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Supplementary Appendix 1 – Participant Information Package for Tracking and Comprehensive Cohort Participants

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Participant Information Package Cover Letter for Tracking Cohort Participants

Dear [Participant],

As a longstanding participant in the Canadian Longitudinal Study on Aging (CLSA), we are inviting you to participate in the CLSA Memory Study. Participants in the CLSA Memory Study will be asked to:

1. Undergo a medical assessment by a study physician at the CLSA Data Collection Site. The CLSA Data Collection Site is within 25 to 50km of your home. You will be given $30 in cash or as a gift card in lieu of expenses such as parking or other travel related expenses. The assessment will include questions about your medical history and a brief cognitive test which includes answering questions and drawing on paper. The doctor will also complete a neurocognitive examination, which involves assessing your ability to see, observing you move, and listening to you speak.
2. Identify a family member or friend who knows you well to complete an interview by phone regarding your cognitive health, ability to complete daily tasks, and behaviour.

The CLSA Memory Study is being funded by the Public Health Agency of Canada (PHAC). The CLSA Memory Study is being led by Dr. Lauren Griffith, Dr. Andrew Costa, and Dr. Parminder Raina, all from McMaster University. Other researchers from universities across Canada are also involved.

[Attached to this email are/This package contains] two documents that will provide you with information to help you make an informed choice about if you would like to take part in this study.

1. **Participant Study Information Package** – This package includes information about the study for you to review.
2. **Family Member or Friend Study Information Package** – This package includes information for the family member or friend you ask to complete the telephone regarding your cognitive health, ability to complete daily tasks, and behaviour. If you see your family member or friend in person, you may choose to share this information package with them. Otherwise, we can arrange to send a physical or electronic copy to them.

Please read the **Participant Study Information Package** carefully. We will call you in the next few weeks and you will have an opportunity to ask any questions you may have. You may also find it helpful to discuss this study with your friends and family.

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If you wish to contact us directly, please feel free to:

- Email at **info@clsa-elcv.ca**
- Call our toll-free line at **1-866-999-8303**

Thank you,

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Participant Information Package Cover Letter for Comprehensive Cohort Participants

Dear [Participant],

As a longstanding participant in the Canadian Longitudinal Study on Aging (CLSA), we are inviting you to participate in the CLSA Memory Study. Participants in this study will be asked to:

1. Undergo a medical assessment by a study physician at the CLSA Data Collection Site. The assessment will include questions about your medical history and a brief cognitive test which includes answering questions and drawing on paper. The doctor will also complete a neurocognitive examination, which involves assessing your ability to see, observing you move, and listening to you speak.
2. Identify a family member or friend who knows you well to complete an interview by phone regarding your cognitive health, ability to complete daily tasks, and behaviour.

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PARTICIPANT STUDY INFORMATION PACKAGE

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

Principal Investigators:

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Dr. Benoît Cossette – Université de Sherbrooke
Dr. Christina Wolfson – McGill University

Ontario
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Dr. Aaron Jones – McMaster University
Dr. Alexandra Mayhew – McMaster University
Dr. Vanessa Taler – University of Ottawa
Dr. Mary Thompson – University of Waterloo
Dr. Changbao Wu – University of Waterloo

Manitoba
Dr. Verena Menec – University of Manitoba

Saskatchewan
Dr. Megan O'Connell – University of Saskatchewan

Alberta
Dr. David Hogan – University of Calgary
Dr. Eric Smith – University of Calgary

British Columbia
Dr. Scott Hofer – University of Victoria
Dr. Teresa Liu-Ambrose – University of British Columbia
Dr. Andrew Wister – Simon Fraser University

Supported by:
The Public Health Agency of Canada

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

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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 local 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 you a few questions to assess if you are eligible to participate and to determine that you understand the study before asking for your consent to participate.

- **Book an appointment for your medical assessment with a study physician at your local Data Collection Site.** This appointment will take place at a time convenient for you and the assessment will last one hour. If you have not yet completed your main CLSA Follow-up 3 interview, your medical assessment appointment will be scheduled on a separate date.

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- **Identify a family member or friend who knows you well and can respond to questions about your cognitive health, ability to complete daily tasks, and behaviour.**
  - We will ask for the name and phone number of your family member or friend when we call to book your medical assessment. If possible, we ask that you discuss the study with this person and to let them know to expect a phone call from the CLSA.
  - Your family member or friend will be asked to complete a 20-minute interview with a CLSA staff member over the phone before your medical assessment. You do not need to be present for the interview with your family member or friend. Your family member or friend may be contacted after your medical assessment to clarify the information provided.
  - The CLSA will not share any personal information about you with your family member or friend.
- **The day before your appointment, the CLSA may contact you to review the screening questions for COVID symptoms and exposure, depending on the requirements of their institution.**
- **You will visit your local Data Collection Site for your medical assessment with the study physician.** The day of your appointment, the Data Collection Site may review the screening questions for COVID symptoms and exposure, according to their own protocols. The study physician will:
  - Conduct an assessment which will include questions about your medical history, your habits, and your ability to do everyday activities.
  - Ask you to complete a brief cognitive test which includes answering questions and drawing on paper.
  - Assess your neurological function by assessing your ability to see, observing you move, and listening to you speak.

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- Ask what medications you are taking. We ask that you bring your physical medications or a list of your medications to your medical assessment for the study physician to review.

Will I receive a medical diagnosis from the CLSA Memory Study?

- The study physician will determine if there is a potential concern about your memory or if your memory seems normal. This is not considered a medical diagnosis.

- If the study physician identifies a potential concern about your memory, they will give you a letter about the study and some of your individual results that you may want to share with your family doctor.

- If you do not have a family doctor, the study physician will provide you with some suggested resources regarding the potential concern about your memory.

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 from taking part in the CLSA Memory Study?

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

- Some participants may feel tired or frustrated during the medical assessment with the study physician. If you need a break during the medical assessment, please ask the study physician.

- Some participants may feel worried about if the study physician will identify a potential concern about their memory. Participants identified as having a

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potential concern about their memory will have an opportunity to speak with the study physician to discuss their concerns.

- It is important to understand that since participation in the CLSA Memory Study will require travel outside your home and potentially increased exposure to others, it may increase your risk of exposure to COVID-19. The Data Collection Sites follow established protocols for working safety during the pandemic and include maintaining physical distance of 2 metres whenever possible and use of appropriate personal protective equipment. The information related to the risks of COVID-19 changes every day, and the risk-reduction strategies that are most effective are also adjusted to meet these changes.

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

- Your participation in this research study will not involve any costs to you except the time it takes you to complete the medical assessment. You will be given $30 to cover any expenses incurred when visiting the Data Collection Site.

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.

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- 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.

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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.
- Your decision to participate in the CLSA Memory Study does not affect your ongoing participation in the main CLSA study that you 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 was collected about you not be used for the study. However, once the study results have been released, we will not be able to be removed 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	By telephone
info@clsa-elcv.ca	**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 withdraw permission for the study to continue

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. As a person taking part in the main CLSA study, you have chosen if you would like to be sent regular updates about the study progress through electronic or mailed newsletters. The results of the CLSA Memory Study will be shared with all CLSA participants through those newsletters. Information about ongoing research, the research team, and general study results will be posted on the CLSA website (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.

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- 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).

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Simon Fraser University
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University of Calgary
Phone: (403) 220-7990

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