

## Supplementary Appendix 2 – Participant Consent Scripts

<b>Participant Consent Script – Tracking Cohort .....</b>	<b>1</b>
<b>Participant Consent Script – Comprehensive Cohort .....</b>	<b>11</b>

## CLSA Memory Study

Participant Consent and Administrative (Informant Identification, Medical Assessment Booking)

– Tracking Cohort Scripts Version 1.0

February 1<sup>st</sup>, 2023

Page 1 of 24

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

**Participant Consent Script – Tracking Cohort**

Each section (e.g., PARINTRO, PARINFO, PARPRE and PARCON) represents a screen of the consent script.

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**INTRODUCTION**
**PARINTRO1**

Hello. I am calling on behalf of the Canadian Longitudinal Study on Aging (CLSA) Memory Study. We recently provided you with an information package about the study. Have you had a chance to read the information package?

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **Go to PARINTRO3**

**PARINTRO2**

After reading the CLSA Memory Study description, are you interested in discussing participating in the CLSA Memory Study?

Yes \_\_\_\_\_ **Go to PAR\_INFO1**

No \_\_\_\_\_ **Go to REFUSAL**

**PARINTRO3**

Did you receive the information package?

**[DO NOT READ: Participants were given the information package during their in-home interview or it was sent by mail or email if the participant had already completed their follow up 3 interview.]**

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **Go to PARINTRO6**

**PARINTRO4**

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**

**PARINTRO5**

**[DO NOT READ: Book a call back time for the participant to complete the informed consent process. Please hit “previous” until you get to the question asking if the participant has received the information package so it will open at the correct spot when you call back.]**

CLSA Memory Study  
Participant Consent and Administrative (Informant Identification, Medical Assessment Booking)  
– Tracking Cohort Scripts Version 1.0  
February 1<sup>st</sup>, 2023

Page 2 of 24

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**

**PARINTRO6** Would you like for us to resend the CLSA Memory Study Participant Information Package?

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **Go to REFUSAL**

**PARINTRO7** **[DO NOT READ: Please arrange for the CLSA Memory Study participant information package to be sent by email or mail to the participant. Let the participant know you will call back in a few days if the information package was sent by email or in a week or two if the information package was sent by mail. Please hit “previous” until you get to the question asking if the participant has received the information package so it will open in the correct spot when you call back.]**

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**

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**INFORMATION**

**PARINFO1** During this phone call, we will review some of the key information about the CLSA Memory Study. You will be able to ask any questions you have about the study. If you are interested in participating, I will ask some questions to see if you are eligible to participate. If you are eligible to participate, we will complete the consent process.

The purpose of the 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. Participants in the CLSA Memory Study will be asked to:

- 1) Undergo a medical assessment by a study physician at their local CLSA Data Collection Site. Please note, your participation in the CLSA has previously included interviews conducted over the phone. Participation in the CLSA Memory Study will require you to come into a CLSA Data Collection Site located within 50km of your home. CLSA Memory Study participant will be given \$30 to cover any expenses incurred when visiting the Data Collection Site. The assessment done at the Data Collection Site will include questions about 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 to complete an interview by phone regarding your cognitive health, ability to complete daily tasks, and behaviour. Your family member or friend will not be required to come to the CLSA Data Collection Site.

**Continue**

**PARINFO2** At the end of the medical assessment, the study physician will tell you if they think 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

CLSAMem\_TRA\_PartConsentandAdminScripts\_v1.0\_2023Feb1

Page 2 of 24

CLSA Memory Study  
 Participant Consent and Administrative (Informant Identification, Medical Assessment Booking)  
 – Tracking Cohort Scripts Version 1.0  
 February 1<sup>st</sup>, 2023

Page 3 of 24

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.

There are no direct benefits to you from taking part in the CLSA Memory Study, but your participation will contribute to potentially developing new ways to identify people with memory problems.

There are no direct medical risks associated with participation in this study. However, some participants may feel tired or frustrated during the medical assessment. Participants may take breaks from the medical assessment as needed. Some participants may also feel worried about if the study physician will identify a potential concern about their memory. Participants will have an opportunity to speak with the study physician to discuss their concerns.

**Continue**

**PARINFO3** Do you have any questions you would like to ask about the CLSA Memory Study?

**[DO NOT READ: Respond to all participant questions before continuing.]**

**PARINFO4** Are you interested in finding out if you are eligible to participate in the CLSA Memory Study?

Yes \_\_\_\_\_ **Go to PARPRE1**

No \_\_\_\_\_ **Go to Refusal**

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**PRECONSENT**

**PARPRE1** I am now going to ask you a few questions to determine your eligibility to participate in the CLSA Memory Study. You may refer to the participant information package to help you answer these questions. Please also let me know if you would like to discuss any of the questions before you answer.

