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Protocol for validating an algorithm to identify neurocognitive disorders in Canadian Longitudinal Study on Aging participants; an observational study

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ABSTRACT

Introduction: In population-based research, disease ascertainment algorithms can be as accurate as, and less costly than, performing supplementary clinical examinations on selected participants to confirm a diagnosis of a neurocognitive disorder (NCD), but they require cohort-specific validation. To optimize the use of the Canadian Longitudinal Study on Aging (CLSA) to understand the epidemiology and burden of NCDs, the CLSA Memory Study will validate an NCD ascertainment algorithm to identify CLSA participants with these disorders using routinely acquired study data.

Methods and analysis: Up to 600 CLSA participants with equal numbers of those likely to have no NCD, mild NCD, or major NCD based on prior self-reported physician-diagnosis of a memory problem or dementia, medication consumption (i.e., cholinesterase inhibitors, memantine) and/or self-reported function will be recruited during the follow-up 3 CLSA evaluations (started August 2021. Participants will undergo an assessment by a study clinician who will also review an informant interview and make a preliminary determination of the presence or absence of an NCD. The clinical assessment and available CLSA data will be reviewed by a Central Review Panel who will make a final categorization of participants as having 1) no NCD; 2) mild NCD; or, 3) major NCD (according to DSM-5 criteria). These will be used as our gold standard diagnosis to determine if the NCD ascertainment algorithm accurately identifies CLSA participants with an NCD. Weighted Kappa statistics will be the primary measure of agreement. Sensitivity, specificity, the C-statistic, and the phi coefficient will also be estimated.

Ethics and dissemination: Ethics approval has been received from the institutional research ethics boards for each CLSA Data Collection Site. The results of this work will be disseminated to public health professionals, researchers, health professionals, administrators and policy makers through journal publications, conference presentations, publicly available reports, and presentations to stakeholder groups.

Keywords: CLSA, neurocognitive disorders, dementia, algorithm, validation

ARTICLE SUMMARY

- Validation of a neurocognitive disorder case ascertainment algorithm for the Canadian Longitudinal Study on Aging (CLSA) will allow use of this longitudinal and comprehensive database of this large population-based study to explore risk factors, early manifestations, etiology, and trajectory of these disorders.
- Two particular challenges being faced in ascertaining the presence of a neurocognitive disorder are the lack of an informant and the use of cognitive measures that were not selected to diagnose a neurocognitive disorder. Lessons learned in overcoming these obstacles will be of use for other longitudinal studies with similar limitations.
- The results of the blinded clinician assessments and the additional information collected from their identified informant will allow us to refine and improve the accuracy of our case ascertainment algorithm.
- If validated, the neurocognitive disorder case ascertainment algorithm developed for the CLSA is validated cannot be utilized by other population-based studies that differ in the data being collected on participants.

INTRODUCTION

A key challenge in population-based studies in aging is to accurately identify individuals who have neurocognitive disorders (NCDs). A common approach is to utilize a two-stage evaluation based on participants' estimated risk of an NCD. High risk participants and a random sample of those at lower risk undergo a clinical assessment specifically designed to identify NCDs. This approach adds complexity and costs to the study while being burdensome for participants. Relying on self-reports is likely insensitive. The Canadian Study of Health and Aging (CSHA), which used a two-stage evaluation to ascertain the presence of dementia, found that nearly two thirds (64%) of participants identified with prevalent dementia in the study had never seen a physician for a memory problem.[1] This was particularly common among those with mild functional impairment. While administrative data can also be used to estimate the burden of physician diagnosed and documented NCDs, the proportion with undocumented mild and major NCD is significant. [2]

The estimated population-based burden of diagnosed and undiagnosed dementia in Canada is based on data collected two decades ago in the CSHA [1] that does not reflect updated criteria for the diagnosis of mild (mild cognitive impairment) and major (dementia) NCD as described in the fifth version of the Diagnostic and Statistical Manual of Mental Disorders [DSM]-5. [3] Moreover, the increased awareness of NCDs over time may have led to earlier and more comprehensive identification and diagnosis. [4] Previous analyses focused on major NCD, but mild NCD, which is viewed as a precursor to major NCD in many cases, has attracted increasing research interest. Approximately 50% of people with milder degrees of impaired cognition in later life progress to dementia within 5 years [5]. Mild NCD is believed by many to be more likely to respond to disease-modifying interventions, making those with this condition a prime target group for their use. [6–8]

Contemporary estimates of the burden of mild and major NCD including in individuals that have not received a diagnosis is important to the understanding of the epidemiology of these disorders, their risk,

and protective factors, associated health outcomes, informing health and social care planning, and possibly leading to improved, proactive care of those living with or at risk for these conditions.

The accuracy of self-reported diagnoses for identifying chronic diseases is dependent on the condition, what is considered the gold standard diagnosis, as well as the population studied. [9–12] To improve the identification of individuals with chronic conditions in observational population-based studies, researchers often create disease ascertainment algorithms. These algorithms include multiple data items such as self-reported diagnosis, disease-specific questionnaires, performance measures, and medication data to classify participants into those with and without diseases. [13] Population-based studies have utilized algorithms to classify individuals as having an NCD or not. The Health and Retirement Study (HRS) found that their algorithms correctly identified 87-94% of participants on dementia status. [14] The Personality and Total Health Through Life Project found that their algorithm had very good performance for identifying major NCD (area under the curve (AUC) of 0.95) and good performance (AUC of 0.76) for identifying mild NCD. [15]

Although the application of algorithms to population-based data has the potential to be cost-effective and meet the need for a standardized and comprehensive identification of cases, because of variability in the studied populations and the data collected on them cohort-specific validation is required. [16] To validate an NCD algorithm, an assessment conducted by a clinician with training to diagnose NCDs is typically used as the gold standard. Ideally this assessment should include a participant interview, cognitive testing, physical examination, and an interview with an informant who knows the participant well enough to answer questions about their cognition, function, and behaviour. Informant ratings have been found to reveal greater loss of everyday functional ability and cognitive competency than self-reports and are more strongly associated with objective measures of cognitive performance compared to how an individual rates their abilities. [17]

The Canadian Longitudinal Study on Aging (CLSA) is a large (51,338 participants aged 45–85 years at enrolment) national, longitudinal research platform that includes participants from all 10 Canadian provinces. [18] It is being used to address a wide variety of aging-related research challenges including NCD. Disease ascertainment algorithms are already being used in the CLSA for several conditions (e.g., type II diabetes mellitus, parkinsonism, chronic obstructive airway disease, osteoarthritis, coronary artery disease). [13]

To better understand the epidemiology and burden of diagnosed and undiagnosed mild and major NCD in CLSA participants (and by extrapolation the Canadian population), the CLSA Memory Study will be conducted to validate a disease ascertainment algorithm for NCD.

METHODS AND ANALYSIS

Study design and participant eligibility

The CLSA Memory Study will recruit participants from the CLSA. The CLSA is composed of two complementary cohorts that may be studied separately or together (**Figure 1**): (1) Tracking cohort of 21,241 participants randomly selected from within all 10 provinces who are interviewed by telephone, and, (2) Comprehensive cohort of 30,097 participants randomly selected from within 25–50 km of 11 data collection sites (DCSs) across the country who are first interviewed at home and then visit their local DCS for a more in-depth assessment that includes additional interviews, physical measures, and

blood and urine samples. Participants are evaluated every 3 years and will be followed for 20 years (until 2033) unless they withdraw, are lost to follow-up, or die.

Consenting CLSA Memory Study participants will be asked to undergo a clinical assessment at a local DCS. For this reason, we will include participants from the Comprehensive cohort as well as Tracking Cohort participants who live within 25-50km of a DCS. CLSA participants unable to visit their local DCS, complete the clinical assessment for any reason (e.g., aphasia, hearing loss), or cannot identify an informant will be excluded from participation.

Patient and public involvement

Participants and the public were not involved in our research design.

Participant selection and recruitment

Participant selection

Prior to being contacted for the CLSA Memory Study, potential participants will be categorized on their presumed cognitive status according to DSM-5 criteria; 1) no NCD; 2) mild NCD; and, 3) major NCD. The categorization will be based on data collected during the CLSA baseline (from 2011-2015), follow-up 1 (conducted from 2015-2018), and follow-up 2 visits (conducted from 2018-2021). This preliminary categorization for participant selection is not the algorithm this project aims to validate.

Participants are **presumed to have a mild NCD** if they have a self-reported physician diagnosis of a memory problem, can both take medicine and manage money without help and have not lost their driver's license or have restrictions on their license other than wearing eyeglasses. Additionally, participants who demonstrated cognitive problems in scheduling or during CLSA DCS visits that were documented by staff will be presumed to have a mild NCD.

Participants are **presumed to have a major NCD** if they meet one or more of the following criteria;

1. Use of prescription medications for the treatment of a major NCD (specifically donepezil, galantamine, rivastigmine, memantine)
2. Self-reported physician diagnosis of dementia or Alzheimer's disease
3. Self-reported physician diagnosis of a memory problem **and** at least one of the following functional limitations;
    - Requires assistance taking medication
    - Requires assistance managing money
    - Among those who formerly drove, no longer having a driver's license or having a driver's license with restrictions other than eyeglasses

Participants that do not meet the criteria for presumed mild or major NCD will be **presumed not to have an NCD.**

Approximately equal numbers from each of the three categories will be recruited, though final recruitment goals will be based on NCD status as determined through the Memory Study (see Statistical Methods section). Participants presumed to have mild or major NCD will first be selected. For 1/3 of the participants presumed to have major NCD and for 2/3 of the participants presumed to have mild NCD, a person of the same age (using participants' age category as of June 1st, 2022 (54-63, 64-73, 74-83, 84+ years) and sex presumed to have no cognitive impairment will be chosen at random.

Participant recruitment

Participants will be recruited into the CLSA Memory Study during CLSA follow-up 3 (started August 2021). Tracking cohort participants and comprehensive cohort participants who have completed their CLSA follow-up 3 interview will be e-mailed/mailed the participant information package (**Supplementary Appendix 1**). Comprehensive cohort participants that have not yet completed their main CLSA follow-up 3 interview will be given the participant information package during their follow-up 3 in-home interview.

After the participant has received an information package, the local CLSA DCS will contact the participant by phone to determine their interest in the study. Interested participants will complete a short questionnaire to determine if they understand the purpose of the study and what participant entails. Potential participants who, as judged by the interviewer, do not understand the details of the study will be ineligible. There are no additional eligibility criteria for participants selected for this sub-study beyond the general requirements for participation in the CLSA. [18] Eligible participants will provide informed consent, identify and provide contact information for an informant and schedule their clinical assessment (**Supplementary Appendix 2**). If a participant is unable or unwilling to identify an informant, they will not be able to participate in the study.

Informant recruitment

Each participant will be asked to identify a family member or friend that knows them well enough to respond to questions about their cognitive health, ability to complete daily tasks, and behaviour. Potential informants will be provided with a copy of the family member or friend information package (**Supplementary Appendix 3**). The local DCS will contact the identified potential informant by phone prior to the participant's clinical assessment to discuss the study, obtain consent from the informant, and schedule a time to complete the informant interview via phone (**Supplementary Appendix 4**). If the identified informant does not wish to take part in the study, the participant will be contacted and asked to identify an alternative informant.

Measurements

The CLSA Memory Study includes a clinical assessment of the study participant and a phone interview with the informant which will take place between September 2022 and March 2024.

Clinical Assessment

The clinical assessments will be conducted by a study clinician (medical specialist or senior trainee in geriatric medicine, geriatric psychiatry, neurology, or psychiatry; internist with training and experience in cognitive assessment; neuropsychologist) who will undergo local and/or virtual training in the performance of the standardized assessment and completion of all required forms. The clinical assessment (**Supplementary Appendix 5)** requires approximately one hour with the participant. It consists of a standardized history and physical examination designed to categorize the participant as having no evidence of an NCD, mild NCD, or major NCD. The study clinician will not have access to CLSA data on the participant other than name, age, sex, gender identity, education, employment status, and occupation and will be blinded to the participant's presumed cognitive status. The clinical assessment has not been designed to determine the likely underlying cause of the NCD, risk of progression, or specific care needs of the participant. The components of the assessment are as follows:

1. Participant interview
    a. Sociodemographic information (age, sex, gender identity, education, occupation, employment status)

b. History of cognitive decline
c. Medical history including medical conditions, a review of medications focusing on those with cognitive effects, use of tobacco, cannabis and alcohol, and a family history of dementia
d. Basic activities of daily living measured using the Older Americans Resource and Services Program (OARS) scale [19]
e. Instrumental activities of daily living measured using the OARS scale [19] with additional questions regarding transportation (i.e., driving)
f. Behavioural symptoms including depression measured using the Patient Health Questionnaire-2 [20], anxiety, psychotic symptoms, and changes in personality.

2. Cognitive testing
   a. The Montreal Cognitive Assessment (MoCA) [21] will be used as a general measure of cognition. The MoCA is a brief instrument that has been shown to be a valid screening test for mild (MCI) and major NCD (dementia) [22] with validated versions and normative data for both English and Quebec-French [23] populations. The MoCA-BLIND version will be used for participants with visual impairments that would prevent them from completing the MoCA. [24] An optional section of the MoCA called the Memory Impairment Score (MIS) will be used to assess uncued and cued (category and multiple-choice options) recall of the memory items. The use of the MoCA total and MoCA-MIS scores with all the other information being collected on participants will be used to help identify participants with mild and major NCD. [25]
3. Physical examination
   a. Alertness
   b. Hearing
   c. Focal/lateralizing neurological findings
   d. Extrapyramidal signs
   e. Balance and gait assessment including transfers, gait, and the Romberg test

Informant Interview

The informant interview will be conducted by CLSA DCS staff using a standardized protocol. All CLSA DCSs have highly trained data collection teams. The informant interview (**Supplementary Appendix 6**) includes several overlapping items to those directly asked of participant. Interview questions will focus on the participant's cognitive, functional, and mood/behavioural history. The components of the interview are as follows:

1. Cognitive changes measured using the eight-item informant interview to differentiate aging and dementia (AD8® Dementia Screening Interview) [26]. The AD8® asks about changes in memory, orientation, judgement, and function that might indicate a dementing illness.
2. Medical history including medical conditions, use of tobacco, cannabis and alcohol, and a family history of dementia
3. Basic activities of daily living measured using the OARS scale [19]
4. Instrumental activities of daily living measured using the OARS scale [19] with additional questions regarding transportation
4. Presence of current mood and psychiatric symptoms using the Mild Behavioural Impairment Checklist (MBI-C). [27]The MBI-C was designed to measure neuropsychiatric symptoms that precede or coincide with the diagnosis of mild cognitive impairment. The instrument measures the domains of 1) decreased motivation; 2) emotional dysregulation; 3) loss of impulse control; 4) social inappropriateness; and, 5) abnormal perception or thought content.

Participant categorization based on clinical assessment and informant interview

Study clinician

Based on the clinical assessment and the informant interview, the study clinician will make a provisional clinical determination of: 1) no evidence of cognitive impairment; 2) mild NCD (MCI); or, 3) major NCD (dementia) based on DSM-5 criteria. [3]

Study physicians will not provide participants with their provisional diagnosis, as to make a clinical diagnosis of mild or major NCD with confidence would require a more in-depth evaluation including review of prior health records, laboratory and/or imaging investigations as well as possible follow-up visits that our study clinicians are unable to provide. The study clinician will verbally tell the participant if there is a potential concern regarding their memory (the term memory will be used to describe any cognitive concern when communicating with the participant) or if they do not have any concerns based on the assessment and informant interview just conducted. The study clinician will tailor the conversation based on the participant's level of understanding and their own degree of concern. Each participant will then be provided with a letter indicating if the clinician identified a potential problem with the participant's memory (**Supplementary Appendix 7**) or no evidence of a potential problem with the participant's memory (**Supplementary Appendix 8**), as well as the participant's total score on the MoCA and details about the CLSA Memory Study. Participants identified by the clinician as having potential concerns about their memory will be encouraged to speak with their family physician and share the information provided verbally and in writing. If the participant does not have a family physician, the study clinician will provide the participant with local resources that the participant may use for follow-up care.

Central Review Panel

A Central Review Panel including medical specialists (e.g., geriatric medicine, geriatric psychiatry, neurology, or psychiatry with training and experience in cognitive assessment) and neuropsychologists will review the clinical assessment, informant interview, and available CLSA data such as performance on the neurocognitive battery conducted at baseline through to the follow-up 2 CLSA assessment (which the examining physician will not have seen). Based on the review of these data, the Panel will make a final study categorization. This will be compared to the one made by the study clinician, and, if different, an explanation for reaching a differing determination will be documented and provided to the examining clinician. The Central Review Panel will help ensure that the study is implemented in a standardized manner across all sites by the participating clinicians. Any concerns will be brought to the attention of the involved clinician and the CLSA Memory Study investigators.

Pilot study and adaptation of recruitment criteria

Prior to the full implementation of the CLSA Memory Study, pilot testing will be conducted on a sample of 10 participants at two DCS sites (Hamilton and Calgary) to 1) identify any issues needing correction and 2) develop implementation advice for all DCS sites. These participants will be included in the final sample with their data retained as study data.

CLSA Memory Study investigators and staff will monitor the number of recruited participants by presumed NCD status, study clinician NCD determinations, and Central Review Panel categorizations at a group level. This monitoring will allow the detection of unbalanced recruitment and the opportunity to adapt the recruitment strategy during the study to ensure we end up with approximately equal number of participants in each NCD diagnostic category based on the Central Review Panel categorizations. For

example, if the number of participants determined by the study clinician and/or Central Review Panel to have major NCD is lower than expected, we will start to oversample from the group of participants presumed to have a major NCD to compensate.

CLSA NCD ascertainment algorithm

Development of the CLSA NCD ascertainment algorithm

This was informed by a systematic review of methods used to identify cases of mild and major NCD in population-based studies (https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=78874). Identified potential items for inclusion were categorized based on DSM-5 criteria and then mapped onto available CLSA data (**Supplementary Appendix 9).** Conditional use (e.g., only include functional data provided by participants who achieve a certain cognitive threshold on the MoCA) and alternative weighting of select items that might improve on the accuracy of the algorithm will be explored in the Study.

Participant categorization based on CLSA ascertainment algorithm

The initial validation of the CLSA ascertainment algorithm will include CLSA data from baseline, follow-up 1, and follow-up 2 assessments. The follow-up 2 interview data were collected three or more years before the Memory Study was initiated and may not accurately reflect the current cognitive status for all participants (e.g., for those with new onset neurocognitive disorders). Therefore, final validation of the algorithm will occur when the follow-up 3 assessment data, which were collected at the time of the CLSA Memory Study, are available to the Central Review Panel in 2024.

Statistical analyses and sample size determination

Kappa using Cicchetti-Allison weights and the percent of agreement between the reference standard and the CLSA NCD algorithm will be calculated to assess the reliability of the CLSA algorithm. Sensitivity, specificity, and C statistics for the CLSA NCD algorithm for each outcome category (major NCD, mild NCD, or no evidence of cognitive impairment) will be estimated using logistic regression. [28] Analyses will be completed overall and stratified by sex and age-group (age 45-65 years old and 65+) using SAS. We have calculated the minimum sample size required based on different combinations of Kappa values and precision (distance between the lower and upper 95% confidence limits) (**Table 1**) using the 'kappaSize' Package in R with 3 outcome categories. This package assumed unweighted kappa to provide a conservative sample size estimate. Our final sample size will range between approximately 200 participants assuming an expected Kappa of 0.7 and precision of 0.2, and 600 participants assuming an expected Kappa of 0.7 and a precision of 0.1. Our aspiration is to recruit as close to 600 participants as possible, but this will be dependent on sufficient funding. We currently have funding confirmed for 320.

Table 1 – Minimum sample size for 95% confidence interval width (0.05, 0.1, 0.15, and 0.2) by Kappa

Kappa	Precision (the distance between the lower and upper 95% confidence limits)	Minimum required total sample size
0.7	0.05	2348
	0.10	619
	0.15	289
	0.20	170
0.8	0.05	1764

	0.10	481
	0.15	231
	0.20	139

ETHICS AND DISSEMINATION

Ethics approval for this project was provided by the Research Ethics Board responsible for each participating site (**Supplementary Appendix 10**).

Our knowledge translation plan includes sharing the results of the project with researchers and health professionals through journal publications and conference presentations. The CLSA will host a webinar on the Memory Study that will be open to researchers, health professionals, public health workers, as well as participants with an interest in NCD research. We will work with other partners to present our results to key groups. The CLSA will develop and disseminate a report that describes the results of the project and implications for health system stakeholders likely to use the results (e.g., health professionals, administrators, policymakers). The report and presentations will be tailored to specific stakeholder groups including those responsible for provincial and national dementia strategies (e.g., Ministerial Advisory Board on Dementia), health professional organizations (e.g., Canadian Geriatrics Society), and health charities (e.g., Alzheimer's Society of Canada). The report will also be available on the CLSA website. The CLSA website and social media platforms will be used to disseminate a summary of the project to participants. It is anticipated that the targets of tailored knowledge translation activities will use the results in various ways including: additional research on risk and protective factors for NCDs; development and implementation of best practices for early intervention and treatment for people with mild and major NCD; and, improving public health surveillance systems that develop population estimates for dementia in Canada that can be used to inform current and future government investment in prevention and care.

DISCUSSION

There are some limitations with the use of CLSA data for developing an NCD ascertainment algorithm. First, CLSA interview data do not include an informant interview on most participants. In clinical settings, informant reports are an important component of the diagnosis of NCDs, as individuals with an NCD may be unaware of their own functional status and behavioural changes. [29] Although the CLSA asks participants over the age of 70 years to identify a proxy, proxy interviews have only been conducted on a small number of participants and under specific conditions. Informant data therefore cannot be used to inform the algorithm. Another limitation is that the CLSA neurocognitive battery was not developed to diagnose NCDs. [30] Rather, the battery items were selected to be applicable to a wide age range without ceiling or floor effects in order to capture decline over time. The neurocognitive battery items reflect the domains of executive function and memory, but not complex attention, language, perceptual-motor, or social cognition.

There are also several strengths of the CLSA dataset for developing an NCD ascertainment algorithm. The breadth of routinely collected CLSA data (e.g., balance and gait performance measures, trajectory of changes in cognitive test performance) and the high percentage of participants (~88%) that have provided permission to the CLSA data to be linked to health care administrative databases provides an opportunity to explore the creation of an expanded and superior NCD ascertainment algorithm. Having

a relatively large (up to 600) group of participants who have gone through a gold standard assessment for NCDs will make this effort possible.

CONCLUSION

If the results of the CLSA Memory Study suggest that the proposed NCD ascertainment algorithm is a valid method of identifying NCD cases, it will be applied to all CLSA participants. This will enhance the CLSA dataset for NCD research and provide important insights regarding the risk and protective factors of NCD and associated health outcomes. Linkage to healthcare administrative databases will allow the CLSA to estimate the burden of mild and major NCD in Canada. Together, these sources of data will help inform health and social care planning for individuals with NCD.

Authorship: The following are members of the CLSA Memory Study Working Group: Andrew Costa, Benoit Cossette, Lauren E. Griffith, David B. Hogan, Aaron Jones, Susan Kirkland, Teresa Liu-Ambrose, Jinhui Ma, Alexandra J. Mayhew, Jacqueline McMillan, Verena Menec, Gerry Mugford, Megan E. O'Connell, Theone Paterson, Christopher Patterson, Parminder Raina, Eric E. Smith, Vanessa Taler, Mary Thompson, Andrew Wister, Christina Wolfson, & Changbao Wu.

Author Contributions: LEG, PR, AC, and DH led the conceptualization of the study methodology. AJM made contributions to the design of the study methods and wrote the first draft of the manuscript. CW, AJ, SK, MO, VT, EES, TL-A, JM, MT, CW, HC made contributions to the design of the study methods and supported the manuscript. All authors critically revised the manuscript and approved the final version.

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REFERENCES

1 Sternberg SA, Wolfson C, Baumgarten M. Undetected dementia in community-dwelling older people: The Canadian study of health and aging. *J Am Geriatr Soc* 2000;**48**:1430–4. doi:10.1111/j.1532-5415.2000.tb02633.x

2 Lang L, Clifford A, Wei L, *et al.* Prevalence and determinants of undetected dementia in the community: A systematic literature review and a meta-analysis. *BMJ Open* 2017;**7**:1–8. doi:10.1136/bmjopen-2016-011146

3 American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*. American Psychiatric Association Publishing 2013.

4 Tang W, Kannaley K, Friedman DB, *et al.* Concern about developing Alzheimer's disease or dementia and intention to be screened: An analysis of national survey data. *Arch Gerontol Geriatr* 2017;**71**:43–9. doi:10.1016/j.archger.2017.02.013

5 Tuokko H, Frerichs RJ. Cognitive impairment with no dementia (CIND): Longitudinal studies, the findings, and the issues. *Clinical Neuropsychologist* 2000;**14**:504–25. doi:10.1076/clin.14.4.504.7200

6 U.S. Department of Health and Human Services Food and Drug Administration. Early Alzheimer's Disease: Developing Drugs for Treatment -Guidance for Industry. 2018. https://www.fda.gov/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/default.htm

7 van Dyck CH, Swanson CJ, Aisen P, *et al.* Lecanemab in Early Alzheimer's Disease. *N Engl J Med* Published Online First: 29 November 2022. doi:10.1056/NEJMoa2212948

8 Getsios D, Blume S, Ishak KJ, *et al.* An economic evaluation of early assessment for Alzheimer's disease in the United Kingdom. *Alzheimer's and Dementia* 2012;**8**:22–30. doi:10.1016/j.jalz.2010.07.001

9 Stoye G, Zaranko B. IFS Working Paper W20/13 How accurate are self-reported diagnoses? Comparing self-reported health events in the English Longitudinal Study of Ageing with administrative hospital records How accurate are self-reported diagnoses? Comparing self-reported health events in the English Longitudinal Study of Ageing with administrative hospital records. 2020.

10 Smith B, Chu LK, Smith TC, *et al.* Challenges of self-reported medical conditions and electronic medical records among members of a large military cohort. *BMC Med Res Methodol* 2008;**8**:1–10. doi:10.1186/1471-2288-8-37

11 Okura Y, Urban LH, Mahoney DW, *et al.* Agreement between self-report questionnaires and medical record data was substantial for diabetes , hypertension , myocardial infarction and stroke but not for heart failure. 2004;**57**:1096–103. doi:10.1016/j.jclinepi.2004.04.005

12 Payette Y, de Moura C, Boileau C, *et al.* Is there an agreement between self-reported medical diagnosis in the CARTaGENE cohort and the Québec administrative health databases? *Int J Popul Data Sci* 2019;**5**.

13 Oremus M, Postuma R, Griffith L, *et al.* Validating chronic disease ascertainment algorithms for use in the Canadian Longitudinal Study on Aging. *Canadian Journal on Aging* 2013;**32**:232–9. doi:10.1017/S0714980813000275

14 Gianattasio KZ, Wu Q, Glymour MM, *et al.* Comparison of Methods for Algorithmic Classification of Dementia Status in the Health and Retirement Study. *Epidemiology* 2019;**30**:291–302. doi:10.1097/EDE.0000000000000945

15 Eramudugolla R, Mortby ME, Sachdev P, *et al.* Evaluation of a research diagnostic algorithm for DSM-5 neurocognitive disorders in a population-based cohort of older adults. *Alzheimers Res Ther* 2017;**9**:1–12. doi:10.1186/s13195-017-0246-x

16 Wilkinson T, Ly A, Schnier C, *et al.* Identifying dementia cases with routinely collected health data: A systematic review. *Alzheimer's and Dementia* 2018;**14**:1038–51. doi:10.1016/j.jalz.2018.02.016

17 Rueda A, Lau K, Saito N, *et al.* Self-rated and informant-rated everyday function in comparison to objective markers of Alzheimer's disease. *Alzheimers Dement* 2016;**11**:1080–9. doi:10.1016/j.jalz.2014.09.002.Self-rated

18 Raina PS, Wolfson C, Kirkland SA, *et al.* Cohort profile: The Canadian Longitudinal Study on Aging (CLSA). *Canadian Journal on Aging* 2009;**28**:221–9. doi:10.1017/S0714980809990055

19 Fillenbaum G, Smyer M. The development, validity, and reliability of the OARS Multidimensional Functional Assessment Questionnaire. *J Gerontol* 1981;**36**:428–34.

20 Kroenke K, Spitzer RL, Williams JBW. The Patient Health Questionnaire-2 Validity of a Two-Item Depression Screener. *Med Care* 2003;**41**:1284–92.

