

CLSA Memory Study
Informant Consent Script Version 1.1
October 12, 2022

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Supplementary Appendix 4 - Using the CLSA Platform to Validate Algorithms to Identify Participants with Dementia (Major Neurocognitive Disorder) and Mild Neurocognitive Disorder in the Canadian Longitudinal Study on Aging (CLSA Memory Study)

INFORMANT CONSENT SCRIPT

Each section (e.g., INFINT, INFINFO, INFCON, and INFINT) represents a screen of the consent script.

INTRODUCTION

INFINT1 Your family member or friend, [participant name], is a participant in the Canadian Longitudinal Study on Aging (CLSA) and is taking part in the CLSA Memory Study. Participants in this study were asked to identify someone who could answer questions about their cognitive health, ability to complete daily tasks, and behaviour. [Participant name] selected you as this person and would like you to complete a 20-minute telephone interview as part of their participation in the CLSA Memory Study.

Have you received a copy of the information package about this study?

Yes _____ **Continue**

No _____ **Go to INFINT4**

INFINT2 Have you had a chance to read the information package?

Yes _____ **Continue**

No _____ **Go to INFINT6**

INFINT3 After reading the CLSA Memory Study information package, are you interested in participating in the CLSA Memory Study by completing the telephone questionnaire about [participant name]?

Yes _____ **Go to INFINFO1**

No _____ **Go to REFUSAL**

INFINT4 Would you like us to send you a copy of the information package by mail or by email?

Yes - by mail _____ **Continue**

Yes - by email _____ **Continue**

No _____ **REFUSAL**

INFINT5 **[DO NOT READ: Please enter or verify the informant's mailing address and email address then arrange for the CLSA Memory Study informant information package to be sent by email or mail to the informant. Let the informant know you will call back in a few days if the information package was sent by email or a couple of weeks if the information package was sent by mail. Please hit "back" until you get to the first page of this script to the question asking if the informant has received the information package.]**

END INTERVIEW

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INFINT6 Would you like for us to call back in a few days when you have had a chance to read the information package?

Yes _____ **Continue**

No _____ **Go to REFUSAL**

INFINT7 **[DO NOT READ: Book a call back time for the informant to complete the informed consent process. Please hit “back” until you get to the first page of the informant script asking if the informant has received the information package.]**

Thank you for your interest in the CLSA Memory Study. We look forward to speaking with you again soon to review the information package. **END INTERVIEW.**

INFORMATION

INFINFO1 As a brief reminder, the purpose of this CLSA Memory 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.

If you choose to take part, you will complete a 20-minute telephone interview now or at a later date and time convenient to you. This interview will involve answering questions asking about [participant name]'s 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.

Continue

INFINFO2 Do you have any questions you would like to ask about the CLSA Memory Study?

RESPOND TO ALL INFORMANT QUESTIONS BEFORE CONTINUING

INFINFO3 Would you like to complete the informed consent process?

Yes _____ **Continue**

No _____ **Go to Refusal**

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INFORMANT CONSENT

INFCON1 Thank you for your time reviewing this information. I will now read a list of statements. Please indicate you if agree or disagree with each statement.

Continue

INFCON2 I have read the Family Member or Friend Study Information Package and I understand it.

Agree _____ **Continue**

Disagree _____ **Go to Refusal**

INFCON3 I have had a chance to ask questions about the study, and all my questions have been answered.

Agree _____ **Continue**

Disagree _____ **Go to Refusal**

INFCON4 I understand that as part of the study, I will be required to complete an interview over the phone answering a questionnaire about my family member or friend's cognitive health, ability to complete daily tasks, and behaviour.

Agree _____ **Continue**

Disagree _____ **Go to Refusal**

INFCON5 I do not give up any of my legal rights by verbally consenting to participate in the CLSA Memory Study.

Agree _____ **Continue**

Disagree _____ **Go to Refusal**

INFCON6 I understand that my information will be used for research purposes only and this research may also have commercial uses that benefit society.

Disagree _____ **Go to Refusal**

Agree _____ **Continue**

INFCON7 I understand that I can withdraw my consent at any time. If I choose to withdraw consent, I will be offered options for how the information already collected about me will be used.

Disagree _____ **Go to Refusal**

Agree _____ **Continue**

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INFCON8 I will now read the consent statement and ask that you please respond with either 'yes' or 'no'. This will act as your consent to participate in the CLSA Memory Study.

I agree to take part in the CLSA Memory Study.

Yes _____ **Go to INFCON9**

No _____ **Go to Refusal**

CONSENTED TO PARTICIPATE

IF PARTICIPANT ANSWERS YES TO STATEMENT INFCON8

INFCON9 Thank you for agreeing to participate in the CLSA Memory Study.

INFCON10 The questionnaire about [participant name's] cognitive health, ability to complete daily tasks, and behaviour is about 20 minutes long. Would you like to complete the questionnaire now or schedule an appointment at an alternative date or time?

Complete interview now _____ **Go to INTERVIEW**

Schedule interview later _____ **Continue**

INFCON11 **[DO NOT READ: Please use Sabretooth to schedule a time to call the informant for their interview.]**

Thank you for agreeing to participate in the CLSA Memory Study. We look forward to speaking with you again soon to complete the questionnaire.

CLICK SUBMIT AND END CALL

REFUSAL

IF ANSWER IS 'NO' TO INFINT3, INFINT6, INFINFO3, OR IF THE PARTICIPANT RESPONDS "NO" TO INFINT4 OR INFCON8, OR DISAGREES WITH INFCON2, INFCON3, INFCON4, INFCON5, INFCON6, INCON7.

Thank you for taking the time to learn about the CLSA Memory Study.

[DO NOT READ: Please contact the participant to identify another informant and update Sabretooth. When you contact the new informant, please hit "previous" to return to the "informant introduction" page.]

END CALL

INTERVIEW

DO NOT END CALL. CLICK SUBMIT AND CONTINUE TO INFORMANT INTERVIEW.

END CALL

CONCLUSION SCREEN

You have completed the CLSA Memory Study Informant Consent Script. You may now exit this window