**[Interviewer note: The goal of these questions is to determine if the participant understands enough about the CLSA Memory Study to provide informed consent. Participants are not expected to have the study information package memorized or to use the exact wording in their response.**

**If a participant does not answer a question correctly, a script will appear that provides information regarding that section of the information package. The question is then asked a second time. If the participant is unable to answer the question on the second attempt, the remaining questions will be skipped.]**

**PARPRE2A** What is the purpose of the study that was just described to you?

**[DO NOT READ: Did the participant's response indicate that the study is about identifying people with memory problems?]**

Yes \_\_\_\_\_ **Go to PARPRE3A**

No \_\_\_\_\_ **Continue**

CLSA Memory Study  
Participant Consent and Administrative (Informant Identification, Medical Assessment Booking)  
– Tracking Cohort Scripts Version 1.0  
February 1<sup>st</sup>, 2023

Page 4 of 24

**PARPRE2B** 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.

In your own words, can you tell me why this study is being done?

[**DO NOT READ:** Did the participant's response indicate that the study is about identifying people with memory problems?]

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **PARPRE11**

**PARPRE3A** Tell me something you will be asked to do during the study.

[**DO NOT READ:** Did the participant's response indicate that they will have to come to the Data Collection Site to complete a medical assessment or that they would be asked to identify a family member or friend as an informant?]

Yes \_\_\_\_\_ **PARPRE4A**

No \_\_\_\_\_ **Continue**

**PARPRE3B** Participants in the CLSA Memory Study will undergo a medical assessment by a study physician at the CLSA Data Collection Site. The assessment will include questions about 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.

In your own words, can you tell me something you will be asked to do during the study?

[**DO NOT READ:** Did the participant's response indicate that they will have to come to the Data Collection Site to complete a medical assessment or that they would be asked to identify a family member or friend as an informant?]

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **PARPRE11**

**PARPRE4A** Can you tell me a possible risk to you of being in this study?

[**DO NOT READ:** Did the participant's response indicate that feeling tired or frustrated during the medical assessment or that worrying about the study physician identifying a potential concern about their cognition are potential risks of this study?]

Yes \_\_\_\_\_ **Go to PARPRE5A**

No \_\_\_\_\_ **Continue**

CLSA Memory Study  
Participant Consent and Administrative (Informant Identification, Medical Assessment Booking)  
– Tracking Cohort Scripts Version 1.0  
February 1<sup>st</sup>, 2023

Page 5 of 24

**PARPRE4B** [DO NOT READ: Did the participant mention that they may be exposed to COVID-19 as a potential risk of this study?]

Yes \_\_\_\_\_ **Go to PARPRE4C**

No \_\_\_\_\_ **Go to PARPRE4D**

**PARPRE4C** In addition to the risk of exposure to COVID-19, feeling tired or frustrated during the medical assessment or worrying that the study physician will identify a potential concern about your cognition are potential risks of this study.

**Go to PARPRE5A**

**PARPRE4D** There are no direct medical risks associated with participation in this study. However, some participants may feel tired or frustrated during the medical assessment. Participants may take breaks from the medical assessment as needed. Some participants may also feel worried about if the study physician will identify a potential concern about their memory. Participants identified as having a potential concern about their memory will have an opportunity to speak with the study physician to discuss their concerns.

In your own words, can you please tell me a possible risk of participating in this study?

[DO NOT READ: Did the participant's response indicate that feeling tired or frustrated during the medical assessment **or** that worrying about the study physician identifying a potential concern about their cognition are potential risks of this study? ]

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **PARPRE11**

**PARPRE5A** Will you receive a medical diagnosis by participating in this study?

[DO NOT READ: Did the participant's response indicate that they understand that being told if there is a potential concern about their memory or not by the study physician is not the same as a medical diagnosis?]

Yes \_\_\_\_\_ **Go to PARPRE6A**

No \_\_\_\_\_ **Continue**

**PARPRE5B** 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 and does not replace your usual medical care. 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.

CLSAMem\_TRA\_PartConsentandAdminScripts\_v1.0\_2023Feb1

Page 5 of 24

CLSA Memory Study  
 Participant Consent and Administrative (Informant Identification, Medical Assessment Booking)  
 – Tracking Cohort Scripts Version 1.0  
 February 1<sup>st</sup>, 2023

Page 6 of 24

Based on this explanation, will you receive a medical diagnosis by participating in this study?

**DO NOT READ:** Did the participant's response indicate that they understand that being told if there is a potential concern about their memory or not by the study physician is not the same as a medical diagnosis?]

Yes \_\_\_\_\_ **Continue**  
 No \_\_\_\_\_ **PARPRE11**

**PARPRE6A** Do you have to participate in this study if you do not want to participate?

**[DO NOT READ:** Does the participant's response indicate that they understand that participation in the CLSA Memory Study is voluntary?]