21 Nasreddine ZS, Phillips NA, Bédirian V, *et al.* The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. *J Am Geriatr Soc* 2005;**53**:695–9. doi:10.1111/j.1532-5415.2005.53221.x

22 Tsoi KKF, Chan JYC, Hirai HW, *et al.* Cognitive tests to detect dementia a systematic review and meta-analysis. *JAMA Intern Med* 2015;**175**:1450–8. doi:10.1001/jamainternmed.2015.2152

23 Larouche E, Tremblay MP, Potvin O, *et al.* Normative Data for the Montreal Cognitive Assessment in Middle-Aged and Elderly Quebec-French People. *Archives of Clinical Neuropsychology* 2016;**31**:819–26. doi:10.1093/arclin/acw076

24 Wittich W, Phillips N, Nasreddine ZS, *et al.* Sensitivity and specificity of the Montreal cognitive assessment modified for individuals who are visually impaired. *J Vis Impair Blind* 2010;**104**:360–8. doi:10.1177/0145482x1010400606

25 Julayanont P, Brousseau M, Chertkow H, *et al.* Montreal Cognitive Assessment Memory Index Score (MoCA-MIS) as a predictor of conversion from mild cognitive impairment to Alzheimer's disease. *J Am Geriatr Soc* 2014;**62**:679–84. doi:10.1111/jgs.12742

26 Galvin JE, Roe CM, Powlishta KK, *et al.* The AD8: A brief informant interview to detect dementia. *Neurology* 2005;**65**:559–64. doi:10.1212/01.wnl.0000172958.95282.2a

27 Ismail Z, Aguera-Ortiz L, Brodaty H, *et al.* The mild behavioral impairment checklist (MBI-C): A rating scale for neuropsychiatric symptoms in pre-dementia populations. *Journal of Alzheimer's Disease* 2017;**56**:929–38. doi:10.3233/JAD-160979.The

28 Cook R, Farewell V. Conditional inference for subject specific and marginal agreement. Two families of agreement measures. *Canadian Journal of Statistics* 1995;**23**:333–44.

29 Schinka JA. Use of informants to identify mild cognitive impairment in older adults. *Curr Psychiatry Rep* 2010;**12**:4–12. doi:10.1007/s11920-009-0079-9

30 Tuokko H, Griffith LE, Simard M, *et al.* Cognitive measures in the Canadian Longitudinal Study on Aging. *Clin Neuropsychol* 2017;**4046**:1–18. doi:10.1080/13854046.2016.1254279

Figure 1. CLSA Study Design: The CLSA Memory Study will recruit Comprehensive Cohort and Tracking Cohort participants who are currently undergoing their follow-up three assessment (started August 2021) for the CLSA.

Note from the Editors: Instructions for reviewers of study protocols

Since launching in 2011, BMJ Open has published study protocols for planned or ongoing research studies. If data collection is complete, we will not consider the manuscript.

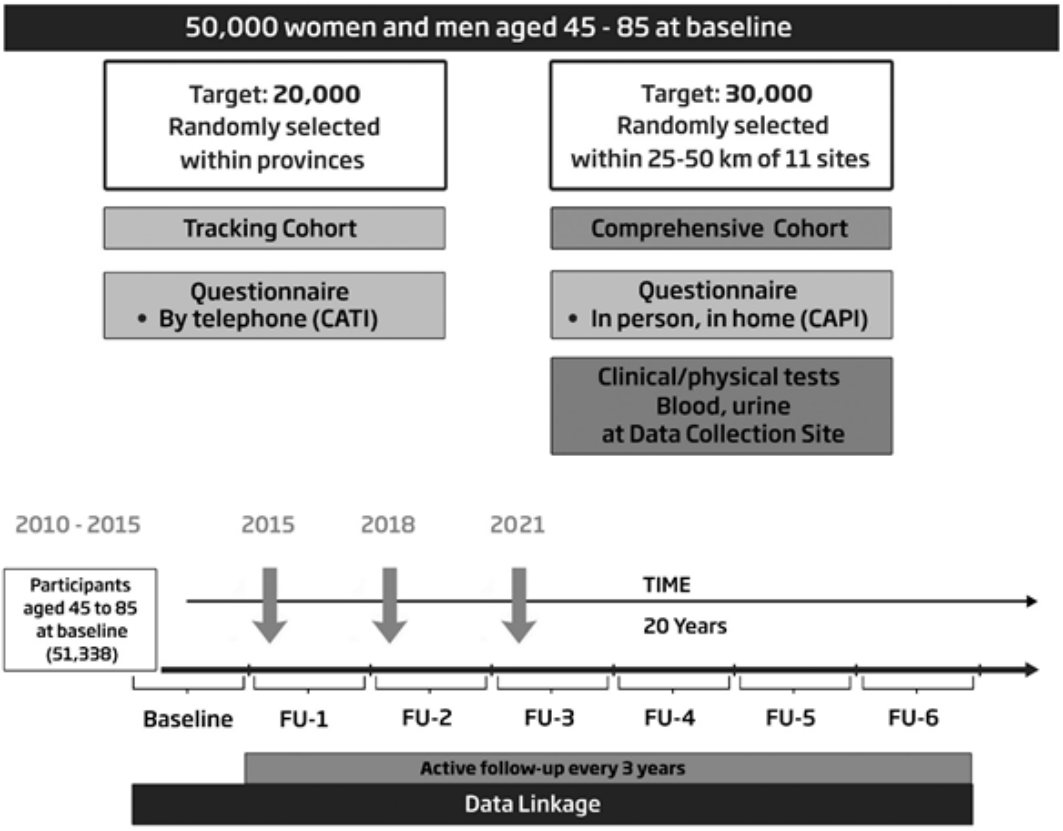
Publishing study protocols enables researchers and funding bodies to stay up to date in their fields by providing exposure to research activity that may not otherwise be widely publicised. This can help prevent unnecessary duplication of work and will hopefully enable collaboration. Publishing protocols in full also makes available more information than is currently required by trial registries and increases transparency, making it easier for others (editors, reviewers and readers) to see and understand any deviations from the protocol that occur during the conduct of the study.

The scientific integrity and the credibility of the study data depend substantially on the study design and methodology, which is why the study protocol requires a thorough peer-review.

BMJ Open will consider for publication protocols for any study design, including observational studies and systematic reviews.

Some things to keep in mind when reviewing the study protocol:

- Protocol papers should report planned or ongoing studies. The dates of the study should be included in the manuscript.
- Unfortunately we are unable to customize the reviewer report form for study protocols. As such, some of the items (i.e., those pertaining to results) on the form should be scored as Not Applicable (N/A).
- While some baseline data can be presented, there should be no results or conclusions present in the study protocol.
- For studies that are ongoing, it is generally the case that very few changes can be made to the methodology. As such, requests for revisions are generally clarifications for the rationale or details relating to the methods. If there is a major flaw in the study that would prevent a sound interpretation of the data, we would expect the study protocol to be rejected.


50,000 women and men aged 45 - 85 at baseline
Target: 20,000
Randomly selected
within provinces
Target: 30,000
Randomly selected
within 25-50 km of 11 sites
Tracking Cohort
Comprehensive Cohort
Questionnaire
• By telephone (CATI)
Questionnaire
• In person, in home (CAPI)
Clinical/physical tests
Blood, urine
at Data Collection Site
2010 - 2015
2015
2018
2021
Participants
aged 45 to 85
at baseline
(51,338)
TIME
20 Years
Baseline
FU-1
FU-2
FU-3
FU-4
FU-5
FU-6
Active follow-up every 3 years
Data Linkage

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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.

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.

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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.

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 STUDY INFORMATION PACKAGE

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

Principal Investigators:

Dr. Lauren Griffith, Department of Health Research Methods, Evidence, and Impact, McMaster University

Dr. Andrew Costa, Department of Health Research Methods, Evidence, and Impact, McMaster University

Dr. Parminder Raina, Department of Health Research Methods, Evidence, and Impact, McMaster University

Co-Investigators:

Newfoundland and Labrador
Dr. Gerry Mugford – Memorial University

Nova Scotia
Dr. Susan Kirkland – Dalhousie University

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

Ontario
Dr. Cynthia Balion – McMaster University
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).

BRITISH COLUMBIA

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Office of Research Ethics
Simon Fraser University
8888 University Drive
Multi-Tenant Facility
Burnaby BC V5A 1S6
Phone: (778) 782-6593
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VICTORIA
Human Research Ethics Office of Research Services
University of Victoria
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Supplementary Appendix 2 – Participant Consent Scripts

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.

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

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. 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

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**

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**

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**

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.

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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**

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 in 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**

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

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]

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.

Disagree _____ **Go to Refusal**

Agree _____ **Continue**

PARCON5 I understand that I can withdraw my consent at any time. If a 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

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.

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.

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.

MEDICAL ASSESSMENT BOOKING

PARMED_1 Would you like to schedule a time for your medical assessment with the study physician?

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.

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

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

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**

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**

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.

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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**

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 in 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**

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

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]

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.

Disagree _____ **Go to Refusal**

Agree _____ **Continue**

PARCON5 I understand that I can withdraw my consent at any time. If a 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.

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.

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.

MEDICAL ASSESSMENT BOOKING

PARMED_1 Would you like to schedule a time for your medical assessment with the study physician?

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.

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Supplementary Appendix 3 – Informant Information Package

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Family Member or Friend Information Package Cover Letter

Dear [Informant],

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.

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 at a time convenient to you.

This study of the CLSA is 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 is/This package contains] the **Family Member or Friend Study Information Package** that will provide you with information to help you make an informed choice about if you would like to take part in this study.

Please read the **Family Member or Friend Study Information Package** carefully. We will call you in the next couple of weeks and you will have an opportunity to ask any questions you may have.

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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FAMILY MEMBER OR FRIEND STUDY INFORMATION PACKAGE

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

Principal Investigators:

Dr. Lauren Griffith, Department of Health Research Methods, Evidence, and Impact, McMaster University

Dr. Andrew Costa, Department of Health Research Methods, Evidence, and Impact, McMaster University

Dr. Parminder Raina, Department of Health Research Methods, Evidence, and Impact, McMaster University

Co-Investigators:

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

Ontario
Dr. Cynthia Balion – McMaster University
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 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.

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- 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.

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- 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.

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- 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	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 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.

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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) 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).

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Phone: (250) 472-4545

VANCOUVER
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Vancouver Island Health Authority
Research Ethics and Compliance Office
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St. John's NL, A1B 2X5
Phone: (709) 777-6974

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

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**

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**

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

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Supplementary Appendix 5 - Medical Assessment

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

v1.2, 2022 October 20th

Table of Contents

Sociodemographic Information (SDC)

Overview	These questions obtain basic sociodemographic information from the participant. They function as an interview icebreaker and, by comparison with the most recent response for each question from the main CLSA interviews when available, a check on their remote memory. Clinicians are expected to complete all items in this module. However, they have flexibility in determining the order in which the questions are asked and the specific wording used for each question.

SDC_1	**SDC_AGEBL_MSP**
Participant's age in years – based on date of birth provided at CLSA Baseline	
CLINICIAN NOTE: If there is no response shown for this item, the participant did not answer this question at baseline.	
NUMBER	_____ [CALCULATED BY PINE USING BASELINE CLSA DATA – AGE_DOB_COM]

SDC_2		**SDC_AGE_MSP**
[ALWAYS ASK]		
What is the participant's **self-reported** age in years?		
NB_SP	Age	_____ **[MASK: MIN=53, MAX=94]**
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

SDC_3	**SDC_SEXBL_MSP**
Participant's sex – self-reported at CLSA baseline	
CLINICIAN NOTE: If there is no response shown for this item, the participant did not answer this question at baseline.	
GENDER	_____ [IMPUTED BY PINE USING BASELINE CLSA DATA – SEX_ASK_COM. IF EMPTY, ANSWER 'DATA UNAVAILABLE']

SDC_4	SDC_GENDER_MSP	
[ALWAYS ASK]		
What is the participant's **self-reported** gender identity?		
CODE ONLY ONE RESPONSE		
MALE	1	Male
FEMALE	2	Female
TRANSMAN	3	Transgender Man/Transman
TRANSWOMAN	4	Transgender Women/Transwoman
GENDERQUEER	5	Genderqueer
OTSP	7	Other (please specify: _____)
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

SDC_5	SDC_EDU4BL_MSP
[ALWAYS ASK]	
Participant's education – self-reported at CLSA Baseline	
CLINICIAN NOTE: If there is no response shown for this item, the participant did not answer this question at baseline.	
EDU4	_____ [IMPUTED BY PINE USING BASELINE CLSA DATA **1 = Less than secondary school graduation** – code if: ED_ELHS_COM = (1, 2, 3) and ED_HSGR_COM = 2 and ED_OTED_COM = 2 **2 = Secondary school graduation, no post-secondary secondary education** – code if: ED_HSGR_COM = 1 and ED_OTED_COM = 2 **3 = Some post-secondary education** – code if: ED_HIGH_COM = 01 **4 = Post-secondary degree/diploma** – code if: 02≤ED_HIGH_COM≤06 or ED_HIGH_COM = 97 **9 = At least one required question as not answered** – code if: ED_ELHS_COM = (8,9, EMPTY) or ED_HSGR_COM = (8,9, EMPTY) or ED_OTED_COM = (7,8,9, EMPTY) or ED_HIGH_COM = (98,99, EMPTY)]

SDC_6	**SDC_EDU_MSP**	
[ALWAYS ASK]		
What is the participant's **self-reported** highest level of education?		
CODE ONLY ONE RESPONSE		
LESS_SEC	1	Less than secondary school graduation
SEC	2	Secondary school graduation, no post-secondary education
SOME_POST	3	Some post-secondary education
POST_SEC	4	Post-secondary degree/diploma
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

SDC_7	**SDC_LBF_MSP**	
[ALWAYS ASK]		
What is the participant's **self-reported** employment status?		
CODE ONLY ONE RESPONSE		
COM_RET	1	Completely retired
PAR_RET	2	Partly retired
NOT_RET_WORK	3	Not retired and currently working
NOT_RET_NO_WORK	4	Not retired and not currently working
NEVER_WORKED	5	Never held a paid job
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

SDC_8	SDC_OCCBL_MSP
[ASK IF SDC_LBF_MSP ≠ NEVER_WORKED]	
Type of job participant did for the longest period of time – self-reported at CLSA Baseline	
CLINICIAN NOTE: Please note that this is not the "main occupation" of the participant. Rather it is the job at which the participant had worked at the longest. If there is no response shown for this item, the participant did not answer this question at baseline.	
OCC_TYPE	_____ [IMPUTED BY PINE USING BASELINE CLSA DATA **Never worked** – code if: LBF_EVER_COM = "NO" **[open text for LFP_TYPE_SP_COM]** – code if: (RET_RTRD_COM = 1 or RET_RTRD_COM = 2) and LFP_LNGST_COM = 1 **[open text for LFP_LGTYPE_SP_COM]** – code if: (RET_RTRD_COM = 1 or RET_RTRD_COM = 2) and LFP_LNGST_COM = 2 **[open text for LBF_TYPE_NB_COM]** – code if: RET_RTRD_COM = 3 and LBF_LGEVER_COM = 2 **[open text for LBF_LGTYPE_SP_COM]** – code if: RET_RTRD_COM = 3 and LBF_LGEVER_COM = 1 **Data unavailable** – code if: ALL required questions do not fit into categories above, or ALL are DK_NA or REFUSED or not answered/missing data

SDC_9	SDC_OCC_MSP
[ASK IF SDC_LBF_MSP = COM_RET, PAR_RET, NOT_RET_WORK, or NOT_RET_NO_WORK]	
What is the participant's **self-reported** primary occupation?	

CLINICIAN NOTE: Provide a brief description of the occupation. Please note, this question refers to the primary occupation of the participant while the previous question from the main CLSA interview refers to the occupation that the participant did for the longest period of time.		
OCC_SP	Occupation	_____
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

SDC_10	**SDC_NOTES_MSP**	
[ALWAYS ASK]		
Do you have any additional notes to include for this module? For example, are there any other sociodemographic characteristics that should be taken into account when interpreting the results of the cognitive testing?		
YES	1	Yes
NO	2	No

SDC_11	**SDC_NOTESSP_MSP**
[ASK IF SDC_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any relevant notes (e.g., how congruent the participant's responses were to previously collected information) below:	

SDC_END

Cognitive Status (COG)

Overview	The purpose of this section is to assess if the participant has experienced cognitive decline. Participants that report the presence of cognitive decline will be asked to provide details regarding the onset, progression, and symptoms related to the cognitive decline. Clinicians are expected to complete all items in this module. However, they have flexibility in determining the order in which the questions are asked and the specific wording used for each question.

COG_1	**COG_DEC_MSP**	
[ALWAYS ASK]		
Has the participant reported experiencing cognitive decline?		
CLINICIAN NOTE: This question should be asked directly to the participant.		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

COG_2	**COG_YRS_MSP**	
[ASK IF COG_DEC_MSP = YES]		
How many years has the participant reported experiencing cognitive decline?		
CLINICIAN NOTE: This question should be asked directly to the participant. Please provide the number of years.		
LESS_YR	001	Less than one year
YEARS	Years	**____ [MASK: MIN=1, MAX=PARTICIPANT'S AGE]**
DK_NA	998	**[DO NOT READ]** Don't know / No answer
REFUSED	999	**[DO NOT READ]** Refused

COG_3	**COG_SEV_MSP**

[ASK IF COG_DEC_MSP = YES]		
The participant describes the severity of their cognitive decline as…		
CODE ONLY ONE RESPONSE		
CLINICIAN NOTE: This question should be asked directly to the participant.		
IRRT	1	Present and may be an irritant but not a concern of theirs
WORR	2	Worrisome but not having overt impact on daily life
IMPT	3	Having an impact on their life (e.g., occupation, autonomy/independence)
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

COG_4	**COG_ONS_MSP**	
[ASK IF COG_DEC_MSP = YES]		
The participant believes the onset of their cognitive decline was…		
CODE ONLY ONE RESPONSE		
GRAD	1	Gradual
ABRT	2	Abrupt
DK_NA	8	[DO NOT READ] Don't know / No answer
REFUSED	9	[DO NOT READ] Refused

COG_5	**COG_VAS_MSP**	
[ASK IF COG_ONS_MSP = ABRT]		
The participant believes their cognitive decline was related to a cerebrovascular event.		
YES	1	Yes
NO	2	No
DK_NA	8	[DO NOT READ] Don't know / No answer
REFUSED	9	[DO NOT READ] Refused

COG_6	**COG_PRO_MSP**
[ASK IF COG_DEC_MSP = YES]	

The participant believes the trajectory of their cognitive impairment was…		
CODE ONLY ONE RESPONSE		
NONE	1	Improvement/none-stability after onset
GRAD	2	Gradual or insidious progression
STEP	3	Stepwise progression
FLUC	4	Fluctuating
DK_NA	8	[DO NOT READ] Don't know / No answer
REFUSED	9	[DO NOT READ] Refused

COG_7	**COG_NOTES_MSP**	
[ALWAYS ASK]		
Do you have any additional notes to include for this module (e.g., whether you concur with the participant's perceptions of presence, severity, onset, and progression of any cognitive decline)?		
YES	1	Yes
NO	2	No

COG_8	**COG_NOTESSP_MSP**
[ASK IF COG_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

COG_END

Medical History (MED)

Overview	The medical history module captures information that will assist the examining physician in determining if any observed cognitive limitations are secondary to medical conditions such as neurodegenerative diseases. This information may also increase the confidence in the physician's diagnosis based on the absence or presence of risk factors for neurocognitive disorders. Clinicians are expected to complete all items in this module. However, they have flexibility in determining the order in which the questions are asked and the specific wording used for each question.

MED_1	MED_CON_MSP	
[ALWAYS ASK]		
Does the participant have any of the following medical conditions?		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96, 98 OR 99 ARE SELECTED), CODE ALL THAT APPLY		
CAD	1	Coronary artery disease
HF	2	Heart failure
AF	3	Atrial fibrillation/flutter
TIA	4	Transient ischemic attack (TIA)
STR	5	Cerebrovascular accident (stroke)
HEM	6	Intracerebral hemorrhage
HYP	7	Hypertension
DIA	8	Diabetes mellitus
DYS	9	Dyslipidemia
PKD	10	Parkinson's Disease or Parkinsonism
DEP	11	Depression
ANX	12	Anxiety disorder
PSY	13	Psychotic illness
HR	14	Hearing impairment
VS	15	Visual impairment
SM	16	Impaired sense of smell
DEM	17	Dementia
DELI	18	Suspected delirium (in the past 5 years)
IN	19	Insomnia
REM	20	REM-Sleep Behaviour Disorder
OSA	21	Obstructive Sleep Apnea
HYPT	22	Hypothyroidism
B12	23	Vitamin B12 deficiency
OTSP	24	Other conditions relevant to cognitive status (e.g. cancer and/or cancer treatments); specify _____
NONE	96	None of the above
DK_NA	98	**[DO NOT READ]** Don't know / No answer
REFUSED	99	**[DO NOT READ]** Refused

MED_2	MED_TBI_MSP	
[ALWAYS ASK]		
Has the participant suffered a head injury or a concussion in the past?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_3	MED_TBI1_MSP	
[ASK IF MED_TBI_MSP = YES]		
How many head injuries or concussions has the participant had in his/her lifetime?		
CLINICIAN NOTES: If the informant cannot remember exact number, please probe for their best estimate		
TBI_NUM	Number	_____ **[MASK: MIN=1]**
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_4	MED_TBI2_MSP	
[ASK IF MED_TBI_MSP = YES]		
At what age or in what year did the participant have the most serious head injury?		
CLINICIAN NOTES: If the informant cannot remember the specific year, please probe for their best estimation of when the head injury occurred.		
YR_SP	Year	_____ **[MASK: MIN=BIRTH YEAR, MAX=CURRENT YEAR]**
NB_SP	Age	_____ **[MASK: MIN=1, MAX=CURRENT AGE]**
DK_NA	998	**[DO NOT READ]** Don't know / No answer
REFUSED	999	**[DO NOT READ]** Refused

MED_5	MED_TBI3_MSP	
[ASK IF MED_TBI_MSP = YES]		
Did the most serious head injury result in…?		
READ LIST, MULTIPLE RESPONSES ALLOWED (EXCEP IF 6, 8 OR 9 ARE SELECTED), CODE ALL THAT APPLY		
DZ	1	Being dazed, confused, or “seeing stars”
DRM	2	Not remembering the injury
KO	3	Losing consciousness (knocked out)
NONE	6	Head injury did not result in any of the above
DK_NA	8	**[DO NOT READ]** Don’t know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_6	MED_TBI4_MSP	
[ASK IF MED_TBI3_MSP = KO]		
How long did you lose consciousness for?		
READ LIST, CODE ONLY ONE RESPONSE		
KO1	1	Less than a minute
KO20	2	1-20 minutes
KO20MORE	3	Longer than 20 minutes
DK_NA	8	**[DO NOT READ]** Don’t know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_7	MED_MED2_MSP
[ALWAYS ASK]	
Which of the following medications is the participant currently taking?	
MULTIPLE RESPONSES ALLOWED (EXCEP IF 96, 98 OR 99 ARE SELECTED), CODE ALL THAT APPLY	
CLINICIAN NOTES: If the participant does not bring in a list of medications or the medications themselves for review, please select option "Don't know / No answer". If you feel that the medication is an essential data element, you can ask if you can call the participant after the assessment when they are home and have access to their medications. Alternatively, you may also ask the participant if he/she would like you to contact the informant about which medications are being used. **To determine if a medication has moderate to high anticholinergic activity, please refer to: https://www.rxfiles.ca/rxfiles/uploads/documents/Psyc-anticholinergic-Ref%20List%20SPDP-complete.pdf** **If the participant is taking a medication with moderate/high anticholinergic activity that also falls under another listed category, please select both options. For example, if a participant is taking desipramine for the treatment of depression, select the options "anti-depressants" and "drugs with moderate/high anticholinergic activity".** **If the participant is not taking a medication regularly but rather as required, please include details in the "Notes" section at the end of this module.**	

DEP	01	Anti-depressants (whether used for depression, anxiety or other reason)
PSY	02	Anti-psychotics
SED	03	Hypnotics and sedatives (whether used for insomnia, anxiety or other reason)
CHL	04	Drugs with moderate/high anticholinergic activity including prescribed and over the counter medications
CON	05	Anticonvulsants
PKD	06	Antiparkinsonian
OPI	07	Opioids
COG	08	Cognitive enhancers (cholinesterase inhibitor, memantine)
OT	09	Other medication that you think may affect cognition: Specify:_____
NONE_	96	None of the above
DK_NA	98	**[DO NOT READ]** Don't know / No answer
REFUSED	99	**[DO NOT READ]** Refused

MED_8	MED_SMKSTATUS_MSP
[ALWAYS ASK]	
What is the participant's smoking status…?	
READ LIST, CODE ONLY ONE RESPONSE	

YES	1	Yes, he/she currently smokes
NEVER	2	No, he/she does not currently smoke and never has
FORM_DAY	4	Former daily smoker (non-smoker now)
FORM_OCC	5	Former occasional smoker (non-smoker now)
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_9	**MED_CAN_MSP**	
[ALWAYS ASK]		
Does the participant use any cannabis products?		
CODE ONLY ONE RESPONSE		
YES	1	Yes, he/she currently uses cannabis products
NEVER	2	No, he/she does not and has never used cannabis products
FORMER	3	Former cannabis user, but does not use cannabis products now
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_10	**MED_ALC_MSP**	
[ALWAYS ASK]		
What is the participant's drinking status?		
CODE ONLY ONE RESPONSE		
NEVER	1	Never drank alcohol
FORMER	2	Used to drink alcohol but does not currently drink
CURRENT	3	Currently consumes alcohol
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_11	**MED_ALCNMB_MSP**	
[ASK IF MED_ALC_MSP = CURRENT]		
A "standard" drink is considered 12 ounces of regular beer (~5% alcohol), 5 ounces of wine (~12% alcohol), or 1.5 ounces of distilled spirits (~40% alcohol). How many estimated standardized drinks per week does the participant consume?		
ALC_NB	Number	_____ **[MASK: MIN=0, MAX=200]**
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_12	MED_ALCMLFQ_MSP	
[ASK IF MED_ALC_MSP = CURRENT AND SDC_SEXBL_MSP = MALE]		
In the past 12 months, has the participant consumed 5 or more drinks in 2 hours at least once a month?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_13	MED_ALCFMFQ_MSP	
[ASK IF MED_ALC_MSP = CURRENT AND SDC_SEXBL_MSP = FEMALE]		
In the past 12 months, has the participant consumed 4 or more drinks in 2 hours at least once a month?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_14	MED_FAM_MSP	
[ALWAYS ASK]		
Does the participant have a first degree relative who has been diagnosed with dementia or Alzheimer's Disease?		
CLINICIAN NOTE: First degree relatives include biological parents, siblings, or children		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_15	MED_NOTES_MSP
[ALWAYS ASK]	

Do you have any additional notes to include for this module? For example, are there any other details regarding the participant's medical history that should be taken into account when interpreting the results of the cognitive testing such as the use of non-prescription drugs?		
YES	1	Yes
NO	2	No

MED_16	**MED_NOTESSP_MSP**
[ASK IF MED_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

MED_END

Basic Activities of Daily Living (ADL)

This module contains a subset of the Activities of Daily Living questions of the OARS Multidimensional Assessment Questionnaire© developed by Dr. Gerda G. Fillenbaum (Duke University Medical Center). The Canadian Longitudinal Study on Aging received permission from Dr. Fillenbaum (instrument developer) for the use of this instrument.

Overview	Activities of daily living assess respondents' ability to perform basic daily activities. Activities of daily living are the tasks considered vital to live independently in the community. This module contains key activities relevant to neurocognitive disorders and is a subset of the list of questions asked to the informant regarding the participant's ability to perform activities independently. The informant supplied data will in most cases be used to determine the participant's functional abilities. Exceptions would include where the informant is not able to respond to the functional questions or where the accuracy of the information they provide is judged less reliable that the information provided by the participant. Clinicians are expected to complete all items in this module. However, they have flexibility in determining the order in which the questions are asked and the specific wording used for each question.

Now I'd like to ask you about activities of daily living. You may feel that some of these questions do not apply to you, but it is important that we ask the same questions of everyone.

