHERBROOKE

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
E-mail: glambert.csss-iugs@ssss.gouv.qc.ca

NOVA SCOTIA

HALIFAX

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

NEWFOUNDLAND & LABRADOR

ST. JOHN'S

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

Thank you for your time.



www.clsa-elcv.ca

For Residents of British Columbia, Alberta, Manitoba, Ontario, Quebec
or Nova Scotia

PLEASE CALL:

Toll-free: 1-866-999-8303

For Residents of Newfoundland or Labrador

PLEASE CALL:

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

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



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