Yes \_\_\_\_\_ **Go to PARPRE7A**  
 No \_\_\_\_\_ **Continue**

**PARPRE6B** Your agreement to participate in the CLSA Memory Study is voluntary. Your decision to participate in the CLSA Dementia Memory does not affect your ongoing participation in the main CLSA study that you have participated in since 2012-2015.

Based on this explanation, do you have to participate in this study if you do not want to participate?

**[DO NOT READ:** Does the participant's response indicate that they understand that participation in the CLSA Memory Study is voluntary?]

Yes \_\_\_\_\_ **Continue**  
 No \_\_\_\_\_ **PARPRE11**

**PARPRE7A** If you want to drop out of the study, when can you do this?

**[DO NOT READ:** Does the participant's response indicate that they understand that they may drop out (or withdraw) from the study at any point?]

Yes \_\_\_\_\_ **Go to PARPRE8A**  
 No \_\_\_\_\_ **Continue**

**PARPRE7B** You can choose to end your participation in the CLSA Memory Study at any time for any reason. If you decide to leave the study, we will stop contacting you about the CLSA Memory Study. You may ask that the information collected about you not be used for the study. However, if the study results have been released, we will not be able to remove your data from our datasets.

CLSMem\_TRA\_PartConsentandAdminScripts\_v1.0\_2023Feb1

Page 6 of 24

## CLSA Memory Study

## Participant Consent and Administrative (Informant Identification, Medical Assessment Booking)

– Tracking Cohort Scripts Version 1.0

February 1<sup>st</sup>, 2023

Page 7 of 24

Based on this information, when can you drop out from the study?

**[DO NOT READ:** Did the participant's response indicate that they understand that they can drop out (or withdraw) from the study whenever they would like?]

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **PARPRE11**

**PARPRE8A** Will your data for the CLSA Memory Study be kept confidential?

**[DO NOT READ:** Did the participant's response indicate that they understood that their data will be kept confidential?]

Yes \_\_\_\_\_ **PARPRE9**

No \_\_\_\_\_ **Continue**

**PARPRE8B** The data you provide to the CLSA Memory Study will be kept confidential. Information that can identify you such as your name and phone number will be kept in a secure database with a unique study identification number. This information will only be used to contact you. Researchers using data from the CLSA Memory Study will not be provided with any identifying information.

Based on this explanation, will your data be kept confidential?

**[DO NOT READ:** Did the participant's response indicate that they understood that their data will be kept confidential?]

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **PARPRE11**

**PARPRE9** **[DO NOT READ:** Based on your discussion with the participant, do you feel that the participant has sufficient understanding of the CLSA Memory Study to provide consent to participate?]

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **PARPRE12**

**PARPRE10** **[SHOW IF (PARPRE2A OR PARPRE2B) AND (PARPRE3A OR PARPRE3B) AND (PARPRE4A OR PARPRE4B OR PARPRE4D) AND (PARPRE5A OR PARPRE5B) AND (PARPRE6A OR PARPRE6B) AND (PARPRE7A OR PARPRE7B) AND (PARPRE8A OR PARPRE8B) AND PARPRE9 ARE "YES"]**

**[DO NOT READ:** The participant answered all of the questions correctly and is eligible to participate in the study.]



## CLSA Memory Study

Participant Consent and Administrative (Informant Identification, Medical Assessment Booking)

– Tracking Cohort Scripts Version 1.0

February 1<sup>st</sup>, 2023

Page 8 of 24

**Go to PARCON1****PARPRE11** [SHOW IF RESPONSE TO ONE OF PARPRE2B, PARPRE3B, PARPRE4D, PARPRE5B, PARPRE6B, PARPRE7B, OR PARPRE8B WAS “NO”]

[DO NOT READ: The participant did not answer a question correctly.]

**Continue****PARPRE12** Based on the questions I have asked you, we would like another staff member to speak with you to determine if you are eligible to participate in the CLSA Memory Study. Do I have your permission for the other staff member to contact you?Yes \_\_\_\_\_ **Go to PARPRE14**No \_\_\_\_\_ **Continue****PARPRE13** You have told me that you do not want another staff member to contact you. This means that you will not be able to participate in the CLSA Memory Study. Thank you for taking the time to learn about the CLSA Memory Study. We will be in touch with you in the future regarding the main CLSA study.**[DO NOT READ: Click “Next” and confirm the participant does not want to participate in the CLSA Memory Study (Go to REFUSAL1)]****PARPRE14** Thank you. The other staff member will call you in within the next week to further discuss your eligibility for the CLSA Memory Study.**[DO NOT READ: Please include any relevant notes in Sabretooth that may assist the CLSA Memory Study staff member in their discussion with the participant.****END INTERVIEW]**

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**CONSENT**

I will now read a list of statements. Please indicate you if agree or disagree with each statement.