ADL_1	**ADL_ABLDR_MSP**	
[ALWAYS ASK]		
Can you dress and undress yourself without help (including picking out clothes and putting on socks and shoes)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_2	**ADL_HPDR_MSP**	
[ASK IF ADL_ABLDR_MSP = NO]		
Can you dress and undress yourself with some help?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_3	**ADL_UNDR_MSP**	
[ASK IF ADL_HPDR_MSP = NO]		
Are you completely unable to dress and undress yourself?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_4	**ADL_ABLBT_MSP**	
[ALWAYS ASK]		
Can you take a bath or shower without help?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_5	**ADL_HPBT_MSP**	
[ASK IF ADL_ABLBT_MSP = NO]		
Can you take a bath or shower with some help (i.e., you need help from someone getting in and out of the tub or you need special attachments on the tub)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_6	**ADL_UNBT_MSP**	
[ASK IF ADL_HPBT_MSP = NO]		
Are you completely unable to take a bath and a shower by yourself?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_7	ADL_BATH_MSP	
[ALWAYS ASK]		
Do you ever have trouble getting to the bathroom in time?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_8	ADL_INCNT_MSP	
[ASK IF ADL_BATH_MSP = YES]		
How often do you wet or soil yourself (either day or night)? Would you say…		
READ LIST, CODE ONLY ONE RESPONSE		
0_1_TIME_WEEK	1	Never or less than once a week
1_2_TIME_WEEK	2	Once or twice a week
3_MORE_TIMES_WEEK	3	Three times a week or more
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_9	ADL_NOTES_MSP	
[ALWAYS ASK]		
Do you have any additional notes to include for this module?		
YES	1	Yes
NO	2	No

ADL_10	ADL_NOTES_SP_MSP
[ASK IF ADL_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

ADL_END

Instrumental Activities of Daily Living (IADL)

This module contains a subset of the Activities of Daily Living questions of the OARS Multidimensional Assessment Questionnaire© developed by Dr. Gerda G. Fillenbaum (Duke University Medical Center). The Canadian Longitudinal Study on Aging received permission from Dr. Fillenbaum (instrument developer) for the use of this instrument.

Overview	The Instrumental Activities of Daily Living (IADL) scale assesses respondents' ability to independently perform a series of daily activities. This module contains key instrumental activities of daily living relevant to neurocognitive disorders and is a subset of the list of questions asked to the informant regarding the participant's ability to perform activities independently. The informant supplied data will in most cases be used to determine the participant's functional abilities. Exceptions would include where the informant is not able to respond to the functional questions or where the accuracy of the information they provide is judged less reliable that the information provided by the participant. Clinicians are expected to complete all items in this module. However, they have flexibility in determining the order in which the questions are asked and the specific wording used for each question.

Now I'd like to ask you about some activities of daily living. You may feel that some of these questions do not apply to you, but it is important that we ask the same questions of everyone.

IAL_1	**IAL_ABLGRO_MSP**	
[ALWAYS ASK]		
Can you go shopping for groceries or clothes without help (taking care of all shopping needs yourself)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_2	**IAL_HPGRO_MSP**	
[ASK IF IAL_ABLGRO_MSP = NO]		
Can you go shopping for groceries or clothes with some help (i.e., you need someone to go with you on all shopping trips)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_3	IAL_UNGRO_MSP	
[ASK IF IAL_HPGRO_MSP = NO]		
Are you completely unable to do any shopping?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_4	IAL_ABLML_MSP	
[ALWAYS ASK]		
Can you prepare your own meals without help (i.e., you plan and cook full meals yourself)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_5	IAL_HPML_MSP	
[ASK IF IAL_ABLML_MSP = NO]		
Can you prepare your own meals with some help (i.e., you can prepare some things but are unable to cook full meals yourself)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_6	IAL_UNML_MSP	
[ASK IF IAL_HPML_MSP = NO]		
Are you completely unable to prepare any meals?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_7	IAL_ABLMED_MSP	
[ALWAYS ASK]		
Can you take your own medicine without help (in the right doses at the right time)?		
CLINICIAN INSTRUCTIONS: IF THE PARTICIPANT OCCASIONALLY FORGETS, CODE AS 'YES'.		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_8	IAL_HPMED_MSP	
[ASK IF IAL_ABLMED_MSP = NO]		
Can you take your own medicine with some help (i.e., you are able to take medicine if someone prepares it for you or reminds you to take it)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_9	IAL_UNMED_MSP	
[ASK IF IAL_HPMED_MSP = NO]		
Are you completely unable to take your medicine?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_10	IAL_ABLMO_MSP	
[ALWAYS ASK]		
Can you handle your own money without help (i.e., you write cheques, pay bills, etc.)?		
CLINICIAN INSTRUCTIONS: IF THE PARTICIPANT OCCASIONALLY FORGETS, CODE AS 'YES'.		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_11	IAL_HPMO_MSP	
[ASK IF IAL_ABLMO_MSP = NO]		
Can you handle your own money with some help (i.e., you manage day-to-day buying but need help with managing your chequebook or paying your bills)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_12	IAL_UNMO_MSP	
[ASK IF IAL_HPMO_MSP = NO]		
Are you completely unable to handle your money?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_13	IAL_FUNCT_MSP	
[ALWAYS ASK]		
Have you experienced any changes in your functional abilities due to cognitive changes?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_14	IAL_NOTES_MSP	
[ALWAYS ASK]		
Do you have any additional notes to include for this module?		
YES	1	Yes
NO	2	No

IAL_15	IAL_NOTES_SP_MSP
[ASK IF IAL_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

IAL_END

Transportation (TRA)

Overview	The questions in this module ask participants about their driving status, and details regarding their license status. The informant is also being asked questions about the participant's driving. The informant supplied data will in most cases be used to determine the participant's driving status. Exceptions would include where the informant is not able to respond to the functional questions or where the accuracy of the information they provide is judged less reliable that the information provided by the participant Clinicians are expected to complete all items in this module. However, they have flexibility in determining the order in which the questions are asked and the specific wording used for each question.

TRA_1	**TRA_DSTATUS_MSP**	
[ALWAYS ASK]		
Which of the following describes the participant's driving status? (Include cars, vans, trucks and motorcycles)		
READ LIST, CODE ONLY ONE RESPONSE		
NEVER	1	Never had a driver's license
FORMER	2	Had a driver's license at one point in his or her life, but currently do not have it
CURRENT	3	Have a driver's license without restrictions (except corrective lenses)
RESTRICTED	4	Have a driver's license with restrictions on time of driving (daylight only), distance from home, type of road (no highway), or number of passengers
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

TRA_2	**TRA_STOP_MSP**	
[ASK IF TRA_STA_MSP = FORMER]		
Why did the participant stop driving?		
CODE ONLY ONE RESPONSE		
VOL_STOP	1	Voluntarily stopped driving
LICS_RESC	2	License rescinded
OT_SP	3	Other (please specify: _____)
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

TRA_3	TRA_STOPYR_MSP	
[ASK IF TRA_STA_MSP = FORMER]		
At what age or in what year did the participant stop driving?		
YR_SP	Year	_____ **[MASK: MIN=YEAR OF BIRTH, MAX=CURRENT YEAR]**
NB_SP	Age	_____ **[MASK:MIN=00, MAX=CURRENT AGE]**
DK_NA	9998	**[DO NOT READ]** Don't know / No answer
REFUSED	9999	**[DO NOT READ]** Refused

TRA_4	TRA_NOTES_MSP	
[ALWAYS ASK]		
Do you have any additional notes to include for this module?		
YES	1	Yes
NO	2	No

TRA_5	TRA_NOTES_SP_MSP
[ASK IF TRA_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

TRA_END

Mood and Behaviour (BHV)

The first two questions of this module are from the Patient Health Questionnaire-2 (PHQ-2). It is publicly available and no permission is required to use, reproduce, or distribute the tools.
Kroenke K, Spitzer RL, Williams JB. The Patient Health Questionnaire-2: Validity of a Two-Item Depression Screener. Medical Care. 2003;41:1284-92. The other questions in this module capture information on mood and behaviour relevant to the diagnosis of neurocognitive disorder.

Overview	The questions in this module ask participants about their mood and behaviour. Clinicians are expected to complete all items in this module. However, with the exception of the first two questions (BHV_DEP1 and BHV_DEP2) they have flexibility in determining the order in which the questions are asked and the specific wording used for each question.

Physician Note: Please read the first two questions verbatim.

Over the past 2 weeks, how often have you been bothered by any of the following problems…?

BHV_1	**BHV_DEP1_MSP**	
[ALWAYS ASK]		
Little interest or pleasure in doing things?		
READ LIST, CODE ONLY ONE RESPONSE		
NO	1	Not at all
SEVERAL	2	Several days
HALF	3	More than half the days
EVERY	4	Almost every day
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

BHV_2	**BHV_DEP2_MSP**	
[ALWAYS ASK]		
Feeling down, depressed or hopeless?		
READ LIST, CODE ONLY ONE RESPONSE		
NO	1	Not at all
SEVERAL	2	Several days
HALF	3	More than half the days
EVERY	4	Almost every day
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

BHV_3	BHV_PERS_MSP	
[ALWAYS ASK]		
Has the participant noted any persistent adverse changes in their personality (such as apathy, irritability, or lability) lasting a year or longer?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

BHV_4	BHV_ANX_MSP	
[ALWAYS ASK]		
Is the participant currently experiencing anxiety?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

BHV_5	BHV_SUS_MSP	
[ALWAYS ASK]		
Is the participant currently experiencing feelings of suspiciousness?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

BHV_6	BHV_PSY_MSP	
[ALWAYS ASK]		
Is the participant currently experiencing psychotic symptoms (delusions and/or hallucinations)?		
YES	1	Yes

NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

BHV_7	**BHV_NOTES_MSP**	
[ALWAYS ASK]		
Do you have any additional notes to include for this module?		
YES	1	Yes
NO	2	No

BHV_8	**BHV_NOTES_SP_MSP**
[ASK IF BHV_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below. For example, are there any other details regarding the participant's mood and behaviour that should be taken into account when interpreting the results of the cognitive testing?	

BHV_END

Physical Examination (EXM)

Overview	Clinicians are expected to complete all items in this module. However, they have flexibility in determining the order in which the physical exam is completed.

EXM_1	**EXM_ALERT_MSP**	
[ALWAYS ASK]		
Is the alertness/level of consciousness of the participant normal or abnormal?		
CODE ONLY ONE RESPONSE		
NRM	1	Normal
ABNRM	2	Abnormal
UNSURE	7	Unsure

EXM_2	**EXM_HEAR_MSP**	
[ALWAYS ASK]		
Is the participant willing to complete the hearing test?		
YES	1	Yes
NO	2	No

To evaluate hearing, please follow these instructions:

1. Position yourself approximately 60cm from the participant's ear
2. Mask the ear not being tested by rubbing the tragus. Do not place your arm across the face of the participant when rubbing the tragus, it is far nicer to occlude the ear from behind the head. If possible shield the participant's eyes to prevent any visual stimulus.
3. Whisper a number or word.
4. Ask the participant to repeat the number or word back to you. If they get two-thirds or more correct then their hearing level is 12db or better. If there is no response use a conversational voice (48db or louder) or loud voice (76db or louder).
5. If there is no response you can move closer and repeat the test at 15cm. Here the thresholds are 34db for a whisper and 56db for a conversational voice.
6. Assess the other ear in the same way.
7. Modifications may have to be made if personal protective equipment is worn.

EXM_3	**EXM_HEARRIGHT12_MSP**

[ASK IF EXM_HEAR_MSP = YES]		
Was the participant able to correctly repeat back the word or number you whispered at a distance of 60cm in their right ear?		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_4	**EXM_HEARRIGHT48_MSP**	
[ASK IF EXM_HEARRIGHT12_MSP = NO]		
Was the participant able to correctly repeat back the word or number you spoke using a conversational volume at a distance of 60cm in their right ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_5	**EXM_HEARRIGHT76_MSP**	
[ASK IF EXM_HEARRIGHT48 _MSP = NO]		
Was the participant able to correctly repeat back the word or number you spoke using a loud voice at a distance of 60cm in their right ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_6	**EXM_HEARRIGHT34_MSP**	
[ASK IF EXM_HEARRIGHT76_MSP = NO]		

Was the participant able to correctly repeat back the word or number you whispered at a distance of 15cm in their right ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_7	**EXM_HEARRIGHT56_MSP**	
[ASK IF EXM_HEARRIGHT34_MSP = NO]		
Was the participant able to correctly repeat back the word or number you spoke using a conversational volume at a distance of 15cm in their right ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_8	**EXM_HEARLEFT12_MSP**	
[ASK IF EXM_HEAR_MSP = YES]		
Was the participant able to correctly repeat back the word or number you whispered at a distance of 60cm in their left ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_9	**EXM_HEARLEFT48_MSP**
[ASK IF EXM_HEARLEFT12_MSP = NO]	

Was the participant able to correctly repeat back the word or number you spoke using a conversational volume at a distance of 60cm in their left ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_10	**EXM_HEARLEFT76_MSP**	
[ASK IF EXM_HEARLEFT48_MSP = NO]		
Was the participant able to correctly repeat back the word or number you spoke using a loud voice at a distance of 60cm in their left ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_11	**EXM_HEARLEFT34_MSP**	
[ASK IF EXM_HEARLEFT76_MSP = NO]		
Was the participant able to correctly repeat the word or number you whispered at a distance of 15cm in their left ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_12	**EXM_HEARLEFT56_MSP**
[ASK IF EXM_HEARLEFT34_MSP = NO]	

Was the participant able to correctly repeat back the word or number you spoke using a conversational volume at a distance of 15cm in their left ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_13	**EXAM_HEARNOTES_MSP**	
[ALWAYS ASK]		
Do you have any additional notes to include regarding the participant's hearing?		
YES	1	Yes
NO	2	No

EXM_14	**EXAM_HEARNOTES_SP_MSP**
[ASK IF EXAM_HEAR_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

EXM_15	**EXM_SMELL_MSP**	
[ALWAYS ASK]		
Is the participant's sense of smell normal or abnormal?		
CODE ONLY ONE RESPONSE		
NRM	1	Normal
ABNRM	2	Abnormal
UNSURE	7	Unsure

EXM_16	**EXM_FOCAL_MSP**
[ALWAYS ASK]	
Are there any focal/lateralizing neurological findings to note?	

MULTIPLE RESPONSES ALLOWED, CODE ALL THAT APPLY (EXCEPT IF 96 IS SELECTED)		
VIS	01	Visual field defect
EXT	02	Abnormal extra-ocular movements
RGD	03	Rigidity
WKN	04	Weakness
SP	05	Speech
NONE	96	None
OTSP	97	Other: Please specify:

EXM_17	**EXM_FOCALVIS_SP_MSP**
[ASK IF EXAM_FOCAL_MSP = VIS]	
Please describe the visual field defect:	
Open text: _____	

EXM_18	**EXM_FOCALEXT_SP_MSP**
[ASK IF EXAM_FOCAL_MSP = EXT]	
Please describe the abnormal extra-ocular movements:	
Open text: _____	

EXM_19	**EXM_FOCALRGD_SP_MSP**
[ASK IF EXAM_FOCAL_MSP = RGD]	
Please describe the rigidity observed in the participant:	
Open text: _____	

EXM_20	**EXM_FOCALWKN_SP_MSP**
[ASK IF EXAM_FOCAL_MSP = WKN]	
Please describe the weakness observed in the participant:	

Open text: _____

EXM_21	**EXM_FOCALSP_SP_MSP**
[ASK IF EXAM_FOCAL_MSP = SP]	
Please describe the speech abnormalities observed in the participant:	
Open text: _____	

EXM_22	**EXM_FOCALOTSP_SP_MSP**
[ASK IF EXAM_FOCAL_MSP = OTSP]	
Please describe any other abnormalities observed in the participant:	
Open text: _____	

EXM_23	**EXM_EXPYR_MSP**	
[ALWAYS ASK]		
Are there any extrapyramidal signs observed?		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96 IS SELECTED), CODE ALL THAT APPLY		
TRM	01	Tremor
RGD	02	Rigidity
BKN	03	Bradykinesia
PST	04	Posture
NONE	96	None
OTSP	97	Other: specify

EXM_24	**EXM_EXPYRNOTES_MSP**
[ASK IF EXM_EXPYR_MSP = TRM, RGD, BKN, or PST]	
Please describe the extrapyramidal signs if required.	

Open text: _____		
DK_NA	8	**[DO NOT READ]** Don't know / No answer

EXM_25	**EXM_TRANSF_MSP**	
[ALWAYS ASK]		
How would you evaluate the participant's ability to do a sit to stand transfer?		
CODE ONLY ONE RESPONSE		
NRM	1	Normal
ABNRM	2	Abnormal
UNSURE	7	Unsure

EXM_26	**EXM_BALANCE_MSP**	
[ALWAYS ASK]		
How would you evaluate the participant's stability using the Romberg test?		
CLINICIAN NOTES: The Romberg test requires that the participant removes their shoes. Participants will be asked to stand with their feet together on a flat, hard surface. The participant will be asked to cross their arms in front of their body or place them at their sides. The participant will be asked to stand still and keep their eyes open for approximately 30 seconds while the examining clinician observes. The participant will then be asked to close their eyes and stand for an addition 30 seconds. The examining clinician will assess body movement and balance.		
CODE ONLY ONE RESPONSE		
NRM	1	Normal
ABNRM	2	Abnormal
NOTDONE	8	Unable to assess

EXM_27	**EXM_GAITSPD_MSP**
[ALWAYS ASK]	
Does the participant have normal or slow gait speed?	

CLINICIAN NOTES: Gait speed may be evaluated by watching the participant move around the Data Collection Site.		
CODE ONLY ONE RESPONSE		
NRM	1	Normal
SLOW	2	Slow
NOTDONE	8	Unable to assess

EXM_28	**EXM_GAIT_MSP**	
[ALWAYS ASK]		
Did you observe any gait abnormalities?		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96 ISSELECTED), CODE ALL THAT APPLY		
NO	01	No gait abnormalities
NN	02	Abnormal gait speed due to non-neurologic cause (e.g. arthritis)
ST	03	Unsteady
FR	04	Frontal
HM	05	Hemiparetic
NR	06	Neuropathic
AT	07	Ataxic
PK	08	Parkinsonian
SP	09	Spastic
NOTDONE	96	Unable to assess

EXM_29	**EXM_BALGAITNOTES_MSP**
[ASK IF EXM_TRANSF_MSP = ABNRM, OR EXM_BALANCE_MSP = ABNRM, OR EXM_GAITSPD_MSP = SLOW, OR EXM_GAITMSP = NN, ST, FR, HM, NR, AT, PK, or SP]	
Please describe any abnormalities in transferring, balance, or gait.	

EXM_30	**EXM_NOTES_MSP**	
[ALWAYS ASK]		
Do you have any additional notes to include for this module? For example, are there any other findings from the physical examination that should be taken into account when interpreting the results of the cognitive testing?		
YES	1	Yes

NO	2	No

EXM_31	**EXM_NOTES_SP_MSP**
[ASK IF EXM_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

EXM_END

Montreal Cognitive Assessment (MoCA)

*Training and certification is required by any clinical, health professional, or worker who wishes to administer, score and interpret the Montreal Cognitive Assessment (MoCA) test. The MoCA © may be used, reproduced, and distributed **WITH** permission for universities/foundations/health professionals/hospitals/clinics/public health institutes.*

Overview	The Montreal Cognitive Assessment (MoCA) was designed as a rapid screening instrument for mild cognitive dysfunction. It assesses different cognitive domains: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation. Time to administer the MoCA is approximately 10 minutes. The total possible score is 30 points; a score of 26 or above is considered normal. There is an additional point added to the obtained score if the person being tested has 12 or fewer years of formal education. For the purposes of the CLSA Memory Study, we will categorize participant that did not graduate from secondary school or those who graduated secondary school but did not complete post-secondary education as having 12 or fewer years of formal education. The MoCA memory section provides two trials to learn a word list of five nouns followed by a delay in which subjects are asked questions from other sections of the MoCA (i.e., attention, sentence repetition, letter fluency, similarities). The delay is variable, but estimated at five minutes followed by free recall of the 5-word list. This is followed by a category-cued semantic recall condition, and, finally, a multiple choice-cued recall from presentation of the correct item paired with two items within the same category but not on the list. Only the points earned in the delayed *free* recall condition of the memory section (1 point per correct word) are added to the MoCA total score. The MoCA-MIS includes points for the free recall condition and the cued conditions (3 points for each word on free recall, 2 for each on category-cued recall, 1 for each on multiple-choice recall). For those with severe visual impairment, the MoCA-BLIND can be utilized. This is scored out of 22 with normal being a score of 18 or higher. The correction for limited formal education described above is also used for the MoCA-BLIND. Clinicians are expected to complete this module using the provided script.

MOC_1	**MOC_SIGHT_MSP**	
[ALWAYS ASK]		
Does the participant have any visual impairments that would prevent them from completing the standard MoCA which requires drawing on a piece of paper?		
YES	1	Yes
NO	2	No

1. Alternating Trail Making:

Administration: The examiner instructs the subject: "*Please draw a line, going from a number to a letter in ascending order. Begin here [point to (1)] and draw a line from 1 then to A then to 2 and so on. End here [point to (E)]*."

MOC_2	**MOC_TRAIL_MSP**	
[ASK IF MOC_SIGHT_MSP = NO]		
Was the participant able to successfully complete the Alternating Trail Making task?		
CLINICIAN NOTE: Successfully completing the Alternating Trail Making task required the participant to successfully draw the following pattern: 1-A-2-B-3-C-4-D-5-E without drawing any lines that cross		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
REFUSED	9	**[DO NOT READ]** Participant refused to do task

2. Visuoconstructional Skills (Cube):

Administration: The examiner gives the following instructions, pointing to the cube: “Copy this drawing as accurately as you can, in the space below”.

MOC_3	**MOC_CUBE_MSP**	
[ASK IF MOC_SIGHT_MSP = NO]		
Was the participant able to successfully complete the cube drawing task?		
CODE ONLY ONE RESPONSE		
CLINICIAN NOTE: A successfully executed drawing must be: x Three-dimensional x All lines are drawn x No line is added x Lines are relatively parallel and their length is similar (rectangular prisms are accepted) If any of the above criteria are not met, the cube was not successfully drawn.		
YES	1	Yes
NO	2	No
REFUSED	9	**[DO NOT READ]** Participant refused to do task

3. Visuoconstructional Skills (Clock):

Administration: Indicate the right third of the space and give the following instructions: "*Draw a clock. Put in all the numbers and set the time to 10 past 11*".

MOC_4	**MOC_CLOCKCON_MSP**	
[ASK IF MOC_SIGHT_MSP = NO]		
Contour - Did the participant successfully draw the circle of the clock?		
CLINICIAN NOTE: For contour, a clock that has been correctly drawn must meet the following criteria: The clock face must be a circle with only minor distortion acceptable (e.g., slight imperfection on closing the circle).		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
REFUSED	9	**[DO NOT READ]** Participant refused to do task

MOC_5	**MOC_CLOCKNUM_MSP**	
[ASK IF MOC_SIGHT_MSP = NO]		
Numbers – Did the participant successfully draw the numbers on the clock?		
CLINICIAN NOTE: For the numbers, a clock that has been correctly drawn must meet the following criteria: All clock numbers must be present with no additional numbers; numbers must be in the correct order and placed in the approximate quadrants on the clock face; Roman numerals are acceptable; numbers can be placed outside the circle contour.		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
REFUSED	9	**[DO NOT READ]** Participant refused to do task

MOC_6	**MOC_CLOCKHAND_MSP**
[ASK IF MOC_SIGHT_MSP = NO]	

Hands - Did the participant successfully draw the hands on the clock?		
CODE ONLY ONE RESPONSE		
CLINICIAN NOTE: For the hands, a clock that has been correctly drawn must meet the following criteria: There must be two hands jointly indicating the correct time; the hour hand must be clearly shorter than the minute hand; hands must be centred within the clock face with their junction close to the clock centre.		
YES	1	Yes
NO	2	No
REFUSED	9	**[DO NOT READ]** Participant refused to do task

4. Naming:

Administration: Beginning on the left, point to each figure and say: "*Tell me the name of this animal*".

MOC_7	**MOC_ANIMALS_MSP**	
[ASK IF MOC_SIGHT_MSP = NO]		
How many animals were correctly named by the participant?		
CLINICIAN NOTES: One point is given for the following responses: (1) lion (2) rhinoceros or rhino (3) camel or dromedary.		
CODE ONLY ONE RESPONSE		
ONE	1	One
TWO	2	Two
THREE	3	Three
NONE	4	None of the animals were correctly named
REFUSED	9	**[DO NOT READ]** Participant refused to do task

5. Memory:

Administration: The examiner reads a list of 5 words at a rate of one per second, giving the following instructions: "*This is a memory test. I am going to read a list of words that you will have to remember now*

and later on. Listen carefully. When I am through, tell me as many words as you can remember. It doesn't matter in what order you say them".

"Face, velvet, church, daisy, red"

Administration: When the subject indicates that (s)he has finished (has recalled all words), or can recall no more words, read the list a second time with the following instructions: "*I am going to read the same list for a second time. Try to remember and tell me as many words as you can, including words you said the first time*."

"Face, velvet, church, daisy, red"

Administration: At the end of the second trial, inform the participant that he/she will be asked to recall these words again by saying: "*I will ask you to recall these words again at the end of the test*."

6. Attention:

Forward Digit Span: Administration: Give the following instruction: "*I am going to say some numbers and when I am through, repeat them to me exactly as I said them*". Read the five number sequence at the rate of one digit per second.

"2, 1, 8, 5, 4"

MOC_8	**MOC_NUMFORW_MSP**	
[ALWAYS ASK]		
Was the participant able to repeat the numbers "2, 1, 8, 5, 4" in the forward order?		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
REFUSED	9	**[DO NOT READ]** Participant refused to do task

Attention, Backward Digit Span: Administration: Give the following instruction: "*Now I am going to say some more numbers, but when I am through you must repeat them to me in the backwards order*.".

"7, 4, 2."

MOC_9	**MOC_NUMBACK_MSP**	
[ALWAYS ASK]		
Was the participant able to repeat the numbers "7, 4, 2" in the backward order?		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
REFUSED	9	**[DO NOT READ]** Participant refused to do task

Vigilance: The examiner reads the list of letters at a rate of one per second, after giving the following instruction: "*I am going to read a sequence of letters. Every time I say the letter A, tap your hand once. If a say a different letter, do not tap your hand*".

"*F B A C M N A A J K L B A F A K D E A A A J A M O F A A B*"

MOC_10	**MOC_LETTER_MSP**	
[ALWAYS ASK]		
Did the participant make zero to one errors (an error is a tap on a wrong letter or a failure to tap on letter A)?		
CODE ONLY ONE RESPONSE		
YES	1	Yes, the participant made 0 or one errors
NO	2	No, the participant made two or more errors
REFUSED	9	**[DO NOT READ]** Participant refused to do task

Serial 7s: The examiner gives the following instruction: "*Now, I will ask you to count by subtracting seven from 100, and then, keep subtracting seven from your answer until I tell you to stop*". Give this instruction twice if necessary.

MOC_11	**MOC_SUBS_MSP**	
[ALWAYS ASK]		
How many correct subtractions did the participant make?		
CLINICIAN NOTES: This item is scored out of 3 points. Give no (0) points for no correct subtractions, 1 point for one correct subtraction, 2 points for two-to-three correct subtractions, and 3 points if the participant successfully makes four or five correct subtractions. Count each correct subtraction of 7 beginning at 100. Each subtraction is evaluated independently; that is, if the participant responds with an incorrect number but continues to correctly subtract 7 from it, give a point for each correct subtraction. For example, a participant may respond "92 – 85 – 78 – 71 – 64" where the "92" is incorrect, but all subsequent numbers are subtracted correctly. This is one error and the item would be given a score of 3.		
CODE ONLY ONE RESPONSE		
ZERO	0	Zero
ONE	1	One
TWO_THREE	2	Two or three
FOUR_FIVE	3	Four or five
REFUSED	9	**[DO NOT READ]** Participant refused to do task

7. Sentence repetition:

Administration: The examiner gives the following instructions: "*I am going to read you a sentence. Repeat it after me, exactly as I say it [pause]: I only know that John is the one to help today*.". Following the response, say: "*Now I am going to read you another sentence. Repeat it after me, exactly as I say it [*pause*]: The cat always hid under the couch when dogs were in the room*".

MOC_12	**MOC_REPET_MSP**	
[ALWAYS ASK]		
How many of the sentences did the participant correctly repeat?		
CLINICIAN NOTES: Repetition must be exact. Be alert for errors that are omissions (e.g., omitting "only", "always") and substitutions/additions (e.g., "John is the one who helped today;" substituting "hides" for "hid", altering plurals, etc.).		
CODE ONLY ONE RESPONSE		
ZERO	0	Zero
ONE	1	One
TWO	2	Two
REFUSED	9	**[DO NOT READ]** Participant refused to do task

8. Verbal fluency:

Administration: The examiner gives the following instruction: *"Tell me as many words as you can think of that begin with a certain letter of the alphabet that I will tell you in a moment. You can say any kind of word you want, except for proper nouns (like Bob or Boston), numbers, or words that begin with the same sound but have a different suffix, for example, love, lover, loving. I will tell you to stop after one minute. Are you ready?* [Pause] *Now, tell me as many words as you can think of that begin with the letter F*. [time for 60 sec]. *Stop*."

