

## **FAMILY MEMBER OR FRIEND STUDY INFORMATION PACKAGE**

**Study Title:** Canadian Longitudinal Study on Aging (CLSA) Memory Study

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The Public Health Agency of Canada

**Conflicts of interest:** There are no conflicts of interest to declare related to this study.

## What is the purpose of the CLSA Memory Study?

- The purpose of this research study is to determine whether information that is collected through CLSA interviews can be used to correctly identify individuals who have memory problems and individuals without memory problems.

## How many people will take part in the CLSA Memory Study?

- We will recruit approximately 600 participants from the 11 CLSA Data Collection Sites in Canada (Surrey, British Columbia; Victoria, British Columbia; Vancouver, British Columbia; Calgary, Alberta; Winnipeg, Manitoba; Hamilton, Ontario; Ottawa, Ontario; Montréal, Quebec; Sherbrooke, Quebec; Halifax, Nova Scotia; and St. John's, Newfoundland).
- This study will take approximately two years to complete and the results should be known in approximately three years.

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

- **A staff member from your family member or friend's local CLSA Data Collection Site will contact you to discuss the CLSA Memory Study in the next couple of weeks.** You will have an opportunity to ask any questions that you may have. If you are interested in participating in the CLSA Memory Study, the CLSA staff member will ask for your consent to participate.
- **You will be asked to complete an interview over the phone with a staff member from the CLSA.** You will be asked questions about your family member or friend's medical history, habits, and ability to complete everyday tasks. The interview will take approximately 20 minutes and can either be completed during this phone call or will be scheduled at a time convenient for you. Your family member or friend does not need to be present for your interview.

- The information you provide will be reviewed by a study physician who will also complete a medical assessment with your family member or friend. The information from your interview and the medical assessment will allow the study physician to determine if there is a potential concern about your family member or friend's memory or if their memory appears normal.
- The study physician may contact you by phone if they have any follow-up questions about the information you provide.

### **How will the information I provide to the CLSA Memory Study be used?**

- The data you provide to the CLSA Memory Study will be used to develop a method of identifying CLSA participants who have memory problems and individuals without memory problems in the main CLSA study.
- If the results of this study are published, your identity will remain confidential. It is expected that the information collected during this study will be used for analyses and will be published and presented to the scientific community at meetings and in journals.

### **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 access the information you have provided without permission of the CLSA. Many levels of safeguards have been put in place to reduce this risk.
- All identifiable information will be kept in a secure database with a unique study number at McMaster University and will only be used to contact you. The information that you provide for us, without your name or contact information, will be stored in a secure database at McMaster University. Data collected by interviewers are transferred to the McMaster database over secure, encrypted connections.
- All CLSA staff will sign an agreement to protect your privacy and confidentiality.

- The CLSA Memory Study data will not be available to other researchers through our general study data access processes. Any requests to access the CLSA Memory Study data will need to be submitted to and approved by the CLSA Memory Study principal investigators. Researchers using data from the CLSA Memory Study will not be provided with any identifying information.
- Records identifying you as a participant in the CLSA Memory Study will be kept confidential and, to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this document. If required, direct authorized representatives of the following organizations may look at your original identifiable data to check that the information collected for the study is correct and follow proper laws and guidelines:
  - The research ethics boards who oversee the ethical conduct of this study at each institution
- If you would like more information about how the CLSA protects your data, please contact us by email at **info@clsa-elcv.ca** or telephone at **1-866-999-8303**.
- Every effort will be made to keep the information you provide private, but risk of accidental disclosure is possible.

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

- Your agreement to participate in the CLSA Memory Study is entirely voluntary.
- If you decide to not take part in the CLSA Memory Study, there will be no penalty or loss of benefit to you
- Your decision to participate in the CLSA Memory Study does not affect your family member or friend's ongoing participation in the CLSA Memory Study, or the main CLSA study that they have participated in since 2011-2015.
- You can choose to end your participation in this research (called withdrawal) at any time without having to provide a reason. If you choose to withdraw from the study, you are encouraged to contact the research team.

- If you decide to leave the study, we will stop contacting you for the CLSA Memory Study. You may ask that the information that you provided not be used for the study. However, once the study results have been released, we will not be able to be remove it from our datasets. If you have any questions about the CLSA Memory Study, please contact us using the provided email address or telephone number.

By email  
**info@clsa-elcv.ca**

By telephone  
**1-866-999-8303**

### **Can participation in the CLSA Memory Study end early?**

- Your participation in the CLSA Memory Study may be stopped early, and without your consent, for reasons such as:
  - New information shows that the research is no longer in your best interest
  - The research team decides to stop the study
  - The research ethics board withdraws permission for the study to continue
  - Your family member or friend decides to withdraw from the CLSA Memory Study

### **Will I get any personal benefit from taking part in the CLSA Memory Study?**

- You will not get any direct personal benefit from taking part in the CLSA Memory Study.
- Your participation in the CLSA Memory Study will contribute to potentially developing new ways to identify individuals with memory problems, even if they have not been diagnosed by a physician.

## **Are there any risks to taking part in the CLSA Memory Study?**

- There are no direct medical risks associated with participation in this study.

## **What are the rights of participants in a research study?**

- You will be told in a timely manner about new information that may be relevant to your willingness to stay in this study.
- You have the right to be informed of the overall results of this research once the entire study is complete. Information about ongoing research, the research team, and general study results will be posted on the CLSA website ([www.clsa-elcv.ca](http://www.clsa-elcv.ca)) as well.
- Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.
- If you consent to participate in the CLSA Memory Study, you do not give up any of your legal rights against the research team, the Public Health Agency of Canada, or involved institutions for compensation, nor does this form relieve the research team, the Public Health Agency of Canada, or their agents of their legal and professional responsibilities.
- Each research ethics board has reviewed this study. The research ethics boards are responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions regarding your rights as a research participant, you may contact the Research Ethics Board associated with your Data Collection Site:

**Note: Please do not call the Ethics office for rescheduling or cancelling appointment. Please call the CLSA toll-free number (1-866-999-8303).**

## **BRITISH COLUMBIA**

### **BURNABY**

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### **VICTORIA**

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