**PARCON1** I have read the participant information package for the Canadian Longitudinal Study on Aging (CLSA) Memory Study and I understand it.Disagree \_\_\_\_\_ **Go to Refusal**Agree \_\_\_\_\_ **Continue****PARCON2** I have had a chance to ask questions about the study, and all my questions have been answered.Disagree \_\_\_\_\_ **Go to Refusal**Agree \_\_\_\_\_ **Continue**

CLSA Memory Study  
Participant Consent and Administrative (Informant Identification, Medical Assessment Booking)  
– Tracking Cohort Scripts Version 1.0  
February 1<sup>st</sup>, 2023

Page 9 of 24

**PARCON3** I do not give up any of my legal rights by verbally consenting to participate in the CLSA Memory Study.

Disagree \_\_\_\_\_ **Go to Refusal**

Agree \_\_\_\_\_ **Continue**

**PARCON4** 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**

**PARCON5** 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**

**PARCON6** I understand that participation in the CLSA Memory Study will require me to visit a CLSA Data Collection Site located within 50km of my home and that I will be given \$30 to cover any expenses incurred when visiting the Data Collection Site. My future participation in the main CLSA study will continue to be over the phone.

Disagree \_\_\_\_\_ **Go to Refusal**

Agree \_\_\_\_\_ **Continue**

**PARCON7** 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.

Disagree \_\_\_\_\_ **Go to Refusal**

Agree \_\_\_\_\_ **Continue**

**PARCON8** Thank you for consenting to participate in the CLSA Memory Study.

**END INTERVIEW AND CLICK SUBMIT.**

**REFUSAL**

**IF ANSWER IS 'NO' TO PARINTRO1 OR PARINFO3 OR PARCON8 IF ANSWER IS 'DISAGREE' TO PARCON1, PARCON2, PARCON3, PARCON4, PARCON5, PARCON6, OR PARCON7**

CLSA Memory Study  
Participant Consent and Administrative (Informant Identification, Medical Assessment Booking)  
– Tracking Cohort Scripts Version 1.0  
February 1<sup>st</sup>, 2023

Page 10 of 24

**REFUSAL1** DO NOT READ: Check the "participant does not wish to participate" option below to confirm that the participant does not want to participate in the CLSA Memory Study.

**REFUSAL2** Thank you for taking the time to learn about the CLSA Memory Study.

We will be in touch with you in the future regarding the main CLSA study.

**END INTERVIEW AND CLICK SUBMIT.**

**CONCLUSION SCREEN**

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

## CLSA Memory Study

Participant Consent and Administrative (Informant Identification, Medical Assessment Booking)

– Tracking Cohort Scripts Version 1.0

February 1<sup>st</sup>, 2023

Page 11 of 24

**Using the Canadian Longitudinal Study on Aging (CLSA) Platform to Validate Algorithms to Identify Participants with Dementia (Major Neurocognitive Disorder) and Mild Neurocognitive Disorder in the CLSA (CLSA Memory Study)****Participant Consent Script – Comprehensive Cohort****Each section (e.g., PARINTRO, PARINFO, PARPRE and PARCON) represents a screen of the consent script.**

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**FAMILY MEMBER OR FRIEND CONTACT INFORMATION**

**PARINF\_1** To participate in this study, we need you to identify a family member or friend that can respond to questions about your cognitive health, ability to complete daily tasks, and behaviour. Would you like to identify this person now or have us call back at another time?

Identify family member or friend **now** \_\_\_\_\_ **Continue**Identify family member or friend **later** \_\_\_\_\_ **Go to PARINF\_5**

**PARINF\_2** **[DO NOT READ: Record the friend or family member identified by the participant as an alternate contact and label as “Memory Study Informant”. If the participant identifies an existing alternate contact as the Memory Study informant, please verify the contact information of the alternate contact before selecting “Memory Study Informant” as an alternate type.]**

**PARINF\_3** Thank you. In the information we sent you for the CLSA Memory Study, we included a copy of the Informant Information Package. Are you able to give the Informant Information Package to your family member or friend, or would you prefer for us to send them a copy?

Participant will give informant the information package \_\_\_\_\_ **Continue**Data Collection Site will send information package \_\_\_\_\_ **Continue**

**PARINF\_4** We encourage you to discuss the CLSA Memory Study with **[family member or friend name]** in the next few days and to let him/her know to expect a phone call from us.

**Go to PARMED\_1**

**PARINF\_5** **[DO NOT READ: Book a call back time for the participant to provide the contact information for a family member or friend]**

When we call you to identify a family member or friend, we will also book an appointment for your medical assessment. Thank you for your interest in the CLSA Memory Study and we look forward to speaking with you again soon.