MOC_13	**MOC_WORDSF_MSP**	
[ALWAYS ASK]		
Please record the words that the participant says		
REFUSED	9	**[DO NOT READ]** Participant refused to do task

MOC_14	MOC_WORDSFNUM_MSP	
[ASK IF MOC_WORDSF ≠ REFUSED]		
How many words did the participant say in one minute that begin with the letter "F"?		
CODE ONLY ONE RESPONSE		
10_LESS	00	Less than 11 words
11_MORE	01	11 or more words
REFUSED	99	**[DO NOT READ]** Participant refused to do task

9. Abstraction:

Administration: The examiner asks the subject to explain what each pair of words has in common, starting with the example: "*Tell me how an orange and a banana are alike*". If the subject answers in a concrete manner, then say only one additional time: "*Tell me another way in which those items are alike*". If the subject does not give the appropriate response (fruit), say, "*Yes, and they are also both fruit*." Do not give any additional instructions or clarification. After the practice trial, say: "*Now, tell me how a train and a bicycle are alike*". Following the response, administer the second trial, saying: "*Now tell me how a ruler and a watch are alike*". Do not give any additional instructions or prompts.

MOC_15	MOC_WORDSIM_MSP	
[ALWAYS ASK]		
How many combinations of words did the participant identify the similarly between?		
CLINICIAN NOTES: Only the last two item pairs are scored. Give 1 point to each item pair correctly answered. The following responses are acceptable: Train-bicycle = means of transportation, means of travelling, you take trips in both; Ruler-watch = measuring instruments, used to measure. The following responses are not acceptable: Train-bicycle = they have wheels; Ruler-watch = they have numbers.		
CODE ONLY ONE RESPONSE		
NONE	0	None
ONE	1	One
TWO	2	Two
REFUSED	9	**[DO NOT READ]** Participant refused to do task

10. Delayed recall:

Administration: The examiner gives the following instruction: "*I read some words to you earlier, which I asked you to remember. Tell me as many of those words as you can remember*."

MOC_16	**MOC_MEM3_MSP**	
[ALWAYS ASK]		
.Please record which words the participant is able to spontaneously recall.		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96, OR 99ARE SELECTED), CODE ALL THAT APPLY		
FACE	01	Face
VELVET	02	Velvet
CHURCH	03	Church
DAISY	04	Daisy
RED	05	Red
NONE	96	Did not remember any of the words
REFUSED	99	**[DO NOT READ]** Participant refused to do task

10b. Delayed recall – optional component:

Administration: Following the delayed free recall trial, prompt the subject with the semantic category cue provided below for any word not recalled. Prompt all non-recalled words in this manner.

Word	**Category cue**
Face	Part of the body
Velvet	Type of fabric
Church	Type of building
Daisy	Type of flower
Red	A colour

MOC_17	**MOC_MISCUE1_MSP**

[SKIP IF MOC_MEM3_MSP = FACE AND VELVET AND CHURCH AND DAISY AND RED]		
Please indicate which words the participant produces on this third trial.		
CLINICIAN NOTE: Please select each word that the participant correctly recalled with the category cue provided. Do not select words that the participant correctly remembered spontaneously. A cue is used for clinical information purposes only and can give the test interpreter additional information about the type of memory disorder. For memory deficits due to retrieval failures, performance can be improved with a cue. For memory deficits due to encoding failures, performance does not improve with a cue.		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96 OR 99ARE SELECTED), CODE ALL THAT APPLY		
FACE	01	Face
VELVET	02	Velvet
CHURCH	03	Church
DAISY	04	Daisy
RED	05	Red
NONE	96	Did not remember any of the words
REFUSED	99	**[DO NOT READ]** Participant refused to do task

If the subject does not recall the word after the category cue, give him/her a multiple choice trial, using the following example instruction, "*Which of the following words do you think it was, NOSE, FACE, or HAND?*"

Word	**Multiple choice cue**
Face	Nose, face, hand
Velvet	Denim, cotton, velvet
Church	Church, school, hospital
Daisy	Rose, daisy, tulip
Red	Red, blue, green

MOC_18	**MOC_MISCUE2_MSP**
SKIP IF MOC_MEM3_MSP OR MOC_MISCUE1_MSP = FACE AND VELVET AND CHURCH AND DAISY AND RED]	

Please indicate which words the participant produces on this third trial.		
CLINICIAN NOTE: Please select each word that the participant correctly recalled with the category cue provided. Do not select words that the participant correctly remembered spontaneously or using the category cues.		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96 OR 99 ARE SELECTED), CODE ALL THAT APPLY		
FACE	01	Face
VELVET	02	Velvet
CHURCH	03	Church
DAISY	04	Daisy
RED	05	Red
NONE	96	Did not remember any of the words
REFUSED	99	**[DO NOT READ]** Participant refused to do task

11. Orientation:

Administration: The examiner gives the following instructions: "*Tell me the date today*". If the subject does not give a complete answer, then prompt accordingly by saying: "*Tell me the [year, month, exact date, and day of the week*]." Then say: "*Now, tell me the name of this place, and which city it is in*."

MOC_19	**MOC_ORIENT_MSP**	
[ALWAYS ASK]		
Which of the following orientation features did the participant correctly identify?		
CLINICIAN NOTES: The subject must tell the exact date and the exact place (name of hospital, clinic, office). No points are allocated if subject makes an error (even of one day) for the day and date.		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96 OR 99 ARE SELECTED), CODE ALL THAT APPLY		
DATE	01	Date
MONTH	02	Month
YEAR	03	Year
DAY	04	Day
PLACE	05	Place
CITY	06	City
NONE	96	None – the participant did not correctly identify any of the orientation features
REFUSED	99	**[DO NOT READ]** Participant refused to do task

MOC_20	**MOC_TOTALSCORE0_MSP**
[CALCULATE IF MOC_SIGHT_MSP = NO]	

The Montreal Cognitive Assessment (MoCA) is scored out of a maximum of 30 points. A final total score of 26 and above is considered normal. Total score on the MoCA: 0
CLINICIAN NOTES: One point has been added for individuals who have 12 years or fewer of formal education.
[CALCULATED VARIABLE: MOC_TRAIL + MOC_CUBE + MOC_CLOCKCON + MOC_CLOCKNUM + MOC_CLOCKHAND + MOC_ANIMALS:ONE + MOC_ANIMALS:TWO + MOC_ANIMALS:TWO + MOC_ANIMALS:THREE + MOC_ANIMALS:THREE + MOC_ANIMALS:THREE + MOC_NUMFORW + MOC_NUMBACK + MOC_LETTER:YES + MOC_SUBS:ONE + $MOC_SUBS:TWO_THREE + MOC_SUBS:TWO_THREE + MOC_SUBS:FOUR_FIVE + MOC_SUBS:FOUR_FIVE + MOC_SUBS:FOUR_FIVE + MOC_REPET:ONE + MOC_REPET:TWO + MOC_REPET:TWO + MOC_WORDSFNUM:11_MORE + MOC_WORDSIM:ONE + MOC_WORDSIM:TWO + MOC_WORDSIM:TWO + MOC_MEM3:FACE + MOC_MEM3:VELVET + MOC_MEM3:CHURCH + MOC_MEM3:DAISY + MOC_MEM3:RED + MOC_ORIENT:DATE + MOC_ORIENT:MONTH + MOC_ORIENT:YEAR + MOC_ORIENT:DAY + MOC_ORIENT:PLACE + MOC_ORIENT:CITY + 1 IF BASELINE EDUCATION WAS 12 YEARS OR LESS == 0]

VARIABLES MOC_21 TO MOC_51 SHOULD BE CALCULATED AS FOLLOWED:

VARIABLE NAME: MOC_TOTALSCORE[NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 1 TO 30.
VARIABLE DESCRIPTION: TOTAL SCORE ON MONTREAL COGNITIVE ASSESSMENT (MOCA): [NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 1 TO 30.
VARIABLE CALCULATION: THE TOTAL SCORE THAT THE VARIABLE CALCULATION EQUALS SHOULD INCREASE SEQUENTIALLY FROM 1 TO 30

MOC_52	**MOC_TOTALMIS0_MSP**
[CALCULATE IF MOC_SIGHT_MSP = NO]	
CLINICIAN NOTES: There were not any skipped items on the Montreal Cognitive Assessment (MoCA).	
[CALCULATED VARIABLE, ($MOC_TRAIL.refuse()$? 1 : 0) + ($MOC_CUBE.refuse()$? 1 : 0) + ($MOC_CLOCKCON.refuse()$? 1 : 0) + ($MOC_CLOCKNUM.refuse()$? 1 : 0) + $MOC_CLOCKHAND.refuse()$? 1 : 0) + ($MOC_ANIMALS.refuse()$? 1 : 0) + $MOC_ANIMALS.refuse()$? 1 : 0) + ($MOC_ANIMALS.refuse()$? 1 : 0) + ($MOC_NUMFORW.refuse()$? 1 : 0) + ($MOC_NUMBACK.refuse()$? 1 : 0) + ($MOC_LETTER.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_REPET.refuse()$? 1 : 0) + ($MOC_REPET.refuse()$? 1 : 0) + ($MOC_WORDSFNUM.refuse()$? 1 : 0) + ($MOC_WORDSIM.refuse()$? 1 : 0) + ($MOC_WORDSIM.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) == 0]	

MOC_53	**MOC_TOTALMIS1_MSP**
[CALCULATE IF MOC_SIGHT_MSP = NO]	
CLINICIAN NOTES: Not all components of the Montreal Cognitive Assessment (MoCA) may have been completed. This variable identifies the number of points out of the total score of 30 that the participant did not receive due to skipping tasks on the MoCA and should be considered when interpreting the total score of the MoCA. Number of points: 1	

[CALCULATED VARIABLE, ($MOC_TRAIL.refuse()$? 1 : 0) + ($MOC_CUBE.refuse()$? 1 : 0) + ($MOC_CLOCKCON.refuse()$? 1 : 0) + ($MOC_CLOCKNUM.refuse()$? 1 : 0) + $MOC_CLOCKHAND.refuse()$? 1 : 0) + ($MOC_ANIMALS.refuse()$? 1 : 0) + $MOC_ANIMALS.refuse()$? 1 : 0) + ($MOC_ANIMALS.refuse()$? 1 : 0) + ($MOC_NUMFORW.refuse()$? 1 : 0) + ($MOC_NUMBACK.refuse()$? 1 : 0) + ($MOC_LETTER.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_REPET.refuse()$? 1 : 0) + ($MOC_REPET.refuse()$? 1 : 0) + ($MOC_WORDSFNUM.refuse()$? 1 : 0) + ($MOC_WORDSIM.refuse()$? 1 : 0) + ($MOC_WORDSIM.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) == 1]

VARIABLES MOC_54 TO MOC_62 SHOULD BE CALCULATED AS FOLLOWED:

VARIABLE NAME: MOC_TOTALMIS[NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 2 TO 10 OR MORE.
VARIABLE DESCRIPTION: TOTAL NUMBER OF MISSING POINTS ON MONTREAL COGNITIVE ASSESSMENT (MOCA): [NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 1 TO 10 OR MORE.
VARIABLE CALCULATION: THE TOTAL SCORE THAT THE VARIABLE CALCULATION EQUALS SHOULD INCREASE SEQUENTIALLY FROM 1 TO 10 OR MORE

MOC_63	**MOC_BLINDTSCORE0_MSP**
[CALCULATE IF MOC_SIGHT_MSP = YES]	
Total score on the Montreal Cognitive Assessment (MoCA) Blind version : 0	
CLINICIAN NOTES: One point has been added for individuals who have 12 years or fewer of formal education, for a possible maximum of 22 points. A final total score of 18 and above is considered normal.	
[CALCULATED VARIABLE: MOC_NUMFORW + MOC_NUMBACK + MOC_LETTER:YES + MOC_SUBS:ONE + $MOC_SUBS:TWO_THREE + MOC_SUBS:TWO_THREE + MOC_SUBS:FOUR_FIVE + MOC_SUBS:FOUR_FIVE + MOC_SUBS:FOUR_FIVE + MOC_REPET:ONE + MOC_REPET:TWO + MOC_REPET:TWO + MOC_WORDSFNUM:11_MORE + MOC_WORDSIM:ONE + MOC_WORDSIM:TWO + MOC_WORDSIM:TWO + MOC_MEM3:FACE + MOC_MEM3:VELVET + MOC_MEM3:CHURCH + MOC_MEM3:DAISY + MOC_MEM3:RED + MOC_ORIENT:DATE + MOC_ORIENT:MONTH + MOC_ORIENT:YEAR + MOC_ORIENT:DAY + MOC_ORIENT:PLACE + MOC_ORIENT:CITY + 1 IF BASELINE EDUCATION WAS 12 YEARS OR LESS == 0]	

VARIABLES MOC_64 TO MOC_86 SHOULD BE CALCULATED AS FOLLOWED:

VARIABLE NAME: MOC_BLINDTSCORE [NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 1 TO 22.
VARIABLE DESCRIPTION: TOTAL SCORE ON MONTREAL COGNITIVE ASSESSMENT (MOCA) BLIND VERSION: [NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 1 TO 22.
VARIABLE CALCULATION: THE TOTAL SCORE THAT THE VARIABLE CALCULATION EQUALS SHOULD INCREASE SEQUENTIALLY FROM 1 TO 22

MOC_87	**MOC_BLINDMIS0_MSP**

[CALCULATE IF MOC_SIGHT_MSP = YES]
CLINICIAN NOTES: There were not any skipped items on the Montreal Cognitive Assessment (MoCA) Blind version..
[CALCULATED VARIABLE, ($MOC_NUMFORW.refuse()$? 1 : 0) + ($MOC_NUMBACK.refuse()$? 1 : 0) + ($MOC_LETTER.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_REPET.refuse()$? 1 : 0) + ($MOC_REPET.refuse()$? 1 : 0) + ($MOC_WORDSFNUM.refuse()$? 1 : 0) + ($MOC_WORDSIM.refuse()$? 1 : 0) + $MOC_WORDSIM.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) == 0]

MOC_88	**MOC_BLINDMIS1_MSP**
[CALCULATE IF MOC_SIGHT_MSP = YES]	
CLINICIAN NOTES: Not all components of the Montreal Cognitive Assessment (MoCA) Blind version may have been completed. This variable identifies the number of points out of the total score of 22 that the participant did not receive due to skipping tasks on the MoCA-BLIND which is administered to participants with severe visual impairment. Number of points: 1	
[CALCULATED VARIABLE, MOC_LETTER_MSP (REFUSED) + MOC_NUMFORW_MSP (REFUSED) +MOC_NUMBACK_MSP (REFUSED) + MOC_SUBS_MSP (REFUSED) + MOC_REPET_MSP (REFUSED) + MOC_WORDSFNUM_MSP (REFUSED), MOC_WORDSIM_MSP (REFUSED), MOC_MEM3_MSP (REFUSED), MOC_ORIENT_MSP (REFUSED)]	

VARIABLES MOC_89 TO MOC_98SHOULD BE CALCULATED AS FOLLOWED:

VARIABLE NAME: MOC_TOTALMIS[NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 2 TO 10 OR MORE.
VARIABLE DESCRIPTION: TOTAL NUMBER OF MISSING POINTS ON MONTREAL COGNITIVE ASSESSMENT (MOCA): [NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 1 TO 10 OR MORE.
VARIABLE CALCULATION: THE TOTAL SCORE THAT THE VARIABLE CALCULATION EQUALS SHOULD INCREASE SEQUENTIALLY FROM 1 TO 10 OR MORE

MOC_99	**MOC_MISSCORE0_MSP**
The Memory Score Index (MIS) is scored out of a maximum of 15. A score of 8 and above is considered normal. The participant's score on the MIS is: 0	
[CALCULATED VARIABLE, SUM OF (MOC_MEM3_MSP = FACE, VELVET, CHURCH, DAISY, AND/OR RED * 3) + (MOC_MISCUE1_MSP = FACE, VELVET, CHURCH, DAISY, AND/OR RED * 2) + (MOC_MISCUE2_MSP = FACE, VELVET, CHURCH, DAISY, AND/OR RED)]	

VARIABLES MOC_100 TO MOC_115 SHOULD BE CALCULATED AS FOLLOWED:

VARIABLE NAME: MOC_MISSCORE[NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 1 TO 15.
VARIABLE DESCRIPTION: TOTAL SCORE MEMORY SCORE INDEX SHOULD INCREASE SEQUENTIALLY FROM 1 TO 15.
VARIABLE CALCULATION: THE TOTAL SCORE THAT THE VARIABLE CALCULATION EQUALS SHOULD INCREASE SEQUENTIALLY FROM 1 TO 15

MOC_116	**MOC_MISSCOREMIS_MSP**
CLINICIAN NOTES: Not all components of the Montreal Cognitive Assessment (MoCA) Memory Impairment Section (MIS) were completed. Please take this into consideration when interpreting the total score of the MIS.	
[CALCULATED VARIABLE, MOC_MEM3_MSP (REFUSED) OR MOC_MISCUE1_MSP (REFUSED) OR MOC_MISCUE2_MSP (REFUSED)]	

MOC_117	**MOC_NOTES_MSP**	
[ALWAYS ASK]		
Do you have any additional notes to include for this module? For example, were there any issues with the testing environment that should be taken into account when interpreting the results of the cognitive testing?		
YES	1	Yes
NO	2	No

MOC_118	**MOC_NOTES_SP_MSP**
[ASK IF MOC_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

MOC_END

Preliminary Diagnosis of Neurocognitive Disorder (NCD)

Overview	Please use this module to document your preliminary diagnosis of the participant's cognitive status based on the clinical assessment and informant interview. This module does not contain questions related to planning the care of individuals diagnosed with neurocognitive disorder.

NCD_1	**NCD_DIA_MSP**	
[ALWAYS ASK]		
Based on the clinical evaluation and informant interview, what is your diagnosis of the participant?		
CLINICIAN NOTE: The category of "no significant cognitive concerns" also includes participants without any cognitive complaints that performed poorly on the Montreal Cognitive Assessment (MoCA) if confounders such as language or education are thought to explain the poor performance.		
CODE ONLY ONE RESPONSE		
NORMAL	1	No significant cognitive concerns
SUB	2	Normal cognition but with subjective cognitive decline (self-reported confusion or memory problems happening more often and getting worse over last year but not meeting the criteria for either mild or major neurocognitive disorder)
DELIRIUM	3	Delirium
MILD	4	Mild neurocognitive disorder
MAJOR	5	Major neurocognitive disorder

NCD_2	**NCD_CONF_MSP**	
[ALWAYS ASK]		
How confident are you in your diagnosis? Please rate on an 11-point scale (0-10; with the anchors of 0, indicating the lowest confidence rating, and 10, the highest confidence rating)		
NUMBER	Number	_____ **[MASK: MIN=0, MAX=10]**

NCD_3	NCD_DOM_MSP	
[ASK IF NCD_DIA_MSP = SUB, MILD ,OR MAJOR]		
What cognitive domains have been impacted by cognitive decline?		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96 IS SELECTED), CODE ALL THAT APPLY		
AT	01	Attention
EF	02	Executive function
LM	03	Learning and memory
LG_	04	Language
PC	05	Perceptual/motor
SC	06	Social cognition
NONE	96	No cognitive domains appear to be impacted

NCD_4	NCD_INFO_MSP	
[ALWAYS ASK]		
What additional information or resources would increase your confidence in your diagnosis?		
MULTIPLE RESPONSES ALLOWED, CODE ALL THAT APPLY		
NONE	1	None
LAB	2	Laboratory investigations
IMG	3	Neuroimaging
REF	4	Referral to a consultant
TIM	5	Opportunity to follow the participant over time
OTSP	7	Other (please specify: _____)

NCD_5	NCD_TYPE_MSP	
[ASK IF NCD_DIA_MSP = MILD OR MAJOR]		
Based on the clinical evaluation and informant interview, what is your diagnosis of the participant?		
CODE ONLY ONE RESPONSE		
ALZ	1	Alzheimer's Disease
LWY	2	Lewy Body Disease
PKD	3	Parkinson's Disease
VSC	4	Vascular Cognitive Impairment
FRT	5	Frontotemporal Degeneration
TBI	6	Traumatic Brain Injury (Including Chronic Traumatic Encephalopathy)
MLT	7	Multiple (or Mixed) etiologies
OTSP	8	Other (please specify: _____)
UNK	9	Unknown

NCD_6	NCD_TYPCONF_MSP	
[ASK IF NCD_DIA_MSP = MILD OR MAJOR]		
How confident are you in your diagnosis of the underlying cause of the mild or major neurocognitive disorder? Please rate on an 11-point scale (0-10; with the anchors of 0, indicating the lowest confidence rating, and 10, the highest confidence rating)		
NUMBER	Number	_____ **[MASK: MIN=0, MAX=10]**

NCD_7	NCD_TYPINF_MSP	
[ASK IF NCD_DIA_MSP = MILD OR MAJOR]		
What additional information or resources would increase your confidence in your diagnosis?		
MULTIPLE RESPONSES ALLOWED, CODE ALL THAT APPLY		
NONE	1	None
LAB	2	Laboratory investigations
IMG	3	Neuroimaging
REF	4	Referral to a consultant
TIM	5	Opportunity to follow the participant over time
OTSP	7	Other (please specify: _____)

NCD_8	NCD_NOTES_MSP	
[ALWAYS ASK]		
Do you have any additional notes? For example, are there any other details regarding your clinical assessment with the participant that you have not previously recorded that impacted the diagnosis you provided to the participant?		
YES	1	Yes
NO	2	No

NCD_9	NCD_NOTES_SP_MSP
[ASK IF NCD_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

NCD_10	NCD_LETTER1_MSP
ALWAYS ASK	
DO NOT READ: If your clinical assessment of the participant indicates that there may be a concern about the participant's memory, please fill out the CLSA Memory Study Participant Letter Template – Potential Cognitive Concerns template with the participant's name and MoCA score. If your clinical assessment of the participant indicates that there are not any concerns about the participant's memory, please fill out the CLSA Memory Study Participant Letter Template – No Cognitive Concerns template with the participant's name and MoCA score. Give the letter to the participant and verbally discuss the content.	

NCD_11	NCD_LETTER2_MSP	
ALWAYS ASK		
Did you give the letter to the participant?		
YES	1	Yes
NO	2	No

NCD_12	NCD_LETTER3_MSP
[ASK IF NCD_LETTER_MSP = NO]	
Why did you not give the letter to the participant? _____	

NCD_END

Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

Supplementary Appendix 6 - Informant Questionnaire

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

v1.1, 2022 October 12

Table of Contents

Relationship to Participant (INF)

Overview	This questionnaire will be completed by an informant, a family member or friend who knows the participant well and can answer questions regarding the participant's medical history, functional abilities, and overall behaviour.

First, I would like to ask you about your relationship with @first_name@.

REL_1	**INF_REL_MSI**	
[ALWAYS ASK]		
What is your relationship with @first_name@?		
CODE ONLY ONE RESPONSE		
PARTNER	1	Spouse/partner
CHILD	2	Child
SIBLING	3	Sibling
FRIEND	4	Friend
OT_SP	5	Other, specify: _____
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

REL_2	**INF_GENDER_MSI**	
[ALWAYS ASK]		
What pronoun should we use when referring to @first_name@?		
CODE ONLY ONE RESPONSE		
HIM	1	He/him/his
HER	2	She/her/hers
THEM	3	They/them/theirs
OT_SP	5	Other, specify: _____
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

REL_END

clsa élcv

CLSA Memory Study Informant Questionnaire
v1.1, 2022 October 12

AD8 Dementia Screening Interview (AD8)

Overview	The Eight-item Informant Interview to Differentiate Aging and Dementia (AD8) was designed as a screening tool to identify early cognitive changes associated with many common subtypes of dementia including Alzheimer's Disease, vascular dementia, Lewy body dementia, and frontotemporal dementia. The informant should specifically be asked to rate changes in the participant's ability for each of the items, without attributing causality. If read aloud to the respondent, it is important for the interviewer to carefully read the phrase as worded and give emphasis to note changes due to cognitive problems (not physical problems). There should be a one second delay between individual items. There is no specific timeframe for change required to be used for this questionnaire.

For the next few questions, please think about @first_name@'s cognitive abilities in regard to thinking and memory problems.

For each question, please respond "yes" if you have noticed a change and "no" if you have not noticed a change in @first_name@ over the past several years.

AD8_1	**AD8_1_MSI**	
[ALWAYS ASK]		
Problems with judgment (e.g., problems with making decisions, bad financial decisions, problems with thinking)		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

AD8_2	**AD8_2_MSI**

[ALWAYS ASK]		
Less interest in hobbies/activities		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

AD8_3	**AD8_3_MSI**	
[ALWAYS ASK]		
Repeats the same things over and over (questions, stories, or statements)		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

AD8_4	**AD8_4_MSI**	
[ALWAYS ASK]		
Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

AD8_5	**AD8_5_MSI**	
[ALWAYS ASK]		
Forgets correct month or year		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

AD8_6	**AD8_6_MSI**

[ALWAYS ASK]		
Trouble handling complicated financial affairs (e.g., balancing check book, income taxes, paying bills)		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

AD8_7	**AD8_7_MSI**	
[ALWAYS ASK]		
Trouble remembering appointments		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

AD8_8	**AD8_8_MSI**	
[ALWAYS ASK]		
Daily problems with thinking and/or memory		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

AD8_9	**AD8_TOTALSCORE0_MSI**
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 0]	
Score on the AD8 Dementia Screening Interview: 0	

AD8_10	**AD8_TOTALSCORE1_MSI**
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 1]	

Score on the AD8 Dementia Screening Interview: 1

AD8_11	AD8_TOTALSCORE2_MSI
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 2]	
Score on the AD8 Dementia Screening Interview: 2	

AD8_12	AD8_TOTALSCORE3_MSI
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 3]	
Score on the AD8 Dementia Screening Interview: 3	

AD8_13	AD8_TOTALSCORE4_MSI
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 4]	
Score on the AD8 Dementia Screening Interview: 4	

AD8_14	AD8_TOTALSCORE5_MSI
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 5]	
Score on the AD8 Dementia Screening Interview: 5	

AD8_15	AD8_TOTALSCORE6_MSI
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 6]	
Score on the AD8 Dementia Screening Interview: 6	

AD8_16	AD8_TOTALSCORE7_MSI
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 7]	

Score on the AD8 Dementia Screening Interview: 7

AD8_17	**AD8_TOTALSCORE8_MSI**
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 8]	
Score on the AD8 Dementia Screening Interview: 8	

This variable identifies the number of items that were not completed on the Eight-item Informant Interview to Differentiate Aging and Dementia (AD8) questionnaire and should be considered when interpreting the total score of the AD8.

AD8_18	**AD8_TOTALMIS0_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 0]	
Number of missed questions on the AD8 Dementia Screening Interview: 0	

AD8_19	**AD8_TOTALMIS1_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 1]	
Number of missed questions on the AD8 Dementia Screening Interview: 1	

AD8_20	**AD8_TOTALMIS2_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 2]	
Number of missed questions on the AD8 Dementia Screening Interview: 2	

AD8_21	**AD8_TOTALMIS3_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 3]	
Number of missed questions on the AD8 Dementia Screening Interview: 3	

AD8_22	**AD8_TOTALMIS4_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 4]	

Number of missed questions on the AD8 Dementia Screening Interview: 4

AD8_23	**AD8_TOTALMIS5_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 5]	
Number of missed questions on the AD8 Dementia Screening Interview: 5	

AD8_24	**AD8_TOTALMIS6_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 6]	
Number of missed questions on the AD8 Dementia Screening Interview: 6	

AD8_25	**AD8_TOTALMIS7_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 7]	
Number of missed questions on the AD8 Dementia Screening Interview: 7	

AD8_26	**AD8_TOTALMIS8_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 8]	
Number of missed questions on the AD8 Dementia Screening Interview: 8	

AD8_END

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Medical History (MED)

Overview	The medical history module captures information that will assist the examining physician in determining if any observed cognitive limitations may be secondary to other diseases such as neurodegenerative diseases. This information may also increase the confidence in the physician's diagnosis based on the absence or presence of risk factors for neurocognitive disorders.

I am now going to ask you some questions regarding @first_name@'s medical history including different medical conditions he/she may have, and use of other substances. We do not expect you to know every detail about @first_name@, but ask that you answer to the best of your ability.