**END INTERVIEW.**

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**MEDICAL ASSESSMENT BOOKING**

**PARMED\_1** Would you like to schedule a time for your medical assessment with the study physician?

CLSAMem\_TRA\_PartConsentandAdminScripts\_v1.0\_2023Feb1

Page 11 of 24

CLSA Memory Study  
Participant Consent and Administrative (Informant Identification, Medical Assessment Booking)  
– Tracking Cohort Scripts Version 1.0  
February 1<sup>st</sup>, 2023

Page 12 of 24

Book medical assessment **now** \_\_\_\_\_ **Continue**

Book medical assessment **later** \_\_\_\_\_ **Go to PARMED\_3**

**PARMED\_2 [DO NOT READ, SITE SPECIFIC: Book medical assessment appointment using your preferred method and the participant's UID. Please confirm the address of the DCS with the participant and any necessary information about parking.]**

Thank you for your interest in the CLSA Memory Study and we look forward to seeing you at your medical assessment.

**END INTERVIEW AND CLICK SUBMIT**

**PARMED\_3 [DO NOT READ: Book a call back time for the participant to schedule a medical assessment.]**

Thank you for your interest in the CLSA Memory Study. We look forward to speaking with you again soon to book your medical assessment.

**END INTERVIEW**

#### CONCLUSION SCREEN

**You have completed the CLSA Memory Study Participant Informant Identification and Medical Assessment Booking Script. You may now exit this window.**

CLSA Memory Study  
Participant Consent and  
Administrative (Informant Identification, Medical Assessment Booking) Scripts Version 1.1  
October 11, 2022

Page 1 of 24

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

**PARTICIPANT CONSENT SCRIPT**

Each section (e.g., PARINTRO, PARINFO, PARPRE and PARCON) represents a screen of the consent script.

---

**INTRODUCTION**

**PARINTRO1**

Hello. I am calling on behalf of the Canadian Longitudinal Study on Aging (CLSA) Memory Study. We recently provided you with an information package about the study. Have you had a chance to read the information package?

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **Go to PARINTRO3**

**PARINTRO2**

After reading the CLSA Memory Study description, are you interested in discussing participating in the CLSA Memory Study?

Yes \_\_\_\_\_ **Go to PAR\_INFO1**

No \_\_\_\_\_ **Go to REFUSAL**

**PARINTRO3**

Did you receive the information package?

**[DO NOT READ: Participants were given the information package during their in-home interview or it was sent by mail or email if the participant had already completed their follow up 3 interview.]**

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **Go to PARINTRO6**

**PARINTRO4**

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**

**PARINTRO5**

**[DO NOT READ: Book a call back time for the participant to complete the informed consent process. Please hit "previous" until you get to the question asking if the participant has received the information package so it will open at the correct spot when you call back.]**

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**

CLSAMem\_PartConsentandAdminScripts\_v1.1\_2022Oct11

Page 1 of 24

CLSA Memory Study  
Participant Consent and  
Administrative (Informant Identification, Medical Assessment Booking) Scripts Version 1.1  
October 11, 2022

Page 2 of 24

**PARINTRO6** Would you like for us to resend the CLSA Memory Study Participant Information Package?

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **Go to REFUSAL**

**PARINTRO7** **[DO NOT READ: Please arrange for the CLSA Memory Study participant information package to be sent by email or mail to the participant. Let the participant know you will call back in a few days if the information package was sent by email or in a week or two if the information package was sent by mail. Please hit “previous” until you get to the question asking if the participant has received the information package so it will open in the correct spot when you call back.]**

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

**PARINFO1** During this phone call, we will review some of the key information about the CLSA Memory Study. You will be able to ask any questions you have about the study. If you are interested in participating, I will ask some questions to see if you are eligible to participate. If you are eligible to participate, we will complete the consent process.

The purpose of the 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. Participants in the CLSA Memory Study will be asked to:

- 1) Undergo a medical assessment by a study physician at their local CLSA Data Collection Site. The assessment will include questions about 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 to complete an interview by phone regarding your cognitive health, ability to complete daily tasks, and behaviour.

**Continue**

**PARINFO2** At the end of the medical assessment, the study physician will tell you if they think 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.

There are no direct benefits to you from taking part in the CLSA Memory Study, but your participation will contribute to potentially developing new ways to identify people with memory problems.

There are no direct medical risks associated with participation in this study. However, some participants may feel tired or frustrated during the medical assessment. Participants may take breaks from the medical

CLSA Memory Study  
 Participant Consent and  
 Administrative (Informant Identification, Medical Assessment Booking) Scripts Version 1.1  
 October 11, 2022

Page 3 of 24

assessment as needed. Some participants may also feel worried about if the study physician will identify a potential concern about their memory. Participants will have an opportunity to speak with the study physician to discuss their concerns.

**Continue**

**PARINFO3** Do you have any questions you would like to ask about the CLSA Memory Study?

**[DO NOT READ: Respond to all participant questions before continuing.]**

**PARINFO4** Are you interested in finding out if you are eligible to participate in the CLSA Memory Study?

Yes \_\_\_\_\_ **Go to PARPRE1**

No \_\_\_\_\_ **Go to Refusal**

**PRECONSENT**

**PARPRE1** I am now going to ask you a few questions to determine your eligibility to participate in the CLSA Memory Study. You may refer to the participant information package to help you answer these questions. Please also let me know if you would like to discuss any of the questions before you answer.

**[Interviewer note: The goal of these questions is to determine if the participant understands enough about the CLSA Memory Study to provide informed consent. Participants are not expected to have the study information package memorized or to use the exact wording in their response.**

**If a participant does not answer a question correctly, a script will appear that provides information regarding that section of the information package. The question is then asked a second time. If the participant is unable to answer the question on the second attempt, the remaining questions will be skipped.]**

**PARPRE2A** What is the purpose of the study that was just described to you?

**[DO NOT READ: Did the participant's response indicate that the study is about identifying people with memory problems?]**

Yes \_\_\_\_\_ **Go to PARPRE3A**

No \_\_\_\_\_ **Continue**

**PARPRE2B** 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.

In your own words, can you tell me why this study is being done?

**[DO NOT READ: Did the participant's response indicate that the study is about identifying people with memory problems?]**

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **PARPRE11**



CLSA Memory Study  
Participant Consent and  
Administrative (Informant Identification, Medical Assessment Booking) Scripts Version 1.1  
October 11, 2022

Page 4 of 24

**PARPRE3A** Tell me something you will be asked to do during the study.

[**DO NOT READ:** Did the participant's response indicate that they will have to come to the Data Collection Site to complete a medical assessment or that they would be asked to identify a family member or friend as an informant?]

Yes \_\_\_\_\_ **PARPRE4A**

No \_\_\_\_\_ **Continue**

**PARPRE3B** Participants in the CLSA Memory Study will undergo a medical assessment by a study physician at the CLSA Data Collection Site. The assessment will include questions about 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.

In your own words, can you tell me something you will be asked to do during the study?

[**DO NOT READ:** Did the participant's response indicate that they will have to come to the Data Collection Site to complete a medical assessment or that they would be asked to identify a family member or friend as an informant?]

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **PARPRE11**

**PARPRE4A** Can you tell me a possible risk to you of being in this study?

[**DO NOT READ:** Did the participant's response indicate that feeling tired or frustrated during the medical assessment **or** that worrying about the study physician identifying a potential concern about their cognition are potential risks of this study?]

Yes \_\_\_\_\_ **Go to PARPRE5A**

No \_\_\_\_\_ **Continue**

**PARPRE4B** [**DO NOT READ:** Did the participant mention that they may be exposed to COVID-19 as a potential risk of this study?]

Yes \_\_\_\_\_ **Go to PARPRE4C**

No \_\_\_\_\_ **Go to PARPRE4D**

CLSA Memory Study  
Participant Consent and  
Administrative (Informant Identification, Medical Assessment Booking) Scripts Version 1.1  
October 11, 2022

Page 5 of 24

**PARPRE4C** In addition to the risk of exposure to COVID-19, feeling tired or frustrated during the medical assessment or worrying that the study physician will identify a potential concern about your cognition are potential risks of this study.

**Go to PARPRE5A**

**PARPRE4D** There are no direct medical risks associated with participation in this study. However, some participants may feel tired or frustrated during the medical assessment. Participants may take breaks from the medical assessment as needed. Some participants may also feel worried about if the study physician will identify a potential concern about their memory. Participants identified as having a potential concern about their memory will have an opportunity to speak with the study physician to discuss their concerns.

In your own words, can you please tell me a possible risk of participating in this study?

[**DO NOT READ:** Did the participant's response indicate that feeling tired or frustrated during the medical assessment **or** that worrying about the study physician identifying a potential concern about their cognition are potential risks of this study? ]

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **PARPRE11**

**PARPRE5A** Will you receive a medical diagnosis by participating in this study?

[**DO NOT READ:** Did the participant's response indicate that they understand that being told if there is a potential concern about their memory or not by the study physician is not the same as a medical diagnosis?]

Yes \_\_\_\_\_ **Go to PARPRE6A**

No \_\_\_\_\_ **Continue**

**PARPRE5B** 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 and does not replace your usual medical care. 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.

Based on this explanation, will you receive a medical diagnosis by participating in this study?

**DO NOT READ:** Did the participant's response indicate that they understand that being told if there is a potential concern about their memory or not by the study physician is not the same as a medical diagnosis?]

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **PARPRE11**

CLSA Memory Study  
Participant Consent and  
Administrative (Informant Identification, Medical Assessment Booking) Scripts Version 1.1  
October 11, 2022

Page 6 of 24

**PARPRE6A** Do you have to participate in this study if you do not want to participate?

**[DO NOT READ:** Does the participant's response indicate that they understand that participation in the CLSA Memory Study is voluntary?]

Yes \_\_\_\_\_ **Go to PARPRE7A**

No \_\_\_\_\_ **Continue**

**PARPRE6B** Your agreement to participate in the CLSA Memory Study is voluntary. Your decision to participate in the CLSA Dementia Memory does not affect your ongoing participation in the main CLSA study that you have participated in since 2012-2015.