MED_1	**MED_CON_MSI**	
[ALWAYS ASK]		
To your knowledge, does @first_name@ have any of the following medical conditions…?		
INTERVIEWER NOTES: Psychotic illnesses include schizophrenia and other conditions which include hallucinations, delusions and disordered forms of thinking.		
READ LIST, MULTIPLE RESPONSES ALLOWED (EXCEPT IF 98 OR 99 ARE SELECTED), CODE ALL THAT APPLY		
CAD	1	Coronary artery disease
HF	2	Heart failure
AF	3	Atrial fibrillation/flutter
TIA	4	Transient ischemic attack (TIA)
STR	5	Cerebrovascular accident (stroke)
HEM	6	Intracerebral hemorrhage
HYP	7	Hypertension
DIA	8	Diabetes mellitus
DYS	9	Dyslipidemia
PKD	10	Parkinson's Disease or Parkinsonism
DEP	11	Depression
ANX	12	Anxiety disorder
PSY	13	Psychotic illness
HR	14	Hearing impairment
VS	15	Visual impairment
SM	16	Impaired sense of smell
DEM	17	Dementia
DELI	18	Suspected delirium (in the past 5 years)
IN	19	Insomnia
REM	20	REM-Sleep Behaviour Disorder
OSA	21	Obstructive Sleep Apnea
HYPT	22	Hypothyroidism
B12	23	Vitamin B12 deficiency

OTSP	24	Other conditions relevant to cognitive status (e.g. cancer and/or cancer treatments); specify _____
NONEI	25	None of the above
DK_NA	98	**[DO NOT READ]** Don't know / No answer
REFUSED	99	**[DO NOT READ]** Refused

MED_2	**MED_TBI_MSI**	
[ALWAYS ASK]		
Has @first_name@ suffered a head injury or a concussion in the past?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_3	**MED_TBI1_MSI**	
[ASK IF MED_TBI_MSI = YES]		
How many head injuries or concussions has @first_name@ had in his/her lifetime?		
INTERVIEWER NOTE: If the informant cannot remember exact number, please probe for their best estimate		
NUM	Number	_____ **[MASK: MIN=1]**
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_4	**MED_TBI2_MSI**	
[ASK IF MED_TBI_MSI = YES]		
At what age or in what year did @first_name@ have the most serious head injury?		
INTERVIEWER NOTE: If the informant cannot remember the specific year, please probe for their best estimation of when the head injury occurred.		
NB_SP	Age	_____ **[MASK: MIN=0, MAX=CURRENT AGE]**
YR_SP	Year	_____ **[MASK: MIN=BIRTH YEAR, MAX=CURRENT YEAR]**
DK_NA	9998	**[DO NOT READ]** Don't know / No answer
REFUSED	9999	**[DO NOT READ]** Refused

MED_5	MED_TBI3_MSI	
[ASK IF MED_TBI_MSI = YES]		
Did the most serious head injury result in…?		
READ LIST, MULTIPLE RESPONSES ALLOWED (EXCEP IF 8 OR 9 ARE SELECTED), CODE ALL THAT APPLY		
DZ	1	Being dazed, confused, or “seeing stars”
DRM	2	Not remembering the injury
KO	3	Losing consciousness (knocked out)
NONE	6	Head injury did not result in any of the above
DK_NA	8	**[DO NOT READ]** Don’t know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_6	MED_TBI4_MSI	
[ASK IF MED_TBI3_MSI = KO**]**		
How long did @first_name@ lose consciousness for?		
READ LIST, CODE ONLY ONE RESPONSE		
KO1	1	Less than a minute
KO20	2	1-20 minutes
K020MORE	3	Longer than minutes
DK_NA	8	**[DO NOT READ]** Don’t know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_7	MED_SMKSTATUS_MSI	
[ALWAYS ASK]		
How would you describe @first_name@’s smoking status…?		
READ LIST, CODE ONLY ONE RESPONSE		
YES	1	Yes, he/she currently smokes
NEVER	2	No, he/she does not currently smoke and never has
FORM_DAY	4	Former daily smoker (non-smoker now)
FORM_OCC	5	Former occasional smoker (non-smoker now)
DK_NA	8	**[DO NOT READ]** Don’t know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_8	MED_CAN_MSI	
[ALWAYS ASK]		
Does @first_name@ use any cannabis products?		
READ LIST, CODE ONLY ONE RESPONSE		
YES	1	Yes, he/she currently uses cannabis products
NEVER	2	No, he/she has never used cannabis products
FORMER	3	Former cannabis user, but does not use cannabis products now
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_9	MED_ALC_MSI	
[ALWAYS ASK]		
How would you describe @first_name@'s alcohol consumption?		
READ LIST, CODE ONLY ONE RESPONSE		
NEVER	1	Never drank alcohol
FORMER	2	Used to drink alcohol but does not currently drink
CURRENT	3	Currently consumes alcohol
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_10	MED_ALCNMB_MSI	
[ASK IF MED_ALC_MSI = CURRENT]		
A "standard" drink is considered 12 ounces of regular beer (~5% alcohol), 5 ounces of wine (~12% alcohol), or 1.5 ounces of distilled spirits (~40% alcohol). How many estimated standardized drinks per week does @first_name@ consume?		
ALC_NB	Number of standard drinks: _____**[MASK: MIN=0, MAX=200]**	
DK_NA	998	**[DO NOT READ]** Don't know / No answer
REFUSED	999	**[DO NOT READ]** Refused

MED_11	MED_ALCMLFQ_MSI	
[ASK IF MED_ALC_MSI = CURRENT AND AND SEX = MALE]		
In the past 12 months, has @first_name@ consumed 5 or more drinks in 2 hours or less at least once a month?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_12	MED_ALCFMFQ_MSI	
[ASK IF MED_ALC_MSI = CURRENT AND SEX = FEMALE]		
In the past 12 months, has @first_name@ consumed 4 or more drinks in 2 hours or less at least once a month?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_13	MED_FAM_MSI	
[ALWAYS ASK]		
Does the @first_name@ have a first degree relative who has been diagnosed with dementia or Alzheimer's Disease?		
INTERVIEWER NOTE: First degree relatives include biological parents, siblings, or children		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_END

Basic Activities of Daily Living (ADL)

This module is a modification of the Activities of Daily Living questions of the OARS Multidimensional Assessment Questionnaire© developed by Dr. Gerda G. Fillenbaum (Duke University Medical Center). The Canadian Longitudinal Study on Aging received permission from Dr. Fillenbaum (instrument developer) for the use of this instrument.

Overview	The Activities of Daily Living (ADL) scale assesses respondents' ability to perform basic daily activities. Activities of daily living are the tasks considered vital to live independently in the community. The informant is asked if the participant requires help when feeding and dressing oneself, taking care of their appearance, walking around, getting in and out of bed, bathing, and whether the participant has incontinence problems. These basic daily activities can be difficult to perform for people with mobility restrictions or limitations. Information on activities of daily living will help provide insights into limitations that Canadians may face in day-to-day living, as well as how these limitations change as people age. It is a measure related to the need for caregivers and home care services.

Now I'd like to ask you about activities of daily living. You may feel that some of these questions do not apply to @first_name@, but it is important that we ask the same questions of everyone.

ADL_1	**ADL_ABLDR_MSI**	
[ALWAYS ASK]		
Can @first_name@ dress and undress without help (including picking out clothes and putting on socks and shoes)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_2	**ADL_HPDR_MSI**	
[ASK IF ADL_ABLDR_MSI = NO]		
Can @first_name@ dress and undress with some help?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_3	ADL_UNDR_MSI	
[ASK IF ADL_HPDR_MSI = NO]		
Is @first_name@ completely unable to dress and undress?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_4	ADL_ABLFD_MSI	
[ALWAYS ASK]		
Can @first_name@ eat without help (i.e., able to feed him or herself completely)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_5	ADL_HPFD_MSI	
[ASK IF ADL_ABLFD_MSI = NO]		
Can @first_name@ eat with some help (i.e., needs help with cutting food, etc.)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_6	ADL_UNFD_MSI	
[ASK IF ADL_HPFD_MSI = NO]		
Is @first_name@ completely unable to feed himself or herself?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_7	ADL_ABLAP_MSI	
[ALWAYS ASK]		
Can @first_name@ take care of his/her own appearance without help, for example, combing hair, shaving (if male)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_8	ADL_HPAP_MSI	
[ASK IF ADL_ABLAP_MSI = NO]		
Can @first_name@ take care of his or her own appearance with some help?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_9	ADL_UNAP_MSI	
[ASK IF ADL_HPAP_MSI = NO]		
Is @first_name@ completely unable to take care of his or her own appearance?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

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ADL_10	**ADL_ABLWK_MSI**	
[ALWAYS ASK]		
Can @first_name@ walk without help?		
INTERVIEWER NOTE: IF PARTICIPANT WALKS WITH A CANE CODE AS YES		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_11	**ADL_HPWK_MSI**	
[ASK IF ADL_ABLWK_MSI = NO]		
Can @first_name@ walk with some help from a person, or with the use of a walker or crutches, etc.?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_12	**ADL_UNWK_MSI**	
[ASK IF ADL_HPWK_MSI = NO]		
Is @first_name@ completely unable to walk?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_13	ADL_ABLBD_MSI	
[ALWAYS ASK]		
Can @first_name@ get in and out of bed without any help or aids?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_14	ADL_HPBD_MSI	
[ASK IF ADL_ABLBD_MSI = NO]		
Can @first_name@ get in and out of bed with some help (either from a person or with the aid of some device)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_15	ADL_UNBD_MSI	
[ASK IF ADL_HPBD_MSI = NO]		
Is @first_name@ totally dependent on someone else to lift him/her in and out of bed?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_16	ADL_ABLBT_MSI	
[ALWAYS ASK]		
Can @first_name@ take a bath or shower without help?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_17	ADL_HPBT_MSI	
[ASK IF ADL_ABLBT_MSI = NO]		
Can @first_name@ take a bath or shower with some help (i.e., needs help from someone getting in and out of the tub or needs special attachments on the tub)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_18	ADL_UNBT_MSI	
[ASK IF ADL_HPBT_MSI = NO]		
Is @first_name@ completely unable to take a bath and a shower by himself/herself?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_19	ADL_BATH_MSI	
[ALWAYS ASK]		
Does @first_name@ ever have trouble getting to the bathroom in time?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_20	ADL_INCNT_MSI	
[ASK IF ADL_BATH_MSI = YES]		
How often does @first_name@ wet or soil himself/herself (either day or night)? Would you say…		
READ LIST, CODE ONLY ONE RESPONSE		
0_1_TIME_WEEK	1	Never or less than once a week
1_2_TIME_WEEK	2	Once or twice a week
3_MORE_TIMES_WEEK	3	Three times a week or more
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_END

Instrumental Activities of Daily Living (IADL)

This module is a modification of the Activities of Daily Living questions of the OARS Multidimensional Assessment Questionnaire© developed by Dr. Gerda G. Fillenbaum (Duke University Medical Center). The Canadian Longitudinal Study on Aging received permission from Dr. Fillenbaum (instrument developer) for the use of this instrument.

Overview	The Instrumental Activities of Daily Living (IADL) scale assesses respondents' ability to independently perform a series of daily activities. The informant is asked if the participant requires help when using the telephone, traveling, shopping, cooking, doing housework, taking medicine and handling money. Information on instrumental activities of daily living will help provide insights into limitations that Canadians may face day-to-day living, as well as how these limitations change as people age. It is a measure related to the need for caregivers and home care services. This module is a companion to the ADL module.

Now I'd like to ask you about activities of daily living. You may feel that some of these questions do not apply to @first_name@, but it is important that we ask the same questions of everyone.

IAL_1	**IAL_ABLTEL_MSI**	
[ALWAYS ASK]		
Can @first_name@ use the telephone without help, including looking up numbers and dialling?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_2	**IAL_HPTEL_MSI**	
[ASK IF IAL_ABLTEL_MSI = NO]		
Can @first_name@ use the telephone with some help (i.e., can answer the phone or dial the operator in an emergency, but needs a special phone or help in getting the number or dialling)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_3	IAL_UNTEL_MSI	
[ASK IF IAL_HPTEL_MSI = NO]		
Is @first_name@ completely unable to use the telephone?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_4	IAL_ABLTRV_MSI	
[ALWAYS ASK]		
Can @first_name@ get to places out of walking distance without help (i.e., drive own car, or travel alone on buses, or taxis)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_5	IAL_HPTRV_MSI	
[ASK IF IAL_ABLTRV_MSI = NO]		
Can @first_name@ get to places out of walking distance with some help (i.e., needs someone to help him/her or go with him/her when travelling)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_6	IAL_UNTRV_MSI	
[ASK IF IAL_HPTRV_MSI = NO]		
Is @first_name@ unable to travel unless emergency arrangements are made for a specialized vehicle, like an ambulance?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_7	IAL_ABLGRO_MSI	
[ALWAYS ASK]		
Can @first_name@ go shopping for groceries or clothes without help (taking care of all shopping needs)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_8	IAL_HPGRO_MSI	
[ASK IF IAL_ABLGRO_MSI = NO]		
Can @first_name@ go shopping for groceries or clothes with some help (i.e., needs someone to go with him/her on all shopping trips)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_9	IAL_UNGRO_MSI	
[ASK IF IAL_HPGRO_MSI = NO]		
Is @first_name@ completely unable to do any shopping?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_10	IAL_ABLML_MSI	
[ALWAYS ASK]		
Can @first_name@ prepare his/her own meals without help (i.e., plan and cook full meals)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_11	IAL_HPML_MSI	
[ASK IF IAL_ABLML_MSI = NO]		
Can @first_name@ prepare his/her own meals with some help (i.e., can prepare some things but are unable to cook full meals)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_12	IAL_UNML_MSI	
[ASK IF IAL_HPML_MSI = NO]		
Is @first_name@ completely unable to prepare any meals?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_13	IAL_ABLWRK_MSI	
[ALWAYS ASK]		
Can @first_name@ do housework without help (i.e., can clean floors, etc.)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_14	IAL_HPWRK_MSI	
[ASK IF IAL_ABLWRK_MSI = NO]		
Can @first_name@ do housework with some help (i.e., can do light housework but needs help with heavy work)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_15	IAL_UNWRK_MSI	
[ASK IF IAL_HPWRK_MSI = NO]		
Is @first_name@ completely unable to do any housework?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_16	IAL_ABLMED_MSI	
[ALWAYS ASK]		
Can @first_name@ take his or her own medicine without help (in the right doses at the right time)?		
INTERVIEWER INSTRUCTIONS: IF THE PARTICIPANT OCCASIONALLY FORGETS, CODE AS 'YES'.		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_17	IAL_HPMED_MSI	
[ASK IF IAL_ABLMED_MSI = NO]		
Can @first_name@ take his or her own medicine with some help (i.e., able to take medicine if someone prepares it for him/her or reminds him/her to take it)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_18	IAL_UNMED_MSI	
[ASK IF IAL_HPMED_MSI = NO]		
Is @first_name@ completely unable to take his/her own medicine?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_19	IAL_ABLMO_MSI	
[ALWAYS ASK]		
Can @first_name@ handle his/her own money without help (i.e., write cheques, pay bills, etc.)?		
INTERVIEWER INSTRUCTIONS: IF THE PARTICIPANT OCCASIONALLY FORGETS, CODE AS 'YES'.		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_20	IAL_HPMO_MSI	
[ASK IF IAL_ABLMO_MSI = NO]		
Can @first_name@ handle his/her own money with some help (i.e., manage day-to-day buying but needs help with managing chequebook or paying bills)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_21	IAL_UNMO_MSI	
[ASK IF IAL_HPMO_MSI = NO]		
Is @first_name@ completely unable to handle his/her own money?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_END

Transportation (TRA)

Overview	The questions in this module ask the informant about the participant's driving status and details regarding their license status.

I will now ask you a few questions about @first_name@'s ability to use different types of transportation.

TRA_1	**TRA_DSTATUS_MSI**	
[ALWAYS ASK]		
Which of the following describes @first_name@ driving status...? (Include cars, vans, trucks and motorcycles)		
READ LIST, CODE ONLY ONE RESPONSE		
NEVER	1	Never had a driver's license
FORMER	2	Had a driver's license at one point in his or her life, but currently does not have it
CURRENT	3	Has a driver's license without restrictions (except corrective lenses)
RESTRICTED	4	Has a driver's license with restrictions on time of driving (daylight only), distance from home, type of road (no highway), or number of passengers
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

TRA_2	**TRA_STOP_MSI**	
[ASK IF TRA_STA_MSI = FORMER]		
Why did @first_name@ stop driving…?		
CODE ONLY ONE RESPONSE		
VOL_STOP	1	Voluntarily stopped driving
LICS_RESC	2	License rescinded
OT_SP	3	Other (please specify: _____)
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

TRA_3	TRA_STOPYR_MSI	
[ASK IF TRA_STA_MSI =FORMER]		
In what year or at what age did @first_name@ stop driving?		
NB_SP	Age	_____ **[MASK: MIN=00, MAX=CURRENT AGE]**
YR_SP	Year	_____ **[MASK: MIN=BIRTH YEAR, MAX=CURRENT YEAR]**
DK_NA	9998	**[DO NOT READ]** Don't know / No answer
REFUSED	9999	**[DO NOT READ]** Refused

TRA_4	TRA_TRANSIT_MSI	
[ALWAYS ASK]		
How would you describe @first_name@ use of public transit…?		
CODE ONLY ONE RESPONSE		
CURR	1	Currently uses
COULD	2	Does not use public transit, but could if they wanted to
CANNOT	3	Does not use public transit and does not think they could
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

TRA_END

Mild Behavioural Impairment Checklist (MBI)

This module consists of the Mild Behavioural Impairment Checklist developed by Dr. Zahinoor Ismail (University of Calgary).

Overview	Mild Behavioural Impairment (MBI) refers to neuropsychiatric symptoms which are usually observed before cognitive decline and dementia in individuals aged 50 years and older. MBI describes symptoms of any severity that persist for at least six months, and occur either before or at the same time as mild neurocognitive disorder. The MBI Checklist is a 34-item instrument which can be completed by a patient/participant, close informant, or clinician. The checklist is designed to quantify the severity of behavioural symptoms in multiple domains. Global and domain-specific scores and thresholds have not yet been developed and validated for clinical diagnosis and prognosis. Ongoing validation work will identify scores and thresholds that predict an increased risk of transition to dementia.

I will now ask you some questions about @first_name@'s behaviour. For each question, please answer "yes" if you have noticed this behaviour continuously or on and off for **at least 6 months**, and if it is a **change** from her/his longstanding pattern of behaviour. Otherwise, please answer "no".

For each question you respond "yes" to indicating a change in behaviour, I will ask you to respond about the severity of the behaviour based on the following options:

1) Mild where the change in behaviour is noticeable, but not a significant change;
2) Moderate where the change in behaviour is significant, but not a dramatic change;
3) Severe where the change in behaviour is marked or prominent, a dramatic change.

If there is more than one behaviour listed in a question, please rate the most severe behavioural change.

The first domain describes interest, motivation, and drive.

MBI_1	**MBI_INTER_MSI**	
[ALWAYS ASK]		
Has the person lost interest in friends, family, or home activities?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_2	MBI_INTERSEV_MSI	
[ASK IF MBI_INTER_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_3	MBI_CURI_MSI	
[ALWAYS ASK]		
Does the person lack curiosity in topics that would usually have attracted her/his interest?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_4	MBI_CURISEV_MSI	
[ASK IF MBI_CURI_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_5	MBI_SPON_MSI	
[ALWAYS ASK]		
Has the person become less spontaneous and active – for example, is she/he less likely to initiate or maintain conversation?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_6	MBI_SPONSEV_MSI	
[ASK IF MBI_SPON_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_7	MBI_MOTI_MSI	
[ALWAYS ASK]		
Has the person lost motivation to act on her/his obligations or interest?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_8	MBI_MOTISEV_MSI

[ASK IF MBI_MOTI_MSI = Yes]

How would you describe the severity of this behaviour…?

CODE ONLY ONE RESPONSE

MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_9	MBI_EMOT_MSI

[ALWAYS ASK]

Is the person less affectionate and/or lacking in emotions when compared to her/his usual self?

YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_10	MBI_EMOTSEV_MSI

[ASK IF MBI_EMOT_MSI = Yes]

How would you describe the severity of this behaviour…?

CODE ONLY ONE RESPONSE

MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_11	MBI_CARE_MSI	
[ALWAYS ASK]		
Does she/he no longer care about anything?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_12	MBI_CARESEV_MSI	
[ASK IF MBI_CARE_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

The second domain describes mood or anxiety symptoms.

Interviewer note, remind the respondent if required: For each questions you respond "yes" to indicating a change in behaviour, I will ask you to respond about the severity of the behaviour based on the following options:

1) Mild where the change in behaviour is noticeable, but not a significant change;
2) Moderate where the change in behaviour is significant, but not a dramatic change;
3) Severe where the change in behaviour is marked or prominent, a dramatic change.

If there is more than one behaviour listed in a question, please rate the most severe behavioural change.

MBI_13	MBI_SAD_MSI	
[ALWAYS ASK]		
Has the person developed sadness or appear to be in low spirits? Does she/he have episodes of tearfulness?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_14	MBI_SADSEV_MSI	
[ASK IF MBI_SAD_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_15	MBI_PLES_MSI	
[ALWAYS ASK]		
Has the person become less able to experience pleasure?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_16	MBI_PLESSEV_MSI	
[ASK IF MBI_PLES_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_17	MBI_DISC_MSI	
[ALWAYS ASK]		
Has the person become discouraged about their future or feel that she/he is a failure?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_18	MBI_DISCSEV_MSI	
[ASK IF MBI_DISC_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_19	MBI_BURD_MSI	
[ALWAYS ASK]		
Does the person view herself/himself as a burden to family?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_20	MBI_BURDSEV_MSI	
[ASK IF MBI_BURD_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_21	MBI_ANX_MSI	
[ALWAYS ASK]		
Has the person become more anxious or worried about things that are routine (e.g. events, visits, etc.)?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_22	MBI_ANXSEV_MSI	
[ASK IF MBI_ANX_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_23	MBI_TENSE_MSI	
[ALWAYS ASK]		
Does the person feel very tense, having developed an inability to relax, or shakiness, or symptoms of panic?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_24	MBI_TENSESEV_MSI	
[ASK IF MBI_TENSE_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

The third domain describes the ability to delay gratification and control behaviour, impulses, oral intake and/or changes in reward.

Interviewer note, remind the respondent if required: For each questions you respond "yes" to indicating a change in behaviour, I will ask you to respond about the severity of the behaviour based on the following options:

1) Mild where the change in behaviour is noticeable, but not a significant change;
2) Moderate where the change in behaviour is significant, but not a dramatic change;
3) Severe where the change in behaviour is marked or prominent, a dramatic change.

If there is more than one behaviour listed in a question, please rate the most severe behavioural change.

MBI_25	MBI_AGGR_MSI	
[ALWAYS ASK]		
Has the person become agitated, aggressive, irritable, or temperamental?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_26	MBI_AGGRSEV_MSI	
[ASK IF MBI_AGGR_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_27	MBI_ARGU_MSI	
[ALWAYS ASK]		
Has she/he become unreasonably or uncharacteristically argumentative?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_28	MBI_ARGUSEV_MSI	
[ASK IF MBI_ARGU_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_29	MBI_IMPU_MSI	
[ALWAYS ASK]		
Has the person become more impulsive, seeming to act without considering things?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_20	MBI_IMPUSEV_MSI	
[ASK IF MBI_IMPU_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_31	MBI_DISI_MSI	
[ALWAYS ASK]		
Does the person display sexually disinhibited or intrusive behaviour, such as touching (themselves/others), hugging, groping, etc., in a manner that is out of character or may cause offense?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_32	MBI_DISISEV_MSI	
[ASK IF MBI_DISI_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_33	MBI_FRUS_MSI	
[ALWAYS ASK]		
Has the person become more easily frustrated or impatient? Does she/he have troubles coping with delays, or waiting for events or for their turn?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_34	MBI_FRUSSEV_MSI	
[ASK IF MBI_FRUS_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_35	MBI_DRIVE_MSI	
[ALWAYS ASK]		
Does the person display a new recklessness or lack of judgement when driving (e.g. speeding, erratic swerving, abrupt lane changes, etc.)?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_36	MBI_DRIVESEV_MSI	
[ASK IF MBI_DRIVE_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_37	MBI_STUB_MSI	
[ALWAYS ASK]		
Has the person become more stubborn on rigid, i.e., uncharacteristically insistent on having their way, or unwilling/unable to see/hear other views?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_38	MBI_STUBSEV_MSI

[ASK IF MBI_STUB_MSI = Yes]

How would you describe the severity of this behaviour…?

CODE ONLY ONE RESPONSE

MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_39	MBI_FOOD_MSI

[ALWAYS ASK]

Is there a change in eating behaviours (e.g., overeating, cramming the mouth, insistent on eating only specific foods, or eating the food in exactly the same order)?

YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_40	MBI_FOODSEV_MSI

[ASK IF MBI_FOOD_MSI = Yes]

How would you describe the severity of this behaviour…?

CODE ONLY ONE RESPONSE

MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_41	MBI_APP_MSI	
[ALWAYS ASK]		
Does the person no longer find food tasteful or enjoyable? Are they eating less?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_42	MBI_APPSEV_MSI	
[ASK IF MBI_APP_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_43	MBI_HOARD_MSI	
[ALWAYS ASK]		
Does the person hoard objects when she/he did not do so before?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_44	MBI_HOARDSEV_MSI

[ASK IF MBI_HOARD_MSI = Yes]

How would you describe the severity of this behaviour…?

CODE ONLY ONE RESPONSE

MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_45	MBI_REP_MSI

[ALWAYS ASK]

Has the person developed simple repetitive behaviours or compulsions?

YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_46	MBI_REPSEV_MSI

[ASK IF MBI_REP_MSI = Yes]

How would you describe the severity of this behaviour…?

CODE ONLY ONE RESPONSE

MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_47	MBI_REGU_MSI	
[ALWAYS ASK]		
Has the person recently developed trouble regulating smoking, alcohol, drug intake or gambling, or started shoplifting?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_48	MBI_REGUSEV_MSI	
[ASK IF MBI_REGU_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

The next domain describes following society norms and having social graces, tact, and empathy.

Interviewer note, remind the respondent if required: For each questions you respond "yes" to indicating a change in behaviour, I will ask you to respond about the severity of the behaviour based on the following options:

1) Mild where the change in behaviour is noticeable, but not a significant change;
2) Moderate where the change in behaviour is significant, but not a dramatic change;

Severe where the change in behaviour is marked or prominent, a dramatic change. If there is more than one behaviour listed in a question, please rate the most severe behavioural change.

MBI_49	MBI_INSEN_MSI	
[ALWAYS ASK]		
Has the person become less concerned about how her/his words or actions affect others? Has she/he become insensitive to others' feelings?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_50	MBI_INSENSEV_MSI	
[ASK IF MBI_INSEN_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_51	MBI_OPEN_MSI	
[ALWAYS ASK]		
Has the person started talking openly about very personal or private matters not usually discussed in public?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_52	MBI_OPENSEV_MSI	
[ASK IF MBI_OPEN_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_53	MBI_RUDE_MSI	
[ALWAYS ASK]		
Does the person say rude or crude things or make lewd sexual remarks that she/he would not have said before?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_54	MBI_RUDESEV_MSI	
[ASK IF MBI_RUDE_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_55	MBI_JUDGE_MSI	
[ALWAYS ASK]		
Does the person seem to lack the social judgement she/he previously had about what to say or how to behave in public or private?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_56	MBI_JUDGESEV_MSI	
[ASK IF MBI_JUDGE_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_57	MBI_TALK_MSI	
[ALWAYS ASK]		
Does the person now talk to strangers as if familiar, or intrude on their activities?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_58	MBI_TALKSEV_MSI	
[ASK IF MBI_TALK_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

This last domain describes strongly held beliefs and sensory experiences.

Interviewer note, remind the respondent if required: For each questions you respond "yes" to indicating a change in behaviour, I will ask you to respond about the severity of the behaviour based on the following options:

1) Mild where the change in behaviour is noticeable, but not a significant change;
2) Moderate where the change in behaviour is significant, but not a dramatic change;
3) Severe where the change in behaviour is marked or prominent, a dramatic change.

If there is more than one behaviour listed in a question, please rate the most severe behavioural change.

MBI_59	**MBI_HARM_MSI**	
[ALWAYS ASK]		
Has the person developed beliefs that they are in danger, or that others are planning to harm them or steal their belongings?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_60	**MBI_HARMSEV_MSI**	
[ASK IF MBI_HARM_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_61	**MBI_SUSP_MSI**	
[ALWAYS ASK]		
Has the person developed suspiciousness about the intentions or motives of other people?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_62	MBI_SUSPSEV_MSI	
[ASK IF MBI_SUSP_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_63	MBI_UNRL_MSI	
[ALWAYS ASK]		
Doe she/he have unrealistic beliefs about her/his power, wealth, or skills?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_64	MBI_UNRLSEV_MSI	
[ASK IF MBI_UNRL_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_65	MBI_VOICE_MSI	
[ALWAYS ASK]		
Does the person describe hearing voices or does she/he talk to imaginary people or “spirits”		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don’t know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_66	MBI_VOICESEV_MSI	
[ASK IF MBI_VOICE_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don’t know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_67	MBI_IMAG_MSI	
[ALWAYS ASK]		
Does the person report or complain about, or act as if seeing things (e.g. people, animals, or insects) that are not there, i.e., that are imaginary to others?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don’t know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_68	MBI_IMAGSEV_MSI	
[ASK IF MBI_IMAG_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_END

Supplementary Appendix 7 – Letter for participants with potential concerns about their cognition

clsa élcv
Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

Parminder Raina, PhD
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Susan Kirkland, PhD
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Department of Community Health & Epidemiology and Department of Medicine
Dalhousie University

Date

Dear [Participant name],

During your Data Collection Site visit for the Canadian Longitudinal Study on Aging (CLSA) Memory Study, our assessment identified a potential concern about your memory. We encourage you to discuss these results with your family physician. Please find below information that may be given to a physician to provide context for the examination result.