Based on this explanation, do you have to participate in this study if you do not want to participate?

**[DO NOT READ:** Does the participant's response indicate that they understand that participation in the CLSA Memory Study is voluntary?]

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **PARPRE11**

**PARPRE7A** If you want to drop out of the study, when can you do this?

**[DO NOT READ:** Does the participant's response indicate that they understand that they may drop out (or withdraw) from the study at any point?]

Yes \_\_\_\_\_ **Go to PARPRE8A**

No \_\_\_\_\_ **Continue**

**PARPRE7B** You can choose to end your participation in the CLSA Memory Study at any time for any reason. If you decide to leave the study, we will stop contacting you about the CLSA Memory Study. You may ask that the information collected about you not be used for the study. However, if the study results have been released, we will not be able to remove your data from our datasets.

Based on this information, when can you drop out from the study?

**[DO NOT READ:** Did the participant's response indicate that they understand that they can drop out (or withdraw) from the study whenever they would like?]

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **PARPRE11**

CLSA Memory Study  
 Participant Consent and  
 Administrative (Informant Identification, Medical Assessment Booking) Scripts Version 1.1  
 October 11, 2022

Page 7 of 24

**PARPRE8A** Will your data for the CLSA Memory Study be kept confidential?

[**DO NOT READ:** Did the participant's response indicate that they understood that their data will be kept confidential?]

Yes \_\_\_\_\_ **PARPRE9**

No \_\_\_\_\_ **Continue**

**PARPRE8B** The data you provide to the CLSA Memory Study will be kept confidential. Information that can identify you such as your name and phone number will be kept in a secure database with a unique study identification number. This information will only be used to contact you. Researchers using data from the CLSA Memory Study will not be provided with any identifying information.

Based on this explanation, will your data be kept confidential?

[**DO NOT READ:** Did the participant's response indicate that they understood that their data will be kept confidential?]

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **PARPRE11**

**PARPRE9** [**DO NOT READ:** Based on your discussion with the participant, do you feel that the participant has sufficient understanding of the CLSA Memory Study to provide consent to participate?]

Yes \_\_\_\_\_ **Continue**

No \_\_\_\_\_ **PARPRE12**

**PARPRE10** [SHOW IF (PARPRE2A OR PARPRE2B) AND (PARPRE3A OR PARPRE3B) AND (PARPRE4A OR PARPRE4B OR PARPRE4D) AND (PARPRE5A OR PARPRE5B) AND (PARPRE6A OR PARPRE6B) AND (PARPRE7A OR PARPRE7B) AND (PARPRE8A OR PARPRE8B) AND PARPRE9 ARE "YES"]

[**DO NOT READ:** The participant answered all of the questions correctly and is eligible to participate in the study.]

**Go to PARCON1**

**PARPRE11** [SHOW IF RESPONSE TO ONE OF PARPRE2B, PARPRE3B, PARPRE4D, PARPRE5B, PARPRE6B, PARPRE7B, OR PARPRE8B WAS "NO"]

[**DO NOT READ:** The participant did not answer a question correctly.]

**Continue**

CLSA Memory Study  
Participant Consent and  
Administrative (Informant Identification, Medical Assessment Booking) Scripts Version 1.1  
October 11, 2022

Page 8 of 24

**PARPRE12** Based on the questions I have asked you, we would like another staff member to speak with you to determine if you are eligible to participate in the CLSA Memory Study. Do I have your permission for the other staff member to contact you?

Yes \_\_\_\_\_ **Go to PARPRE14**

No \_\_\_\_\_ **Continue**

**PARPRE13** You have told me that you do not want another staff member to contact you. This means that you will not be able to participate in the CLSA Memory Study. Thank you for taking the time to learn about the CLSA Memory Study. We will be in touch with you in the future regarding the main CLSA study.

**[DO NOT READ: Click “Next” and confirm the participant does not want to participate in the CLSA Memory Study (Go to REFUSAL1)]**

**PARPRE14** Thank you. The other staff member will call you in within the next week to further discuss your eligibility for the CLSA Memory Study.

**[DO NOT READ:** Please include any relevant notes in Sabretooth that may assist the CLSA Memory Study staff member in their discussion with the participant.

**END INTERVIEW]**

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## CONSENT

I will now read a list of statements. Please indicate you if agree or disagree with each statement.

**PARCON1** I have read the participant information package for the Canadian Longitudinal Study on Aging (CLSA) Memory Study and I understand it.

Disagree \_\_\_\_\_ **Go to Refusal**

Agree \_\_\_\_\_ **Continue**

**PARCON2** I have had a chance to ask questions about the study, and all my questions have been answered.

Disagree \_\_\_\_\_ **Go to Refusal**

Agree \_\_\_\_\_ **Continue**

**PARCON3** I do not give up any of my legal rights by verbally consenting to participate in the CLSA Memory Study.

Disagree \_\_\_\_\_ **Go to Refusal**

Agree \_\_\_\_\_ **Continue**

**PARCON4** I understand that my information will be used for research purposes only and this research may also have commercial uses that benefit society.