This person is a participant in the Canadian Longitudinal Study on Aging (CLSA) (www.clsa/elcv.ca). The study is funded by the Canadian Institutes of Health Research (CIHR) and will involve 50,000 participants aged 45 to 85 years from across Canada who will be followed for up to 20 years.

The CLSA is conducting a substudy on the topic of memory funded by the Public Health Agency of Canada (PHAC). Participants in this study complete a clinical assessment done by a clinician specializing in geriatric psychiatry, neurology, or psychiatry with experience in cognitive assessment. The clinical assessment includes questions about the participant's medical history, a brief cognitive test, a neurocognitive examination, and observation of mobility. A family member or friend who knows the participant well answered questions regarding the participant's cognitive health, ability to complete daily tasks, and behaviour.

The clinical assessment was completed for research purposes only and was not intended for clinical use. One component of the clinical assessment was the administration of the Montreal Cognitive Assessment (MoCA) which is used to screen for potential cognitive problems. The participant score on the MoCA was _____. The interpretation of a MoCA score requires judgement by an experienced clinician who is aware of other aspects of the participant's health. A score itself does not indicate a specific diagnosis.

If you have any questions, please feel free to contact [*Site Coordinator name or Site PI name as per DCS-specific protocol*] at [*phone number*].

Sincerely,

[Clinician name]

Supported by the **Government of Canada** through the **Canadian Institutes of Health Research** and the **Canada Foundation for Innovation**.

Appuyée par le **gouvernement du Canada** par l'entremise des **Instituts de recherche en santé du Canada** et de la **Fondation canadienne pour l'innovation**.

1·866·999·8303
www.clsa-elcv.ca

Supplementary Appendix 8 – Letter for participants without potential concerns about their cognition

clsa élcv
Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

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Susan Kirkland, PhD
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Department of Community Health & Epidemiology and Department of Medicine
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Date

Dear [Participant name],

During your Data Collection Site visit for the Canadian Longitudinal Study on Aging (CLSA) Memory Study, our assessment did not identify any concerns about your memory. Please find below information that may be given to a physician to provide context for the examination result.

This person is a participant in the Canadian Longitudinal Study on Aging (CLSA) (www.clsa/elcv.ca). The study is funded by the Canadian Institutes of Health Research (CIHR) and will involve 50,000 participants aged 45 to 85 years from across Canada who will be followed for up to 20 years.

The CLSA is conducting a substudy on the topic of memory funded by the Public Health Agency of Canada (PHAC). Participants in this study complete a clinical assessment done by a clinician specializing in geriatric psychiatry, neurology, or psychiatry with experience in cognitive assessment. The clinical assessment includes questions about the participant's medical history, a brief cognitive test, a neurocognitive examination, and observation of mobility. A family member or friend who knows the participant well answered questions regarding the participant's cognitive health, ability to complete daily tasks, and behaviour.

The clinical assessment was completed for research purposes only and was not intended for clinical use. One component of the clinical assessment was the administration of the Montreal Cognitive Assessment (MoCA) which is used to screen for potential cognitive problems. The participant score on the MoCA was _____. The interpretation of a MoCA score requires judgement by an experienced clinician who is aware of other aspects of the participant's health. A score itself does not indicate a specific diagnosis.

If you have any questions, please feel free to contact [*Site Coordinator name or Site PI name as per DCS-specific protocol*] at [*phone number*].

Sincerely,

[Clinician name]

Supported by the **Government of Canada** through the **Canadian Institutes of Health Research** and the **Canada Foundation for Innovation**.

Appuyée par le **gouvernement du Canada** par l'entremise des **Instituts de recherche en santé du Canada** et de la **Fondation canadienne pour l'innovation**.

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Supplementary Appendix 9, Table 1 – DSM-5 Diagnostic criteria mapped on to CLSA data for mild NCD

DSM-5 Diagnostic Criteria	Components of algorithm in the CLSA	Operationalization	Limitations
A - Modest cognitive decline in one or more cognitive domains based on: **1) concern about mild decline, expressed by individual or reliable informant, or observed by clinicians**	Subjective cognitive decline	Responds "yes" to "Do you feel like your memory is becoming worse" and if yes, responds "strongly agree" or "agree" to "does this worry you?"	Questions not available at baseline
	Physician diagnosis of memory problem	Responds "yes" to "Has a doctor ever told you that you have a memory problem"	Underestimates burden of memory problems
	Multifactorial Memory Questionnaire	Individual participant t-scores will be derived and interpreted based on the recommendations of the developer. Participants categorized as "low" or "very low" based on their t-score will be classified as having mild decline	Questions not available at baseline
2) AND/OR modest impairment documented by objective cognitive assessment	Performance on the Rey Auditory Verbal Learning Test (REY1 and REY2), the Animal Fluency Test (AFT2), and the Mental Alternation Test (MAT)	Mean Z score of >-2.0 but <1.5 on two or more cognitive tests	**x** CLSA cognitive tests not designed to detect mild/major NCD **x** Missing data due to participant refusing test, technology issues, and other non-participant related factors
B - The cognitive deficits do not interfere with capacity for independence in everyday activities	Instrumental Activities of Daily Living (IADL)	Participant reports doing the following activities independently; grocery shopping, money management, housework, preparing meals, medication management, preparing meals, using telephone, getting to places out of walking distance	**x** Self-reported, ideal to have informant reported IADLs **x** Mobility, hearing, visions, and physical limitations may explain inability to complete IADLs independently. Basic Activities of Daily Living, self-rated and measured hearing/vision, and

			physical function tests such as gait speed, the Timed Up and Go, Chair Rise test, balance, and grip strength will be explored to determine if reasons other than problems with cognition may explain the presence of IADL limitations.
C- The cognitive deficits do not occur exclusively in the context of a delirium	Assumed to not be present - participants being seen for a scheduled data collection visit are unlikely to have delirium		The CLSA does not collect this information
D - The cognitive deficits are not better explained by another mental disorders (e.g., major depressive disorder, schizophrenia)	The Centre for Epidemiological Studies Depression Scale (CESD-10)	Exclude participants who have a score of ≥ 10 indicating the presence of significant depressive symptoms	May have both a cognitive disorder and a current mood disorder
	Physician diagnosis of a mood disorder	Responds "yes" to "Has a doctor ever told you that you have a mood disorder such as depression (including manic depression), bipolar disorder, mania, or dysthymia? " Responds "yes" to "Has a doctor ever told you that you suffer from major depression?"	x Without data on current mood (e.g., CESD-10 score), unclear if mood disorders are historic or active x Self-reported data may underestimate x May have both a cognitive disorder and a history of mood disorders.

Supplementary Appendix 9, Table 2 – DSM-5 Diagnostic criteria mapped on to CLSA data for major NCD

DSM-5 Diagnostic Criteria	Components of algorithm in the CLSA	Operationalization	Limitations
A – Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition) based on: **3) Concern of the individual, knowledgeable informant, or the clinician** **4) AND/OR substantial impairment in cognitive performance, preferably documented by standardized neuropsychological testing**	Physician diagnosis of dementia or Alzheimer's disease	Responds "yes" to "Has a doctor ever told you that you have dementia or Alzheimer's disease?	Underestimates burden of memory problems
		Prescription for dementia-specific medication including cholinesterase inhibitor, or memantine	Only aware of the medications provided to interviewer by participant
	All participants - Performance on the Rey Auditory Verbal Learning Test (REY1 and REY2), the Animal Fluency Test (AFT2), and the Mental Alternation Test (MAT) Comprehensive cohort participants - the Stroop test, Controlled Oral Word Association Test, and Miami Prospective Memory Tests will additionally be used.	Mean Z score of ≤-2.0 on two or more cognitive tests	**x** CLSA cognitive tests not designed to detect mild/major NCD **x** Missing data due to participant refusing test, technology issues, and other non-participant related factors
B - The cognitive deficits interfere with capacity for independence in everyday activities	Instrumental Activities of Daily Living (IADL)	Participant or proxy reports requiring assistance with one or more of the following activities; grocery shopping, money management, housework, preparing meals, medication management, preparing meals, using	**x** Self-reported, ideal to have informant reported IADLs **x** Mobility, hearing, visions, and physical limitations may explain inability to complete IADLs independently. Basic Activities of Daily Living, self-rated and

		telephone, getting to places out of walking distance.	measured hearing/vision, and physical function tests such as gait speed, the Timed Up and Go, Chair Rise test, balance, and grip strength will be explored to determine if reasons other than problems with cognition may explain the presences of IADL limitations.
C- The cognitive deficits do not occur exclusively in the context of a delirium	Assumed to not be present - participants being seen for a scheduled data collection visit are unlikely to have delirium		The CLSA does not collect this information
D - The cognitive deficits are not better explained by another mental disorders (e.g., major depressive disorder, schizophrenia)	The Centre for Epidemiological Studies Depression Scale (CESD-10)	Participant has a score of ≥ 10 indicating the presence of depressive symptoms	May have both a cognitive disorder and a current mood disorder
	Physical diagnosis of a mood disorder	Responds "yes" to "Has a doctor ever told you that you have a mood disorder such as depression (including manic depression), bipolar disorder, mania, or dysthymia? " Responds "yes" to "Has a doctor ever told you that you suffer from major depression?"	x Without data on current mood (e.g., CESD-10 score), unclear if mood disorders are historic or active x Self-reported data may underestimate x May have both a cognitive disorder and a current or history of mood disorder

Supplementary Appendix 10 – Locally responsible research ethics boards

- Université de Sherbrooke (Project ID 2009-18)
- Hamilton Integrated Research Ethics Board (Project ID 14406)
- Dalhousie University (Project ID 2010-2336)
- University of Manitoba (Project ID H2010:330), McGill University (Project ID A05-E59-10A)
- McGill University Health Centre Research Institute (Project ID: 2018-3497)
- Memorial University of Newfoundland (Project ID 11.003)
- University of Victoria (Project ID 11-320-C)
- Élisabeth Bruyère Research Institute of Ottawa (Project ID M16-10-023)
- University of British Columbia (Project ID H10-02143)
- Island Health (Formerly the Vancouver Island Health Authority, Project ID C2010-80)
- Simon Fraser University (Project ID 2010s0527)
- Calgary Conjoint Health Research Ethics Board (Project E-23489).

BMJ Open

Protocol for validating an algorithm to identify neurocognitive disorders in Canadian Longitudinal Study on Aging participants; an observational study

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Protocol for validating an algorithm to identify neurocognitive disorders in Canadian Longitudinal Study on Aging participants; an observational study

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ABSTRACT

Introduction: In population-based research, disease ascertainment algorithms can be as accurate as, and less costly than, performing supplementary clinical examinations on selected participants to confirm a diagnosis of a neurocognitive disorder (NCD), but they require cohort-specific validation. To optimize the use of the Canadian Longitudinal Study on Aging (CLSA) to understand the epidemiology and burden of NCDs, the CLSA Memory Study will validate an NCD ascertainment algorithm to identify CLSA participants with these disorders using routinely acquired study data.

Methods and analysis: Up to 600 CLSA participants with equal numbers of those likely to have no NCD, mild NCD, or major NCD based on prior self-reported physician-diagnosis of a memory problem or dementia, medication consumption (i.e., cholinesterase inhibitors, memantine) and/or self-reported function will be recruited during the follow-up 3 CLSA evaluations (started August 2021. Participants will undergo an assessment by a study clinician who will also review an informant interview and make a preliminary determination of the presence or absence of an NCD. The clinical assessment and available CLSA data will be reviewed by a Central Review Panel who will make a final categorization of participants as having 1) no NCD; 2) mild NCD; or, 3) major NCD (according to DSM-5 criteria). These will be used as our gold standard diagnosis to determine if the NCD ascertainment algorithm accurately identifies CLSA participants with an NCD. Weighted Kappa statistics will be the primary measure of agreement. Sensitivity, specificity, the C-statistic, and the phi coefficient will also be estimated.

Ethics and dissemination: Ethics approval has been received from the institutional research ethics boards for each CLSA Data Collection Site (Université de Sherbrooke, Hamilton Integrated Research Ethics Board, Dalhousie University, Nova Scotia Health Research Ethics Board, University of Manitoba, McGill University, McGill University Health Centre Research Institute, Memorial University of Newfoundland, University of Victoria, Élisabeth Bruyère Research Institute of Ottawa, University of British Columbia, Island Health (Formerly the Vancouver Island Health Authority, Simon Fraser University, Calgary Conjoint Health Research Ethics Board.

The results of this work will be disseminated to public health professionals, researchers, health professionals, administrators and policy makers through journal publications, conference presentations, publicly available reports, and presentations to stakeholder groups.

Keywords: CLSA, neurocognitive disorders, dementia, algorithm, validation

ARTICLE SUMMARY

- Validation of a neurocognitive disorder case ascertainment algorithm for the Canadian Longitudinal Study on Aging (CLSA) will allow use of this longitudinal and comprehensive database of this large population-based study to explore risk factors, early manifestations, etiology, and trajectory of these disorders.
- Two particular challenges being faced in ascertaining the presence of a neurocognitive disorder are the lack of an informant and the use of cognitive measures that were not selected to diagnose a neurocognitive disorder. Lessons learned in overcoming these obstacles will be of use for other longitudinal studies with similar limitations.
- The results of the blinded clinician assessments and the additional information collected from their identified informant will allow us to refine and improve the accuracy of our case ascertainment algorithm.
- If validated, the neurocognitive disorder case ascertainment algorithm developed for the CLSA is validated cannot be utilized by other population-based studies that differ in the data being collected on participants.

INTRODUCTION

A key challenge in population-based studies in aging is to accurately identify individuals who have neurocognitive disorders (NCDs). A common approach is to utilize a two-stage evaluation based on participants' estimated risk of an NCD. High risk participants and a random sample of those at lower risk undergo a clinical assessment specifically designed to identify NCDs. This approach adds complexity and costs to the study while being burdensome for participants. Relying on self-reports is likely insensitive. The Canadian Study of Health and Aging (CSHA), which used a two-stage evaluation to ascertain the presence of dementia, found that nearly two thirds (64%) of participants identified with prevalent dementia in the study had never seen a physician for a memory problem.[1] This was particularly common among those with mild functional impairment. While administrative data can also be used to estimate the burden of physician diagnosed and documented NCDs, the proportion with undocumented mild and major NCD is significant. [2]

The estimated population-based burden of diagnosed and undiagnosed dementia in Canada is based on data collected two decades ago in the CSHA [1] that does not reflect updated criteria for the diagnosis of mild (mild cognitive impairment) and major (dementia) NCD as described in the fifth version of the Diagnostic and Statistical Manual of Mental Disorders [DSM]-5. [3] Moreover, the increased awareness of NCDs over time may have led to earlier and more comprehensive identification and diagnosis. [4] Previous analyses focused on major NCD, but mild NCD, which is viewed as a precursor to major NCD in many cases, has attracted increasing research interest. Approximately 50% of people with milder degrees of impaired cognition in later life progress to dementia within 5 years [5]. Mild NCD is believed by many to be more likely to respond to disease-modifying interventions, making those with this condition a prime target group for their use. [6–8]

Contemporary estimates of the burden of mild and major NCD including in individuals that have not received a diagnosis is important to the understanding of the epidemiology of these disorders, their risk, and protective factors, associated health outcomes, informing health and social care planning, and possibly leading to improved, proactive care of those living with or at risk for these conditions.

The accuracy of self-reported diagnoses for identifying chronic diseases is dependent on the condition, what is considered the gold standard diagnosis, as well as the population studied. [9–12] To improve the identification of individuals with chronic conditions in observational population-based studies, researchers often create disease ascertainment algorithms. These algorithms include multiple data items such as self-reported diagnosis, disease-specific questionnaires, performance measures, and medication data to classify participants into those with and without diseases. [13] Population-based studies have utilized algorithms to classify individuals as having an NCD or not. The Health and Retirement Study (HRS) found that their algorithms correctly identified 87-94% of participants on dementia status. [14] The Personality and Total Health Through Life Project found that their algorithm had very good performance for identifying major NCD (area under the curve (AUC) of 0.95) and good performance (AUC of 0.76) for identifying mild NCD. [15]

Although the application of algorithms to population-based data has the potential to be cost-effective and meet the need for a standardized and comprehensive identification of cases, because of variability in the studied populations and the data collected on them cohort-specific validation is required. [16] To validate an NCD algorithm, an assessment conducted by a clinician with training to diagnose NCDs is typically used as the gold standard. Ideally this assessment should include a participant interview, cognitive testing, physical examination, and an interview with an informant who knows the participant

well enough to answer questions about their cognition, function, and behaviour. Informant ratings have been found to reveal greater loss of everyday functional ability and cognitive competency than self-reports and are more strongly associated with objective measures of cognitive performance compared to how an individual rates their abilities. [17]

The Canadian Longitudinal Study on Aging (CLSA) is a large (51,338 participants aged 45–85 years at enrolment) national, longitudinal research platform that includes participants from all 10 Canadian provinces. [18] It is being used to address a wide variety of aging-related research challenges including NCD. Disease ascertainment algorithms are already being used in the CLSA for several conditions (e.g., type II diabetes mellitus, parkinsonism, chronic obstructive airway disease, osteoarthritis, coronary artery disease). [13]

To better understand the epidemiology and burden of diagnosed and undiagnosed mild and major NCD in CLSA participants (and by extrapolation the Canadian population), the CLSA Memory Study will be conducted to validate a disease ascertainment algorithm for NCD.

METHODS AND ANALYSIS

Study design and participant eligibility

The CLSA Memory Study will recruit participants from the CLSA. The CLSA is composed of two complementary cohorts that may be studied separately or together (**Figure 1**): (1) Tracking cohort of 21,241 participants randomly selected from within all 10 provinces who are interviewed by telephone, and, (2) Comprehensive cohort of 30,097 participants randomly selected from within 25–50 km of 11 data collection sites (DCSs) across the country who are first interviewed at home and then visit their local DCS for a more in-depth assessment that includes additional interviews, physical measures, and blood and urine samples. Participants are evaluated every 3 years and will be followed for 20 years (until 2033) unless they withdraw, are lost to follow-up, or die.

Consenting CLSA Memory Study participants will be asked to undergo a clinical assessment at a local DCS. For this reason, we will include participants from the Comprehensive cohort as well as Tracking Cohort participants who live within 25-50km of a DCS. CLSA participants unable to visit their local DCS, complete the clinical assessment for any reason (e.g., aphasia, hearing loss), or cannot identify an informant will be excluded from participation.

Patient and public involvement

Participants and the public were not involved in our research design.

Participant selection and recruitment

Participant selection

Prior to being contacted for the CLSA Memory Study, potential participants will be categorized on their presumed cognitive status according to DSM-5 criteria; 1) no NCD; 2) mild NCD; and, 3) major NCD. The categorization will be based on data collected during the CLSA baseline (from 2011-2015), follow-up 1 (conducted from 2015-2018), and follow-up 2 visits (conducted from 2018-2021). This preliminary categorization for participant selection is not the algorithm this project aims to validate.

Participants are **presumed to have a mild NCD** if they have a self-reported physician diagnosis of a memory problem, can both take medicine and manage money without help and have not lost their driver's license or have restrictions on their license other than wearing eyeglasses. Additionally, participants who demonstrated cognitive problems in scheduling or during CLSA DCS visits that were documented by staff will be presumed to have a mild NCD.

Participants are **presumed to have a major NCD** if they meet one or more of the following criteria;

1. Use of prescription medications for the treatment of a major NCD (specifically donepezil, galantamine, rivastigmine, memantine)
2. Self-reported physician diagnosis of dementia or Alzheimer's disease
3. Self-reported physician diagnosis of a memory problem **and** at least one of the following functional limitations;
    - Requires assistance taking medication
    - Requires assistance managing money
    - Among those who formerly drove, no longer having a driver's license or having a driver's license with restrictions other than eyeglasses

Participants that do not meet the criteria for presumed mild or major NCD will be **presumed not to have an NCD.**

Approximately equal numbers from each of the three categories will be recruited, though final recruitment goals will be based on NCD status as determined through the Memory Study (see Statistical Methods section). Participants presumed to have mild or major NCD will first be selected. For 1/3 of the participants presumed to have major NCD and for 2/3 of the participants presumed to have mild NCD, a person of the same age (using participants' age category as of June 1st, 2022 (54-63, 64-73, 74-83, 84+ years) and sex presumed to have no cognitive impairment will be chosen at random.

Participant recruitment

Participants will be recruited into the CLSA Memory Study during CLSA follow-up 3 (started August 2021). Recruitment for the CLSA Memory Study started on August 25th, 2022 and all data collection will be completed by March 31st, 2024. Tracking cohort participants and comprehensive cohort participants who have completed their CLSA follow-up 3 interview will be e-mailed/mailed the participant information package (**Supplementary Appendix 1**). Comprehensive cohort participants that have not yet completed their main CLSA follow-up 3 interview will be given the participant information package during their follow-up 3 in-home interview.

After the participant has received an information package, the local CLSA DCS will contact the participant by phone to determine their interest in the study. Interested participants will complete a short questionnaire to determine if they understand the purpose of the study and what participant entails. Potential participants who, as judged by the interviewer, do not understand the details of the study will be ineligible. There are no additional eligibility criteria for participants selected for this sub-study beyond the general requirements for participation in the CLSA. [18] Eligible participants will provide informed consent, identify and provide contact information for an informant and schedule their clinical assessment (**Supplementary Appendix 2**). If a participant is unable or unwilling to identify an informant, they will not be able to participate in the study.

Informant recruitment

Each participant will be asked to identify a family member or friend that knows them well enough to respond to questions about their cognitive health, ability to complete daily tasks, and behaviour. Potential informants will be provided with a copy of the family member or friend information package (**Supplementary Appendix 3**). The local DCS will contact the identified potential informant by phone prior to the participant's clinical assessment to discuss the study, obtain consent from the informant, and schedule a time to complete the informant interview via phone (**Supplementary Appendix 4**). If the identified informant does not wish to take part in the study, the participant will be contacted and asked to identify an alternative informant.

Measurements

The CLSA Memory Study includes a clinical assessment of the study participant and a phone interview with the informant which will take place between September 2022 and March 2024. This information will be used to provide a provisional study diagnosis of 1) no evidence of cognitive impairment; 2) mild NCD (MCI); or, 3) major NCD (dementia) based on DSM-5 criteria which will be used as the reference standard for which the algorithm will be compared.

Clinical Assessment

The clinical assessments will be conducted by a study clinician (medical specialist or senior trainee in geriatric medicine, geriatric psychiatry, neurology, or psychiatry; internist with training and experience in cognitive assessment; neuropsychologist) who will undergo local and/or virtual training in the performance of the standardized assessment and completion of all required forms. The clinical assessment (**Supplementary Appendix 5)** requires approximately one hour with the participant. It consists of a standardized history and physical examination designed to categorize the participant as having no evidence of an NCD, mild NCD, or major NCD. The study clinician will not have access to CLSA data on the participant other than name, age, sex, gender identity, education, employment status, and occupation and will be blinded to the participant's presumed cognitive status. The clinical assessment has not been designed to determine the likely underlying cause of the NCD, risk of progression, or specific care needs of the participant. The components of the assessment are as follows:

1. Participant interview
    a. Sociodemographic information (age, sex, gender identity, education, occupation, employment status)
    b. History of cognitive decline
    c. Medical history including medical conditions, a review of medications focusing on those with cognitive effects, use of tobacco, cannabis and alcohol, and a family history of dementia
    d. Basic activities of daily living measured using the Older Americans Resource and Services Program (OARS) scale [19]
    e. Instrumental activities of daily living measured using the OARS scale [19] with additional questions regarding transportation (i.e., driving)
    f. Behavioural symptoms including depression measured using the Patient Health Questionnaire-2 [20], anxiety, psychotic symptoms, and changes in personality.

2. Cognitive testing
    a. The Montreal Cognitive Assessment (MoCA) [21] will be used as a general measure of cognition. The MoCA is a brief instrument that has been shown to be a valid screening test for mild (MCI) and major NCD (dementia) [22] with validated versions and

normative data for both English and Quebec-French [23] populations. The MoCA-BLIND version will be used for participants with visual impairments that would prevent them from completing the MoCA. [24] An optional section of the MoCA called the Memory Impairment Score (MIS) will be used to assess uncued and cued (category and multiple-choice options) recall of the memory items. The use of the MoCA total and MoCA-MIS scores with all the other information being collected on participants will be used to help identify participants with mild and major NCD. [25]

3. Physical examination
    a. Alertness
    b. Hearing
    c. Focal/lateralizing neurological findings
    d. Extrapyramidal signs
    e. Balance and gait assessment including transfers, gait, and the Romberg test

Informant Interview

The informant interview will be conducted by CLSA DCS staff using a standardized protocol. All CLSA DCSs have highly trained data collection teams. The informant interview (**Supplementary Appendix 6**) includes several overlapping items to those directly asked of participant. Interview questions will focus on the participant's cognitive, functional, and mood/behavioural history. The components of the interview are as follows:

1. Cognitive changes measured using the eight-item informant interview to differentiate aging and dementia (AD8® Dementia Screening Interview) [26]. The AD8® asks about changes in memory, orientation, judgement, and function that might indicate a dementing illness.

2. Medical history including medical conditions, use of tobacco, cannabis and alcohol, and a family history of dementia

3. Basic activities of daily living measured using the OARS scale [19]

4. Instrumental activities of daily living measured using the OARS scale [19] with additional questions regarding transportation

5. Presence of current mood and psychiatric symptoms using the Mild Behavioural Impairment Checklist (MBI-C). [27]The MBI-C was designed to measure neuropsychiatric symptoms that precede or coincide with the diagnosis of mild cognitive impairment. The instrument measures the domains of 1) decreased motivation; 2) emotional dysregulation; 3) loss of impulse control; 4) social inappropriateness; and, 5) abnormal perception or thought content.

Participant categorization based on clinical assessment and informant interview

Study clinician

Based on the clinical assessment and the informant interview, the study clinician will make a provisional clinical determination of: 1) no evidence of cognitive impairment; 2) mild NCD (MCI); or, 3) major NCD (dementia) based on DSM-5 criteria. [3] All participants that complete the medical assessment will have a provisional clinical determination.

Study physicians will not provide participants with their provisional diagnosis, as to make a clinical diagnosis of mild or major NCD with confidence would require a more in-depth evaluation including review of prior health records, laboratory and/or imaging investigations as well as possible follow-up visits that our study clinicians are unable to provide. The study clinician will verbally tell the participant if there is a potential concern regarding their memory (the term memory will be used to describe any cognitive concern when communicating with the participant) or if they do not have any concerns based on the assessment and informant interview just conducted. The study clinician will tailor the conversation based on the participant's level of understanding and their own degree of concern. Each participant will then be provided with a letter indicating if the clinician identified a potential problem with the participant's memory (**Supplementary Appendix 7**) or no evidence of a potential problem with the participant's memory (**Supplementary Appendix 8**), as well as the participant's total score on the MoCA and details about the CLSA Memory Study. Participants identified by the clinician as having potential concerns about their memory will be encouraged to speak with their family physician and share the information provided verbally and in writing. If the participant does not have a family physician, the study clinician will provide the participant with local resources that the participant may use for follow-up care.

Central Review Panel

A Central Review Panel including medical specialists (e.g., geriatric medicine, geriatric psychiatry, neurology, or psychiatry with training and experience in cognitive assessment) and neuropsychologists will review the clinical assessment, informant interview, and available CLSA data such as performance on the neurocognitive battery conducted at baseline through to the follow-up 2 CLSA assessment (which the examining physician will not have seen). Based on the review of these data, the Panel will make a final study categorization. This will be compared to the one made by the study clinician, and, if different, an explanation for reaching a differing determination will be documented and provided to the examining clinician. The Central Review Panel will help ensure that the study is implemented in a standardized manner across all sites by the participating clinicians. Any concerns will be brought to the attention of the involved clinician and the CLSA Memory Study investigators.

Pilot study and adaptation of recruitment criteria

Prior to the full implementation of the CLSA Memory Study, pilot testing will be conducted on a sample of 10 participants at two DCS sites (Hamilton and Calgary) to 1) identify any issues needing correction and 2) develop implementation advice for all DCS sites. These participants will be included in the final sample with their data retained as study data.

CLSA Memory Study investigators and staff will monitor the number of recruited participants by presumed NCD status, study clinician NCD determinations, and Central Review Panel categorizations at a group level. This monitoring will allow the detection of unbalanced recruitment and the opportunity to adapt the recruitment strategy during the study to ensure we end up with approximately equal number of participants in each NCD diagnostic category based on the Central Review Panel categorizations. For example, if the number of participants determined by the study clinician and/or Central Review Panel to have major NCD is lower than expected, we will start to oversample from the group of participants presumed to have a major NCD to compensate.

CLSA NCD ascertainment algorithm

Development of the CLSA NCD ascertainment algorithm

The CLSA NCD ascertainment algorithm was informed by a systematic review of methods used to identify cases of mild and major NCD in population-based studies (https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=78874). Identified potential items for inclusion were categorized based on DSM-5 criteria and then mapped onto available CLSA data (**Supplementary Appendix 9).** Conditional use (e.g., only include functional data provided by participants who achieve a certain cognitive threshold on the MoCA) and alternative weighting of select items that might improve on the accuracy of the algorithm will be explored in the study.

Participant categorization based on CLSA ascertainment algorithm

The initial validation of the CLSA ascertainment algorithm will include CLSA data from baseline, follow-up 1, and follow-up 2 assessments. The follow-up 2 interview data were collected three or more years before the Memory Study was initiated and may not accurately reflect the current cognitive status for all participants (e.g., for those with new onset neurocognitive disorders). Therefore, final validation of the algorithm will occur when the follow-up 3 assessment data, which were collected at the time of the CLSA Memory Study, are available to the Central Review Panel in 2024. The algorithm will only include previously collected CLSA data and will not include information that was collected as part of the CLSA Memory Study (e.g., informant interview, clinical assessment).

Broadly, the ascertainment algorithm will determine NCD status as; 1) no evidence of cognitive impairment; 2) mild NCD (MCI); or, 3) major NCD (dementia) hierarchically using the criteria identified in **Supplementary Appendix 9**; first identifying participants meeting the DSM-5 criteria for major NCD, then of the remaining participants, identifying those that meet the DSM-5 criteria for mild NCD. The algorithm will then classify participants as either having no evidence of cognitive impairment, or indeterminant for participants with missing data that prevents the algorithm from making a final determination. A version of the algorithm using an imputed dataset which considers other waves of data collection and missing data patterns will also be developed. The imputed algorithm will not have an indeterminant category.

Statistical analyses and sample size determination

Kappa using Cicchetti-Allison weights and the percent of agreement between the reference standard and the CLSA NCD algorithm will be calculated to assess the reliability of the CLSA algorithm. Sensitivity, specificity, and C statistics for the CLSA NCD algorithm for each outcome category (major NCD, mild NCD, or no evidence of cognitive impairment) will be estimated using logistic regression. [28] Analyses will be completed overall and stratified by sex and age-group (age 45-65 years old and 65+) using SAS. We will conduct the analyses using the version of the algorithm with the indeterminate category for participants with missing data as well as using the version of the algorithm with imputed data.

We have calculated the minimum sample size required based on different combinations of Kappa values and precision (distance between the lower and upper 95% confidence limits) (**Table 1**) using the 'kappaSize' Package in R with 3 outcome categories. This package assumed unweighted kappa to provide a conservative sample size estimate. Our final sample size will range between approximately 200 participants assuming an expected Kappa of 0.7 and precision of 0.2, and 600 participants assuming an expected Kappa of 0.7 and a precision of 0.1. Our aspiration is to recruit as close to 600 participants

as possible, but this will be dependent on sufficient funding. We currently have funding confirmed for 320.

Table 1 – Minimum sample size for 95% confidence interval width (0.05, 0.1, 0.15, and 0.2) by Kappa

Kappa	Precision (the distance between the lower and upper 95% confidence limits)	Minimum required total sample size
0.7	0.05	2348
	0.10	619
	0.15	289
	0.20	170
0.8	0.05	1764
	0.10	481
	0.15	231
	0.20	139

ETHICS AND DISSEMINATION

Ethics approval for this project was provided by the Research Ethics Board responsible for each participating site (**Supplementary Appendix 10**).

Our knowledge translation plan includes sharing the results of the project with researchers and health professionals through journal publications and conference presentations. The CLSA will host a webinar on the Memory Study that will be open to researchers, health professionals, public health workers, as well as participants with an interest in NCD research. We will work with other partners to present our results to key groups. The CLSA will develop and disseminate a report that describes the results of the project and implications for health system stakeholders likely to use the results (e.g., health professionals, administrators, policymakers). The report and presentations will be tailored to specific stakeholder groups including those responsible for provincial and national dementia strategies (e.g., Ministerial Advisory Board on Dementia), health professional organizations (e.g., Canadian Geriatrics Society), and health charities (e.g., Alzheimer's Society of Canada). The report will also be available on the CLSA website. The CLSA website and social media platforms will be used to disseminate a summary of the project to participants. It is anticipated that the targets of tailored knowledge translation activities will use the results in various ways including: additional research on risk and protective factors for NCDs; development and implementation of best practices for early intervention and treatment for people with mild and major NCD; and, improving public health surveillance systems that develop population estimates for dementia in Canada that can be used to inform current and future government investment in prevention and care.

DISCUSSION

There are some limitations with the use of CLSA data for developing an NCD ascertainment algorithm. First, CLSA interview data do not include an informant interview on most participants. In clinical settings, informant reports are an important component of the diagnosis of NCDs, as individuals with an NCD may be unaware of their own functional status and behavioural changes. [29] Although the CLSA asks participants over the age of 70 years to identify a proxy, proxy interviews have only been conducted on a small number of participants and under specific conditions. Informant data therefore cannot be used

to inform the algorithm. Another limitation is that the CLSA neurocognitive battery was not developed to diagnose NCDs. [30] Rather, the battery items were selected to be applicable to a wide age range without ceiling or floor effects in order to capture decline over time. The neurocognitive battery items reflect the domains of executive function and memory, but not complex attention, language, perceptual-motor, or social cognition.

There are also several strengths of the CLSA dataset for developing an NCD ascertainment algorithm. The breadth of routinely collected CLSA data (e.g., balance and gait performance measures, trajectory of changes in cognitive test performance) and the high percentage of participants (~88%) that have provided permission to the CLSA data to be linked to health care administrative databases provides an opportunity to explore the creation of an expanded and superior NCD ascertainment algorithm. Having a relatively large (up to 600) group of participants who have gone through a gold standard assessment for NCDs will make this effort possible.

CONCLUSION

If the results of the CLSA Memory Study suggest that the proposed NCD ascertainment algorithm is a valid method of identifying NCD cases, it will be applied to all CLSA participants. This will enhance the CLSA dataset for NCD research and provide important insights regarding the risk and protective factors of NCD and associated health outcomes. Linkage to healthcare administrative databases will allow the CLSA to estimate the burden of mild and major NCD in Canada. Together, these sources of data will help inform health and social care planning for individuals with NCD.

Authorship: The following are members of the CLSA Memory Study Working Group: Andrew Costa, Benoit Cossette, Lauren E. Griffith, David B. Hogan, Aaron Jones, Susan Kirkland, Teresa Liu-Ambrose, Jinhui Ma, Alexandra J. Mayhew, Jacqueline McMillan, Verena Menec, Gerry Mugford, Megan E. O'Connell, Theone Paterson, Christopher Patterson, Parminder Raina, Eric E. Smith, Vanessa Taler, Mary Thompson, Andrew Wister, Christina Wolfson, & Changbao Wu.

Author Contributions: LEG, PR, AC, and DH led the conceptualization of the study methodology. AJM made contributions to the design of the study methods and wrote the first draft of the manuscript. CW, AJ, SK, MO, VT, EES, TL-A, JM, MT, CW, HC made contributions to the design of the study methods and supported the manuscript. All authors critically revised the manuscript, approved the final version, and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved

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REFERENCES

1 Sternberg SA, Wolfson C, Baumgarten M. Undetected dementia in community-dwelling older people: The Canadian study of health and aging. *J Am Geriatr Soc* 2000;**48**:1430–4. doi:10.1111/j.1532-5415.2000.tb02633.x

2 Lang L, Clifford A, Wei L, *et al.* Prevalence and determinants of undetected dementia in the community: A systematic literature review and a meta-analysis. *BMJ Open* 2017;**7**:1–8. doi:10.1136/bmjopen-2016-011146

3 American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*. American Psychiatric Association Publishing 2013.

4 Tang W, Kannaley K, Friedman DB, *et al.* Concern about developing Alzheimer's disease or dementia and intention to be screened: An analysis of national survey data. *Arch Gerontol Geriatr* 2017;**71**:43–9. doi:10.1016/j.archger.2017.02.013

5 Tuokko H, Frerichs RJ. Cognitive impairment with no dementia (CIND): Longitudinal studies, the findings, and the issues. *Clinical Neuropsychologist* 2000;**14**:504–25. doi:10.1076/clin.14.4.504.7200

6 U.S. Department of Health and Human Services Food and Drug Administration. Early Alzheimer's Disease: Developing Drugs for Treatment -Guidance for Industry. 2018. https://www.fda.gov/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/default.htm

7 van Dyck CH, Swanson CJ, Aisen P, *et al.* Lecanemab in Early Alzheimer's Disease. *N Engl J Med* Published Online First: 29 November 2022. doi:10.1056/NEJMoa2212948

8 Getsios D, Blume S, Ishak KJ, *et al.* An economic evaluation of early assessment for Alzheimer's disease in the United Kingdom. *Alzheimer's and Dementia* 2012;**8**:22–30. doi:10.1016/j.jalz.2010.07.001

9 Stoye G, Zaranko B. IFS Working Paper W20/13 How accurate are self-reported diagnoses? Comparing self-reported health events in the English Longitudinal Study of Ageing with administrative hospital records How accurate are self-reported diagnoses? Comparing self-reported health events in the English Longitudinal Study of Ageing with administrative hospital records. 2020.

10 Smith B, Chu LK, Smith TC, *et al.* Challenges of self-reported medical conditions and electronic medical records among members of a large military cohort. *BMC Med Res Methodol* 2008;**8**:1–10. doi:10.1186/1471-2288-8-37

11 Okura Y, Urban LH, Mahoney DW, *et al.* Agreement between self-report questionnaires and medical record data was substantial for diabetes , hypertension , myocardial infarction and stroke but not for heart failure. 2004;**57**:1096–103. doi:10.1016/j.jclinepi.2004.04.005

12 Payette Y, de Moura C, Boileau C, *et al.* Is there an agreement between self-reported medical diagnosis in the CARTaGENE cohort and the Québec administrative health databases? *Int J Popul Data Sci* 2019;**5**.

13 Oremus M, Postuma R, Griffith L, *et al.* Validating chronic disease ascertainment algorithms for use in the Canadian Longitudinal Study on Aging. *Canadian Journal on Aging* 2013;**32**:232–9. doi:10.1017/S0714980813000275

14 Gianattasio KZ, Wu Q, Glymour MM, *et al.* Comparison of Methods for Algorithmic Classification of Dementia Status in the Health and Retirement Study. *Epidemiology* 2019;**30**:291–302. doi:10.1097/EDE.0000000000000945

15 Eramudugolla R, Mortby ME, Sachdev P, *et al.* Evaluation of a research diagnostic algorithm for DSM-5 neurocognitive disorders in a population-based cohort of older adults. *Alzheimers Res Ther* 2017;**9**:1–12. doi:10.1186/s13195-017-0246-x

16 Wilkinson T, Ly A, Schnier C, *et al.* Identifying dementia cases with routinely collected health data: A systematic review. *Alzheimer's and Dementia* 2018;**14**:1038–51. doi:10.1016/j.jalz.2018.02.016

17 Rueda A, Lau K, Saito N, *et al.* Self-rated and informant-rated everyday function in comparison to objective markers of Alzheimer's disease. *Alzheimers Dement* 2016;**11**:1080–9. doi:10.1016/j.jalz.2014.09.002.Self-rated

18 Raina PS, Wolfson C, Kirkland SA, *et al.* Cohort profile: The Canadian Longitudinal Study on Aging (CLSA). *Canadian Journal on Aging* 2009;**28**:221–9. doi:10.1017/S0714980809990055

19 Fillenbaum G, Smyer M. The development, validity, and reliability of the OARS Multidimensional Functional Assessment Questionnaire. *J Gerontol* 1981;**36**:428–34.

20 Kroenke K, Spitzer RL, Williams JBW. The Patient Health Questionnaire-2 Validity of a Two-Item Depression Screener. *Med Care* 2003;**41**:1284–92.

21 Nasreddine ZS, Phillips NA, Bédirian V, *et al.* The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. *J Am Geriatr Soc* 2005;**53**:695–9. doi:10.1111/j.1532-5415.2005.53221.x

22 Tsoi KKF, Chan JYC, Hirai HW, *et al.* Cognitive tests to detect dementia a systematic review and meta-analysis. *JAMA Intern Med* 2015;**175**:1450–8. doi:10.1001/jamainternmed.2015.2152

23 Larouche E, Tremblay MP, Potvin O, *et al.* Normative Data for the Montreal Cognitive Assessment in Middle-Aged and Elderly Quebec-French People. *Archives of Clinical Neuropsychology* 2016;**31**:819–26. doi:10.1093/arclin/acw076

24 Wittich W, Phillips N, Nasreddine ZS, *et al.* Sensitivity and specificity of the Montreal cognitive assessment modified for individuals who are visually impaired. *J Vis Impair Blind* 2010;**104**:360–8. doi:10.1177/0145482x1010400606

25 Julayanont P, Brousseau M, Chertkow H, *et al.* Montreal Cognitive Assessment Memory Index Score (MoCA-MIS) as a predictor of conversion from mild cognitive impairment to Alzheimer's disease. *J Am Geriatr Soc* 2014;**62**:679–84. doi:10.1111/jgs.12742

26 Galvin JE, Roe CM, Powlishta KK, *et al.* The AD8: A brief informant interview to detect dementia. *Neurology* 2005;**65**:559–64. doi:10.1212/01.wnl.0000172958.95282.2a

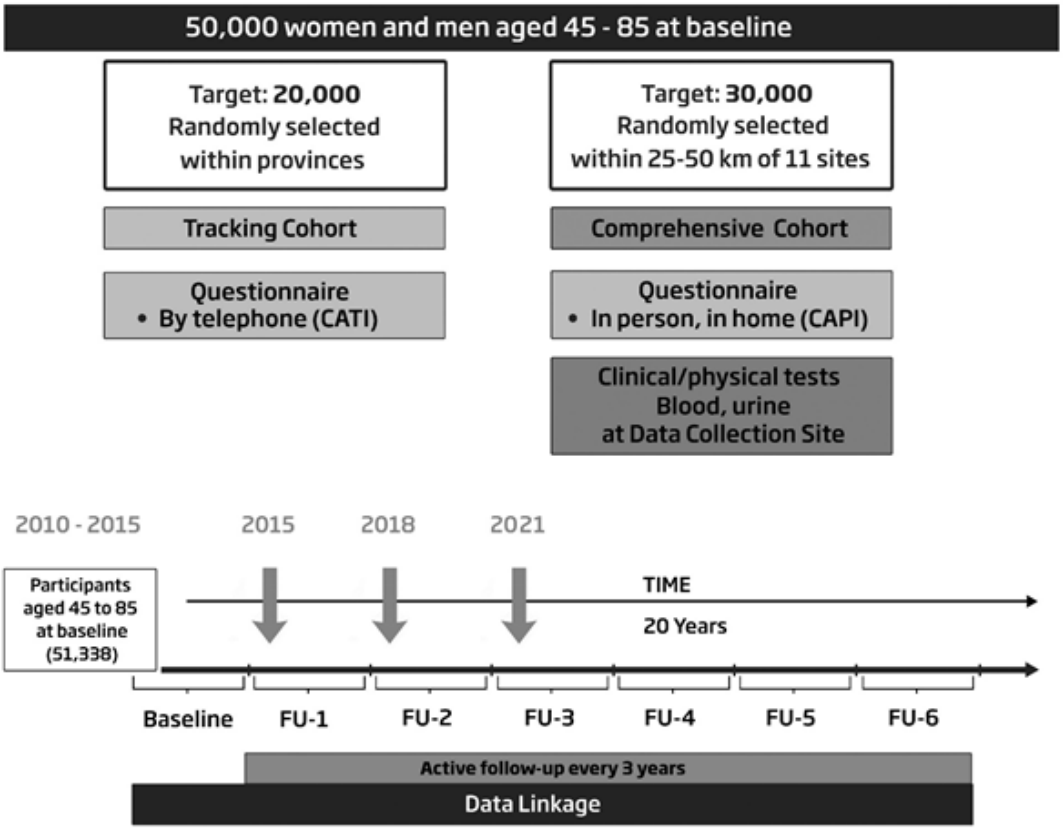
27 Ismail Z, Aguera-Ortiz L, Brodaty H, *et al.* The mild behavioral impairment checklist (MBI-C): A rating scale for neuropsychiatric symptoms in pre-dementia populations. *Journal of Alzheimer's Disease* 2017;**56**:929–38. doi:10.3233/JAD-160979.The

28 Cook R, Farewell V. Conditional inference for subject specific and marginal agreement. Two families of agreement measures. *Canadian Journal of Statistics* 1995;**23**:333–44.

29 Schinka JA. Use of informants to identify mild cognitive impairment in older adults. *Curr Psychiatry Rep* 2010;**12**:4–12. doi:10.1007/s11920-009-0079-9

30 Tuokko H, Griffith LE, Simard M, *et al.* Cognitive measures in the Canadian Longitudinal Study on Aging. *Clin Neuropsychol* 2017;**4046**:1–18. doi:10.1080/13854046.2016.1254279

Figure 1. CLSA Study Design: The CLSA Memory Study will recruit Comprehensive Cohort and Tracking Cohort participants who are currently undergoing their follow-up three assessment (started August 2021) for the CLSA.


50,000 women and men aged 45 - 85 at baseline
Target: 20,000
Randomly selected
within provinces
Target: 30,000
Randomly selected
within 25-50 km of 11 sites
Tracking Cohort
Comprehensive Cohort
Questionnaire
• By telephone (CATI)
Questionnaire
• In person, in home (CAPI)
Clinical/physical tests
Blood, urine
at Data Collection Site
2010 - 2015
2015
2018
2021
Participants
aged 45 to 85
at baseline
(51,338)
TIME
20 Years
Baseline
FU-1
FU-2
FU-3
FU-4
FU-5
FU-6
Active follow-up every 3 years
Data Linkage

clsa élcv
Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

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

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Étude longitudinale canadienne sur le vieillissement

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.

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.

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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.

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 STUDY INFORMATION PACKAGE

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

Principal Investigators:

Dr. Lauren Griffith, Department of Health Research Methods, Evidence, and Impact, McMaster University

Dr. Andrew Costa, Department of Health Research Methods, Evidence, and Impact, McMaster University

Dr. Parminder Raina, Department of Health Research Methods, Evidence, and Impact, McMaster University

Co-Investigators:

Newfoundland and Labrador
Dr. Gerry Mugford – Memorial University

Nova Scotia
Dr. Susan Kirkland – Dalhousie University

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

Ontario
Dr. Cynthia Balion – McMaster University
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).

BRITISH COLUMBIA

BURNABY
Office of Research Ethics
Simon Fraser University
8888 University Drive
Multi-Tenant Facility
Burnaby BC V5A 1S6
Phone: (778) 782-6593
E-mail: dore@sfu.ca

VICTORIA
Human Research Ethics Office of Research Services
University of Victoria
Administrative Services Building (ASB), Room B202
PO Box 1700 Stn CSC
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VANCOUVER
University of British Columbia
Office of Research Services
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Vancouver BC V6T 1Z3
Phone: toll free 1-877-822-8298
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Vancouver Island Health Authority
Research Ethics and Compliance Office
Queen Alexandra Centre, Main Building Room 205
2400 Arbutus Road
Victoria BC V8N 1V7
Phone: (250) 519-6726

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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 Integrated Research Ethics Board (HiREB)
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Phone: (905) 521-2100 ext. 42013

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Health Research Ethics Authority
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St. John's NL, A1B 2X5
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Supplementary Appendix 2 – Participant Consent Scripts

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.

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

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. 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

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**

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**

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**

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.

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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**

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 in 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**

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

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]

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.

Disagree _____ **Go to Refusal**

Agree _____ **Continue**

PARCON5 I understand that I can withdraw my consent at any time. If a 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

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.

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.

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.

MEDICAL ASSESSMENT BOOKING

PARMED_1 Would you like to schedule a time for your medical assessment with the study physician?

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.

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

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

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**

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**

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**

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 in 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**

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

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]

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.

Disagree _____ **Go to Refusal**

Agree _____ **Continue**

PARCON5 I understand that I can withdraw my consent at any time. If a 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.

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.

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.

MEDICAL ASSESSMENT BOOKING

PARMED_1 Would you like to schedule a time for your medical assessment with the study physician?

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.

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Supplementary Appendix 3 – Informant Information Package

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Family Member or Friend Information Package Cover Letter

Dear [Informant],

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.

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 at a time convenient to you.

This study of the CLSA is 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 is/This package contains] the **Family Member or Friend Study Information Package** that will provide you with information to help you make an informed choice about if you would like to take part in this study.

Please read the **Family Member or Friend Study Information Package** carefully. We will call you in the next couple of weeks and you will have an opportunity to ask any questions you may have.

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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FAMILY MEMBER OR FRIEND STUDY INFORMATION PACKAGE

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

Principal Investigators:

Dr. Lauren Griffith, Department of Health Research Methods, Evidence, and Impact, McMaster University

Dr. Andrew Costa, Department of Health Research Methods, Evidence, and Impact, McMaster University

Dr. Parminder Raina, Department of Health Research Methods, Evidence, and Impact, McMaster University

Co-Investigators:

Newfoundland and Labrador
Dr. Gerry Mugford – Memorial University

Nova Scotia
Dr. Susan Kirkland – Dalhousie University

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

Ontario
Dr. Cynthia Balion – McMaster University
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 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.

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- 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.

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- 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.

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- 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	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 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.

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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) 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).

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St. JOHN'S
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St. John's NL, A1B 2X5
Phone: (709) 777-6974

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

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**

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**

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

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Supplementary Appendix 5 - Medical Assessment

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

v1.2, 2022 October 20th

Table of Contents

Sociodemographic Information (SDC)

Overview	These questions obtain basic sociodemographic information from the participant. They function as an interview icebreaker and, by comparison with the most recent response for each question from the main CLSA interviews when available, a check on their remote memory. Clinicians are expected to complete all items in this module. However, they have flexibility in determining the order in which the questions are asked and the specific wording used for each question.

SDC_1	**SDC_AGEBL_MSP**
Participant's age in years – based on date of birth provided at CLSA Baseline	
CLINICIAN NOTE: If there is no response shown for this item, the participant did not answer this question at baseline.	
NUMBER	_____ [CALCULATED BY PINE USING BASELINE CLSA DATA – AGE_DOB_COM]

SDC_2	**SDC_AGE_MSP**	
[ALWAYS ASK]		
What is the participant's **self-reported** age in years?		
NB_SP	Age	_____ **[MASK: MIN=53, MAX=94]**
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

SDC_3	**SDC_SEXBL_MSP**
Participant's sex – self-reported at CLSA baseline	
CLINICIAN NOTE: If there is no response shown for this item, the participant did not answer this question at baseline.	
GENDER	_____ [IMPUTED BY PINE USING BASELINE CLSA DATA – SEX_ASK_COM. IF EMPTY, ANSWER 'DATA UNAVAILABLE']

SDC_4	SDC_GENDER_MSP	
[ALWAYS ASK]		
What is the participant's **self-reported** gender identity?		
CODE ONLY ONE RESPONSE		
MALE	1	Male
FEMALE	2	Female
TRANSMAN	3	Transgender Man/Transman
TRANSWOMAN	4	Transgender Women/Transwoman
GENDERQUEER	5	Genderqueer
OTSP	7	Other (please specify: _____)
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

SDC_5	SDC_EDU4BL_MSP
[ALWAYS ASK]	
Participant's education – self-reported at CLSA Baseline	
CLINICIAN NOTE: If there is no response shown for this item, the participant did not answer this question at baseline.	
EDU4	_____ [IMPUTED BY PINE USING BASELINE CLSA DATA **1 = Less than secondary school graduation** – code if: ED_ELHS_COM = (1, 2, 3) and ED_HSGR_COM = 2 and ED_OTED_COM = 2 **2 = Secondary school graduation, no post-secondary secondary education** – code if: ED_HSGR_COM = 1 and ED_OTED_COM = 2 **3 = Some post-secondary education** – code if: ED_HIGH_COM = 01 **4 = Post-secondary degree/diploma** – code if: 02≤ED_HIGH_COM≤06 or ED_HIGH_COM = 97 **9 = At least one required question as not answered** – code if: ED_ELHS_COM = (8,9, EMPTY) or ED_HSGR_COM = (8,9, EMPTY) or ED_OTED_COM = (7,8,9, EMPTY) or ED_HIGH_COM = (98,99, EMPTY)]

SDC_6	SDC_EDU_MSP	
[ALWAYS ASK]		
What is the participant's **self-reported** highest level of education?		
CODE ONLY ONE RESPONSE		
LESS_SEC	1	Less than secondary school graduation
SEC	2	Secondary school graduation, no post-secondary education
SOME_POST	3	Some post-secondary education
POST_SEC	4	Post-secondary degree/diploma
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

SDC_7	SDC_LBF_MSP	
[ALWAYS ASK]		
What is the participant's **self-reported** employment status?		
CODE ONLY ONE RESPONSE		
COM_RET	1	Completely retired
PAR_RET	2	Partly retired
NOT_RET_WORK	3	Not retired and currently working
NOT_RET_NO_WORK	4	Not retired and not currently working
NEVER_WORKED	5	Never held a paid job
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

SDC_8	**SDC_OCCBL_MSP**
[ASK IF SDC_LBF_MSP ≠ NEVER_WORKED]	
Type of job participant did for the longest period of time – self-reported at CLSA Baseline	
CLINICIAN NOTE: Please note that this is not the "main occupation" of the participant. Rather it is the job at which the participant had worked at the longest. If there is no response shown for this item, the participant did not answer this question at baseline.	
OCC_TYPE	_____ [IMPUTED BY PINE USING BASELINE CLSA DATA **Never worked** – code if: LBF_EVER_COM = "NO" **[open text for LFP_TYPE_SP_COM]** – code if: (RET_RTRD_COM = 1 or RET_RTRD_COM = 2) and LFP_LNGST_COM = 1 **[open text for LFP_LGTYPE_SP_COM]** – code if: (RET_RTRD_COM = 1 or RET_RTRD_COM = 2) and LFP_LNGST_COM = 2 **[open text for LBF_TYPE_NB_COM]** – code if: RET_RTRD_COM = 3 and LBF_LGEVER_COM = 2 **[open text for LBF_LGTYPE_SP_COM]** – code if: RET_RTRD_COM = 3 and LBF_LGEVER_COM = 1 **Data unavailable** – code if: ALL required questions do not fit into categories above, or ALL are DK_NA or REFUSED or not answered/missing data

SDC_9	**SDC_OCC_MSP**
[ASK IF SDC_LBF_MSP = COM_RET, PAR_RET, NOT_RET_WORK, or NOT_RET_NO_WORK]	
What is the participant's **self-reported** primary occupation?	

CLINICIAN NOTE: Provide a brief description of the occupation. Please note, this question refers to the primary occupation of the participant while the previous question from the main CLSA interview refers to the occupation that the participant did for the longest period of time.		
OCC_SP	Occupation	_____
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

SDC_10	**SDC_NOTES_MSP**	
[ALWAYS ASK]		
Do you have any additional notes to include for this module? For example, are there any other sociodemographic characteristics that should be taken into account when interpreting the results of the cognitive testing?		
YES	1	Yes
NO	2	No

SDC_11	**SDC_NOTESSP_MSP**
[ASK IF SDC_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any relevant notes (e.g., how congruent the participant's responses were to previously collected information) below:	

SDC_END

Cognitive Status (COG)

Overview	The purpose of this section is to assess if the participant has experienced cognitive decline. Participants that report the presence of cognitive decline will be asked to provide details regarding the onset, progression, and symptoms related to the cognitive decline. Clinicians are expected to complete all items in this module. However, they have flexibility in determining the order in which the questions are asked and the specific wording used for each question.