CLSA Memory Study  
Participant Consent and  
Administrative (Informant Identification, Medical Assessment Booking) Scripts Version 1.1  
October 11, 2022

Page 9 of 24

Disagree \_\_\_\_\_ **Go to Refusal**

Agree \_\_\_\_\_ **Continue**

**PARCON5** 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**

**PARCON6** 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.

Disagree \_\_\_\_\_ **Go to Refusal**

Agree \_\_\_\_\_ **Continue**

**PARCON7** Thank you for consenting to participate in the CLSA Memory Study.

**END INTERVIEW AND CLICK SUBMIT.**

#### REFUSAL

**IF ANSWER IS 'NO' TO PARINTRO1 OR PARINFO3 OR PARCON8 IF ANSWER IS 'DISAGREE' TO PARCON1, PARCON2, PARCON3, PARCON4, PARCON5, PARCON6, OR PARCON7**

**REFUSAL1** DO NOT READ: Check the "participant does not wish to participate" option below to confirm that the participant does not want to participate in the CLSA Memory Study.

**REFUSAL2** Thank you for taking the time to learn about the CLSA Memory Study.

We will be in touch with you in the future regarding the main CLSA study.

**END INTERVIEW AND CLICK SUBMIT.**

#### CONCLUSION SCREEN

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

CLSA Memory Study  
 Participant Consent and  
 Administrative (Informant Identification, Medical Assessment Booking) Scripts Version 1.1  
 October 11, 2022

Page 10 of 24

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

**PARTICIPANT INFORMANT IDENTIFICATION AND MEDICAL ASSESSMENT BOOKING SCRIPT**

Each section (e.g., PARINTRO, PARINFO, PARPRE and PARCON) represents a screen of the consent script.

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**FAMILY MEMBER OR FRIEND CONTACT INFORMATION**

**PARINF\_1** To participate in this study, we need you to identify a family member or friend that can respond to questions about your cognitive health, ability to complete daily tasks, and behaviour. Would you like to identify this person now or have us call back at another time?

Identify family member or friend **now** \_\_\_\_\_ **Continue**

Identify family member or friend **later** \_\_\_\_\_ **Go to PARINF\_5**

**PARINF\_2** **[DO NOT READ: Record the friend or family member identified by the participant as an alternate contact and label as “Memory Study Informant”. If the participant identifies an existing alternate contact as the Memory Study informant, please verify the contact information of the alternate contact before selecting “Memory Study Informant” as an alternate type.]**

**PARINF\_3** Thank you. In the information we sent you for the CLSA Memory Study, we included a copy of the Informant Information Package. Are you able to give the Informant Information Package to your family member or friend, or would you prefer for us to send them a copy?

Participant will give informant the information package \_\_\_\_\_ **Continue**

Data Collection Site will send information package \_\_\_\_\_ **Continue**

**PARINF\_4** We encourage you to discuss the CLSA Memory Study with **[family member or friend name]** in the next few days and to let him/her know to expect a phone call from us.

**Go to PARMED\_1**

**PARINF\_5** **[DO NOT READ: Book a call back time for the participant to provide the contact information for a family member or friend]**

When we call you to identify a family member or friend, we will also book an appointment for your medical assessment. Thank you for your interest in the CLSA Memory Study and we look forward to speaking with you again soon.

**END INTERVIEW.**

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**MEDICAL ASSESSMENT BOOKING**

**PARMED\_1** Would you like to schedule a time for your medical assessment with the study physician?

CLSAMem\_PartConsentandAdminScripts\_v1.1\_2022Oct11

Page 10 of 24

CLSA Memory Study  
Participant Consent and  
Administrative (Informant Identification, Medical Assessment Booking) Scripts Version 1.1  
October 11, 2022

Page 11 of 24

Book medical assessment **now** \_\_\_\_\_ **Continue**

Book medical assessment **later** \_\_\_\_\_ **Go to PARMED\_3**

**PARMED\_2 [DO NOT READ, SITE SPECIFIC: Book medical assessment appointment using your preferred method and the participant's UID.**

Thank you for your interest in the CLSA Memory Study and we look forward to seeing you at your medical assessment.

**END INTERVIEW AND CLICK SUBMIT**

**PARMED\_3 [DO NOT READ: Book a call back time for the participant to schedule a medical assessment.]**

Thank you for your interest in the CLSA Memory Study. We look forward to speaking with you again soon to book your medical assessment.

**END INTERVIEW**

#### **CONCLUSION SCREEN**

**You have completed the CLSA Memory Study Participant Informant Identification and Medical Assessment Booking Script. You may now exit this window.**