COG_1	**COG_DEC_MSP**	
[ALWAYS ASK]		
Has the participant reported experiencing cognitive decline?		
CLINICIAN NOTE: This question should be asked directly to the participant.		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

COG_2	**COG_YRS_MSP**	
[ASK IF COG_DEC_MSP = YES]		
How many years has the participant reported experiencing cognitive decline?		
CLINICIAN NOTE: This question should be asked directly to the participant. Please provide the number of years.		
LESS_YR	001	Less than one year
YEARS	Years	**____ [MASK: MIN=1, MAX=PARTICIPANT'S AGE]**
DK_NA	998	**[DO NOT READ]** Don't know / No answer
REFUSED	999	**[DO NOT READ]** Refused

COG_3	**COG_SEV_MSP**

[ASK IF COG_DEC_MSP = YES]		
The participant describes the severity of their cognitive decline as…		
CODE ONLY ONE RESPONSE		
CLINICIAN NOTE: This question should be asked directly to the participant.		
IRRT	1	Present and may be an irritant but not a concern of theirs
WORR	2	Worrisome but not having overt impact on daily life
IMPT	3	Having an impact on their life (e.g., occupation, autonomy/independence)
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

COG_4	**COG_ONS_MSP**	
[ASK IF COG_DEC_MSP = YES]		
The participant believes the onset of their cognitive decline was…		
CODE ONLY ONE RESPONSE		
GRAD	1	Gradual
ABRT	2	Abrupt
DK_NA	8	[DO NOT READ] Don't know / No answer
REFUSED	9	[DO NOT READ] Refused

COG_5	**COG_VAS_MSP**	
[ASK IF COG_ONS_MSP = ABRT]		
The participant believes their cognitive decline was related to a cerebrovascular event.		
YES	1	Yes
NO	2	No
DK_NA	8	[DO NOT READ] Don't know / No answer
REFUSED	9	[DO NOT READ] Refused

COG_6	**COG_PRO_MSP**
[ASK IF COG_DEC_MSP = YES]	

The participant believes the trajectory of their cognitive impairment was…		
CODE ONLY ONE RESPONSE		
NONE	1	Improvement/none-stability after onset
GRAD	2	Gradual or insidious progression
STEP	3	Stepwise progression
FLUC	4	Fluctuating
DK_NA	8	[DO NOT READ] Don't know / No answer
REFUSED	9	[DO NOT READ] Refused

COG_7	**COG_NOTES_MSP**	
[ALWAYS ASK]		
Do you have any additional notes to include for this module (e.g., whether you concur with the participant's perceptions of presence, severity, onset, and progression of any cognitive decline)?		
YES	1	Yes
NO	2	No

COG_8	**COG_NOTESSP_MSP**
[ASK IF COG_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

COG_END

Medical History (MED)

Overview	The medical history module captures information that will assist the examining physician in determining if any observed cognitive limitations are secondary to medical conditions such as neurodegenerative diseases. This information may also increase the confidence in the physician's diagnosis based on the absence or presence of risk factors for neurocognitive disorders. Clinicians are expected to complete all items in this module. However, they have flexibility in determining the order in which the questions are asked and the specific wording used for each question.

MED_1	MED_CON_MSP	
[ALWAYS ASK]		
Does the participant have any of the following medical conditions?		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96, 98 OR 99 ARE SELECTED), CODE ALL THAT APPLY		
CAD	1	Coronary artery disease
HF	2	Heart failure
AF	3	Atrial fibrillation/flutter
TIA	4	Transient ischemic attack (TIA)
STR	5	Cerebrovascular accident (stroke)
HEM	6	Intracerebral hemorrhage
HYP	7	Hypertension
DIA	8	Diabetes mellitus
DYS	9	Dyslipidemia
PKD	10	Parkinson's Disease or Parkinsonism
DEP	11	Depression
ANX	12	Anxiety disorder
PSY	13	Psychotic illness
HR	14	Hearing impairment
VS	15	Visual impairment
SM	16	Impaired sense of smell
DEM	17	Dementia
DELI	18	Suspected delirium (in the past 5 years)
IN	19	Insomnia
REM	20	REM-Sleep Behaviour Disorder
OSA	21	Obstructive Sleep Apnea
HYPT	22	Hypothyroidism
B12	23	Vitamin B12 deficiency
OTSP	24	Other conditions relevant to cognitive status (e.g. cancer and/or cancer treatments); specify _____
NONE	96	None of the above
DK_NA	98	**[DO NOT READ]** Don't know / No answer
REFUSED	99	**[DO NOT READ]** Refused

MED_2	MED_TBI_MSP	
[ALWAYS ASK]		
Has the participant suffered a head injury or a concussion in the past?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_3	MED_TBI1_MSP	
[ASK IF MED_TBI_MSP = YES]		
How many head injuries or concussions has the participant had in his/her lifetime?		
CLINICIAN NOTES: If the informant cannot remember exact number, please probe for their best estimate		
TBI_NUM	Number	_____ **[MASK: MIN=1]**
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_4	MED_TBI2_MSP	
[ASK IF MED_TBI_MSP = YES]		
At what age or in what year did the participant have the most serious head injury?		
CLINICIAN NOTES: If the informant cannot remember the specific year, please probe for their best estimation of when the head injury occurred.		
YR_SP	Year	_____ **[MASK: MIN=BIRTH YEAR, MAX=CURRENT YEAR]**
NB_SP	Age	_____ **[MASK: MIN=1, MAX=CURRENT AGE]**
DK_NA	998	**[DO NOT READ]** Don't know / No answer
REFUSED	999	**[DO NOT READ]** Refused

MED_5	MED_TBI3_MSP	
[ASK IF MED_TBI_MSP = YES]		
Did the most serious head injury result in…?		
READ LIST, MULTIPLE RESPONSES ALLOWED (EXCEP IF 6, 8 OR 9 ARE SELECTED), CODE ALL THAT APPLY		
DZ	1	Being dazed, confused, or “seeing stars”
DRM	2	Not remembering the injury
KO	3	Losing consciousness (knocked out)
NONE	6	Head injury did not result in any of the above
DK_NA	8	**[DO NOT READ]** Don’t know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_6	MED_TBI4_MSP	
[ASK IF MED_TBI3_MSP = KO]		
How long did you lose consciousness for?		
READ LIST, CODE ONLY ONE RESPONSE		
KO1	1	Less than a minute
KO20	2	1-20 minutes
KO20MORE	3	Longer than 20 minutes
DK_NA	8	**[DO NOT READ]** Don’t know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_7	MED_MED2_MSP
[ALWAYS ASK]	
Which of the following medications is the participant currently taking?	
MULTIPLE RESPONSES ALLOWED (EXCEP IF 96, 98 OR 99 ARE SELECTED), CODE ALL THAT APPLY	
CLINICIAN NOTES: If the participant does not bring in a list of medications or the medications themselves for review, please select option "Don't know / No answer". If you feel that the medication is an essential data element, you can ask if you can call the participant after the assessment when they are home and have access to their medications. Alternatively, you may also ask the participant if he/she would like you to contact the informant about which medications are being used. **To determine if a medication has moderate to high anticholinergic activity, please refer to: https://www.rxfiles.ca/rxfiles/uploads/documents/Psyc-anticholinergic-Ref%20List%20SPDP-complete.pdf** **If the participant is taking a medication with moderate/high anticholinergic activity that also falls under another listed category, please select both options. For example, if a participant is taking desipramine for the treatment of depression, select the options "anti-depressants" and "drugs with moderate/high anticholinergic activity".** **If the participant is not taking a medication regularly but rather as required, please include details in the "Notes" section at the end of this module.**	

DEP	01	Anti-depressants (whether used for depression, anxiety or other reason)
PSY	02	Anti-psychotics
SED	03	Hypnotics and sedatives (whether used for insomnia, anxiety or other reason)
CHL	04	Drugs with moderate/high anticholinergic activity including prescribed and over the counter medications
CON	05	Anticonvulsants
PKD	06	Antiparkinsonian
OPI	07	Opioids
COG	08	Cognitive enhancers (cholinesterase inhibitor, memantine)
OT	09	Other medication that you think may affect cognition: Specify:_____
NONE_	96	None of the above
DK_NA	98	**[DO NOT READ]** Don't know / No answer
REFUSED	99	**[DO NOT READ]** Refused

MED_8	MED_SMKSTATUS_MSP
[ALWAYS ASK]	
What is the participant's smoking status…?	
READ LIST, CODE ONLY ONE RESPONSE	

YES	1	Yes, he/she currently smokes
NEVER	2	No, he/she does not currently smoke and never has
FORM_DAY	4	Former daily smoker (non-smoker now)
FORM_OCC	5	Former occasional smoker (non-smoker now)
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_9	**MED_CAN_MSP**	
[ALWAYS ASK]		
Does the participant use any cannabis products?		
CODE ONLY ONE RESPONSE		
YES	1	Yes, he/she currently uses cannabis products
NEVER	2	No, he/she does not and has never used cannabis products
FORMER	3	Former cannabis user, but does not use cannabis products now
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_10	**MED_ALC_MSP**	
[ALWAYS ASK]		
What is the participant's drinking status?		
CODE ONLY ONE RESPONSE		
NEVER	1	Never drank alcohol
FORMER	2	Used to drink alcohol but does not currently drink
CURRENT	3	Currently consumes alcohol
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_11	**MED_ALCNMB_MSP**	
[ASK IF MED_ALC_MSP = CURRENT]		
A "standard" drink is considered 12 ounces of regular beer (~5% alcohol), 5 ounces of wine (~12% alcohol), or 1.5 ounces of distilled spirits (~40% alcohol). How many estimated standardized drinks per week does the participant consume?		
ALC_NB	Number	_____ **[MASK: MIN=0, MAX=200]**
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_12	MED_ALCMLFQ_MSP	
[ASK IF MED_ALC_MSP = CURRENT AND SDC_SEXBL_MSP = MALE]		
In the past 12 months, has the participant consumed 5 or more drinks in 2 hours at least once a month?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_13	MED_ALCFMFQ_MSP	
[ASK IF MED_ALC_MSP = CURRENT AND SDC_SEXBL_MSP = FEMALE]		
In the past 12 months, has the participant consumed 4 or more drinks in 2 hours at least once a month?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_14	MED_FAM_MSP	
[ALWAYS ASK]		
Does the participant have a first degree relative who has been diagnosed with dementia or Alzheimer's Disease?		
CLINICIAN NOTE: First degree relatives include biological parents, siblings, or children		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_15	MED_NOTES_MSP
[ALWAYS ASK]	

Do you have any additional notes to include for this module? For example, are there any other details regarding the participant's medical history that should be taken into account when interpreting the results of the cognitive testing such as the use of non-prescription drugs?		
YES	1	Yes
NO	2	No

MED_16	**MED_NOTESSP_MSP**
[ASK IF MED_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

MED_END

Basic Activities of Daily Living (ADL)

This module contains a subset of the Activities of Daily Living questions of the OARS Multidimensional Assessment Questionnaire© developed by Dr. Gerda G. Fillenbaum (Duke University Medical Center). The Canadian Longitudinal Study on Aging received permission from Dr. Fillenbaum (instrument developer) for the use of this instrument.

Overview	Activities of daily living assess respondents' ability to perform basic daily activities. Activities of daily living are the tasks considered vital to live independently in the community. This module contains key activities relevant to neurocognitive disorders and is a subset of the list of questions asked to the informant regarding the participant's ability to perform activities independently. The informant supplied data will in most cases be used to determine the participant's functional abilities. Exceptions would include where the informant is not able to respond to the functional questions or where the accuracy of the information they provide is judged less reliable that the information provided by the participant. Clinicians are expected to complete all items in this module. However, they have flexibility in determining the order in which the questions are asked and the specific wording used for each question.

Now I'd like to ask you about activities of daily living. You may feel that some of these questions do not apply to you, but it is important that we ask the same questions of everyone.

ADL_1	**ADL_ABLDR_MSP**	
[ALWAYS ASK]		
Can you dress and undress yourself without help (including picking out clothes and putting on socks and shoes)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_2	**ADL_HPDR_MSP**	
[ASK IF ADL_ABLDR_MSP = NO]		
Can you dress and undress yourself with some help?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_3	**ADL_UNDR_MSP**	
[ASK IF ADL_HPDR_MSP = NO]		
Are you completely unable to dress and undress yourself?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_4	**ADL_ABLBT_MSP**	
[ALWAYS ASK]		
Can you take a bath or shower without help?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_5	**ADL_HPBT_MSP**	
[ASK IF ADL_ABLBT_MSP = NO]		
Can you take a bath or shower with some help (i.e., you need help from someone getting in and out of the tub or you need special attachments on the tub)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_6	**ADL_UNBT_MSP**	
[ASK IF ADL_HPBT_MSP = NO]		
Are you completely unable to take a bath and a shower by yourself?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_7	**ADL_BATH_MSP**	
[ALWAYS ASK]		
Do you ever have trouble getting to the bathroom in time?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_8	**ADL_INCNT_MSP**	
[ASK IF ADL_BATH_MSP = YES]		
How often do you wet or soil yourself (either day or night)? Would you say…		
READ LIST, CODE ONLY ONE RESPONSE		
0_1_TIME_WEEK	1	Never or less than once a week
1_2_TIME_WEEK	2	Once or twice a week
3_MORE_TIMES_WEEK	3	Three times a week or more
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_9	**ADL_NOTES_MSP**	
[ALWAYS ASK]		
Do you have any additional notes to include for this module?		
YES	1	Yes
NO	2	No

ADL_10	**ADL_NOTES_SP_MSP**
[ASK IF ADL_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

ADL_END

Instrumental Activities of Daily Living (IADL)

This module contains a subset of the Activities of Daily Living questions of the OARS Multidimensional Assessment Questionnaire© developed by Dr. Gerda G. Fillenbaum (Duke University Medical Center). The Canadian Longitudinal Study on Aging received permission from Dr. Fillenbaum (instrument developer) for the use of this instrument.

Overview	The Instrumental Activities of Daily Living (IADL) scale assesses respondents' ability to independently perform a series of daily activities. This module contains key instrumental activities of daily living relevant to neurocognitive disorders and is a subset of the list of questions asked to the informant regarding the participant's ability to perform activities independently. The informant supplied data will in most cases be used to determine the participant's functional abilities. Exceptions would include where the informant is not able to respond to the functional questions or where the accuracy of the information they provide is judged less reliable that the information provided by the participant. Clinicians are expected to complete all items in this module. However, they have flexibility in determining the order in which the questions are asked and the specific wording used for each question.

Now I'd like to ask you about some activities of daily living. You may feel that some of these questions do not apply to you, but it is important that we ask the same questions of everyone.

IAL_1	**IAL_ABLGRO_MSP**	
[ALWAYS ASK]		
Can you go shopping for groceries or clothes without help (taking care of all shopping needs yourself)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_2	**IAL_HPGRO_MSP**	
[ASK IF IAL_ABLGRO_MSP = NO]		
Can you go shopping for groceries or clothes with some help (i.e., you need someone to go with you on all shopping trips)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_3	IAL_UNGRO_MSP	
[ASK IF IAL_HPGRO_MSP = NO]		
Are you completely unable to do any shopping?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_4	IAL_ABLML_MSP	
[ALWAYS ASK]		
Can you prepare your own meals without help (i.e., you plan and cook full meals yourself)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_5	IAL_HPML_MSP	
[ASK IF IAL_ABLML_MSP = NO]		
Can you prepare your own meals with some help (i.e., you can prepare some things but are unable to cook full meals yourself)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_6	IAL_UNML_MSP	
[ASK IF IAL_HPML_MSP = NO]		
Are you completely unable to prepare any meals?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_7	IAL_ABLMED_MSP	
[ALWAYS ASK]		
Can you take your own medicine without help (in the right doses at the right time)?		
CLINICIAN INSTRUCTIONS: IF THE PARTICIPANT OCCASIONALLY FORGETS, CODE AS 'YES'.		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_8	IAL_HPMED_MSP	
[ASK IF IAL_ABLMED_MSP = NO]		
Can you take your own medicine with some help (i.e., you are able to take medicine if someone prepares it for you or reminds you to take it)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_9	IAL_UNMED_MSP	
[ASK IF IAL_HPMED_MSP = NO]		
Are you completely unable to take your medicine?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_10	IAL_ABLMO_MSP	
[ALWAYS ASK]		
Can you handle your own money without help (i.e., you write cheques, pay bills, etc.)?		
CLINICIAN INSTRUCTIONS: IF THE PARTICIPANT OCCASIONALLY FORGETS, CODE AS 'YES'.		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_11	IAL_HPMO_MSP	
[ASK IF IAL_ABLMO_MSP = NO]		
Can you handle your own money with some help (i.e., you manage day-to-day buying but need help with managing your chequebook or paying your bills)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_12	IAL_UNMO_MSP	
[ASK IF IAL_HPMO_MSP = NO]		
Are you completely unable to handle your money?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_13	IAL_FUNCT_MSP	
[ALWAYS ASK]		
Have you experienced any changes in your functional abilities due to cognitive changes?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_14	IAL_NOTES_MSP	
[ALWAYS ASK]		
Do you have any additional notes to include for this module?		
YES	1	Yes
NO	2	No

IAL_15	IAL_NOTES_SP_MSP
[ASK IF IAL_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

IAL_END

Transportation (TRA)

Overview	The questions in this module ask participants about their driving status, and details regarding their license status. The informant is also being asked questions about the participant's driving. The informant supplied data will in most cases be used to determine the participant's driving status. Exceptions would include where the informant is not able to respond to the functional questions or where the accuracy of the information they provide is judged less reliable that the information provided by the participant Clinicians are expected to complete all items in this module. However, they have flexibility in determining the order in which the questions are asked and the specific wording used for each question.

TRA_1	**TRA_DSTATUS_MSP**	
[ALWAYS ASK]		
Which of the following describes the participant's driving status? (Include cars, vans, trucks and motorcycles)		
READ LIST, CODE ONLY ONE RESPONSE		
NEVER	1	Never had a driver's license
FORMER	2	Had a driver's license at one point in his or her life, but currently do not have it
CURRENT	3	Have a driver's license without restrictions (except corrective lenses)
RESTRICTED	4	Have a driver's license with restrictions on time of driving (daylight only), distance from home, type of road (no highway), or number of passengers
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

TRA_2	**TRA_STOP_MSP**	
[ASK IF TRA_STA_MSP = FORMER]		
Why did the participant stop driving?		
CODE ONLY ONE RESPONSE		
VOL_STOP	1	Voluntarily stopped driving
LICS_RESC	2	License rescinded
OT_SP	3	Other (please specify: _____)
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

TRA_3	TRA_STOPYR_MSP	
[ASK IF TRA_STA_MSP = FORMER]		
At what age or in what year did the participant stop driving?		
YR_SP	Year	_____ **[MASK: MIN=YEAR OF BIRTH, MAX=CURRENT YEAR]**
NB_SP	Age	_____ **[MASK:MIN=00, MAX=CURRENT AGE]**
DK_NA	9998	**[DO NOT READ]** Don't know / No answer
REFUSED	9999	**[DO NOT READ]** Refused

TRA_4	TRA_NOTES_MSP	
[ALWAYS ASK]		
Do you have any additional notes to include for this module?		
YES	1	Yes
NO	2	No

TRA_5	TRA_NOTES_SP_MSP
[ASK IF TRA_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

TRA_END

Mood and Behaviour (BHV)

The first two questions of this module are from the Patient Health Questionnaire-2 (PHQ-2). It is publicly available and no permission is required to use, reproduce, or distribute the tools.
Kroenke K, Spitzer RL, Williams JB. The Patient Health Questionnaire-2: Validity of a Two-Item Depression Screener. Medical Care. 2003;41:1284-92. The other questions in this module capture information on mood and behaviour relevant to the diagnosis of neurocognitive disorder.

Overview	The questions in this module ask participants about their mood and behaviour. Clinicians are expected to complete all items in this module. However, with the exception of the first two questions (BHV_DEP1 and BHV_DEP2) they have flexibility in determining the order in which the questions are asked and the specific wording used for each question.

Physician Note: Please read the first two questions verbatim.

Over the past 2 weeks, how often have you been bothered by any of the following problems…?

BHV_1	**BHV_DEP1_MSP**	
[ALWAYS ASK]		
Little interest or pleasure in doing things?		
READ LIST, CODE ONLY ONE RESPONSE		
NO	1	Not at all
SEVERAL	2	Several days
HALF	3	More than half the days
EVERY	4	Almost every day
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

BHV_2	**BHV_DEP2_MSP**	
[ALWAYS ASK]		
Feeling down, depressed or hopeless?		
READ LIST, CODE ONLY ONE RESPONSE		
NO	1	Not at all
SEVERAL	2	Several days
HALF	3	More than half the days
EVERY	4	Almost every day
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

BHV_3	BHV_PERS_MSP	
[ALWAYS ASK]		
Has the participant noted any persistent adverse changes in their personality (such as apathy, irritability, or lability) lasting a year or longer?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

BHV_4	BHV_ANX_MSP	
[ALWAYS ASK]		
Is the participant currently experiencing anxiety?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

BHV_5	BHV_SUS_MSP	
[ALWAYS ASK]		
Is the participant currently experiencing feelings of suspiciousness?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

BHV_6	BHV_PSY_MSP	
[ALWAYS ASK]		
Is the participant currently experiencing psychotic symptoms (delusions and/or hallucinations)?		
YES	1	Yes

NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

BHV_7	**BHV_NOTES_MSP**

[ALWAYS ASK]		
Do you have any additional notes to include for this module?		
YES	1	Yes
NO	2	No

BHV_8	**BHV_NOTES_SP_MSP**
[ASK IF BHV_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below. For example, are there any other details regarding the participant's mood and behaviour that should be taken into account when interpreting the results of the cognitive testing?	

BHV_END

Physical Examination (EXM)

Overview	Clinicians are expected to complete all items in this module. However, they have flexibility in determining the order in which the physical exam is completed.

EXM_1	**EXM_ALERT_MSP**	
[ALWAYS ASK]		
Is the alertness/level of consciousness of the participant normal or abnormal?		
CODE ONLY ONE RESPONSE		
NRM	1	Normal
ABNRM	2	Abnormal
UNSURE	7	Unsure

EXM_2	**EXM_HEAR_MSP**	
[ALWAYS ASK]		
Is the participant willing to complete the hearing test?		
YES	1	Yes
NO	2	No

To evaluate hearing, please follow these instructions:

1. Position yourself approximately 60cm from the participant's ear
2. Mask the ear not being tested by rubbing the tragus. Do not place your arm across the face of the participant when rubbing the tragus, it is far nicer to occlude the ear from behind the head. If possible shield the participant's eyes to prevent any visual stimulus.
3. Whisper a number or word.
4. Ask the participant to repeat the number or word back to you. If they get two-thirds or more correct then their hearing level is 12db or better. If there is no response use a conversational voice (48db or louder) or loud voice (76db or louder).
5. If there is no response you can move closer and repeat the test at 15cm. Here the thresholds are 34db for a whisper and 56db for a conversational voice.
6. Assess the other ear in the same way.
7. Modifications may have to be made if personal protective equipment is worn.

EXM_3	**EXM_HEARRIGHT12_MSP**

[ASK IF EXM_HEAR_MSP = YES]		
Was the participant able to correctly repeat back the word or number you whispered at a distance of 60cm in their right ear?		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_4	**EXM_HEARRIGHT48_MSP**	
[ASK IF EXM_HEARRIGHT12_MSP = NO]		
Was the participant able to correctly repeat back the word or number you spoke using a conversational volume at a distance of 60cm in their right ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_5	**EXM_HEARRIGHT76_MSP**	
[ASK IF EXM_HEARRIGHT48 _MSP = NO]		
Was the participant able to correctly repeat back the word or number you spoke using a loud voice at a distance of 60cm in their right ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_6	**EXM_HEARRIGHT34_MSP**	
[ASK IF EXM_HEARRIGHT76_MSP = NO]		

Was the participant able to correctly repeat back the word or number you whispered at a distance of 15cm in their right ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_7	**EXM_HEARRIGHT56_MSP**	
[ASK IF EXM_HEARRIGHT34_MSP = NO]		
Was the participant able to correctly repeat back the word or number you spoke using a conversational volume at a distance of 15cm in their right ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_8	**EXM_HEARLEFT12_MSP**	
[ASK IF EXM_HEAR_MSP = YES]		
Was the participant able to correctly repeat back the word or number you whispered at a distance of 60cm in their left ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_9	**EXM_HEARLEFT48_MSP**
[ASK IF EXM_HEARLEFT12_MSP = NO]	

Was the participant able to correctly repeat back the word or number you spoke using a conversational volume at a distance of 60cm in their left ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_10	**EXM_HEARLEFT76_MSP**	
[ASK IF EXM_HEARLEFT48_MSP = NO]		
Was the participant able to correctly repeat back the word or number you spoke using a loud voice at a distance of 60cm in their left ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_11	**EXM_HEARLEFT34_MSP**	
[ASK IF EXM_HEARLEFT76_MSP = NO]		
Was the participant able to correctly repeat the word or number you whispered at a distance of 15cm in their left ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_12	**EXM_HEARLEFT56_MSP**
[ASK IF EXM_HEARLEFT34_MSP = NO]	

Was the participant able to correctly repeat back the word or number you spoke using a conversational volume at a distance of 15cm in their left ear??		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
NOTDONE	8	Unable to assess

EXM_13	**EXAM_HEARNOTES_MSP**	
[ALWAYS ASK]		
Do you have any additional notes to include regarding the participant's hearing?		
YES	1	Yes
NO	2	No

EXM_14	**EXAM_HEARNOTES_SP_MSP**
[ASK IF EXAM_HEAR_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

EXM_15	**EXM_SMELL_MSP**	
[ALWAYS ASK]		
Is the participant's sense of smell normal or abnormal?		
CODE ONLY ONE RESPONSE		
NRM	1	Normal
ABNRM	2	Abnormal
UNSURE	7	Unsure

EXM_16	**EXM_FOCAL_MSP**
[ALWAYS ASK]	
Are there any focal/lateralizing neurological findings to note?	

MULTIPLE RESPONSES ALLOWED, CODE ALL THAT APPLY (EXCEPT IF 96 IS SELECTED)		
VIS	01	Visual field defect
EXT	02	Abnormal extra-ocular movements
RGD	03	Rigidity
WKN	04	Weakness
SP	05	Speech
NONE	96	None
OTSP	97	Other: Please specify:

EXM_17	**EXM_FOCALVIS_SP_MSP**
[ASK IF EXAM_FOCAL_MSP = VIS]	
Please describe the visual field defect:	
Open text: _____	

EXM_18	**EXM_FOCALEXT_SP_MSP**
[ASK IF EXAM_FOCAL_MSP = EXT]	
Please describe the abnormal extra-ocular movements:	
Open text: _____	

EXM_19	**EXM_FOCALRGD_SP_MSP**
[ASK IF EXAM_FOCAL_MSP = RGD]	
Please describe the rigidity observed in the participant:	
Open text: _____	

EXM_20	**EXM_FOCALWKN_SP_MSP**
[ASK IF EXAM_FOCAL_MSP = WKN]	
Please describe the weakness observed in the participant:	

Open text: _____

EXM_21	**EXM_FOCALSP_SP_MSP**
[ASK IF EXAM_FOCAL_MSP = SP]	
Please describe the speech abnormalities observed in the participant:	
Open text: _____	

EXM_22	**EXM_FOCALOTSP_SP_MSP**
[ASK IF EXAM_FOCAL_MSP = OTSP]	
Please describe any other abnormalities observed in the participant:	
Open text: _____	

EXM_23	**EXM_EXPYR_MSP**	
[ALWAYS ASK]		
Are there any extrapyramidal signs observed?		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96 IS SELECTED), CODE ALL THAT APPLY		
TRM	01	Tremor
RGD	02	Rigidity
BKN	03	Bradykinesia
PST	04	Posture
NONE	96	None
OTSP	97	Other: specify

EXM_24	**EXM_EXPYRNOTES_MSP**
[ASK IF EXM_EXPYR_MSP = TRM, RGD, BKN, or PST]	
Please describe the extrapyramidal signs if required.	

Open text: _____		
DK_NA	8	**[DO NOT READ]** Don't know / No answer

EXM_25	**EXM_TRANSF_MSP**	
[ALWAYS ASK]		
How would you evaluate the participant's ability to do a sit to stand transfer?		
CODE ONLY ONE RESPONSE		
NRM	1	Normal
ABNRM	2	Abnormal
UNSURE	7	Unsure

EXM_26	**EXM_BALANCE_MSP**	
[ALWAYS ASK]		
How would you evaluate the participant's stability using the Romberg test?		
CLINICIAN NOTES: The Romberg test requires that the participant removes their shoes. Participants will be asked to stand with their feet together on a flat, hard surface. The participant will be asked to cross their arms in front of their body or place them at their sides. The participant will be asked to stand still and keep their eyes open for approximately 30 seconds while the examining clinician observes. The participant will then be asked to close their eyes and stand for an addition 30 seconds. The examining clinician will assess body movement and balance.		
CODE ONLY ONE RESPONSE		
NRM	1	Normal
ABNRM	2	Abnormal
NOTDONE	8	Unable to assess

EXM_27	**EXM_GAITSPD_MSP**
[ALWAYS ASK]	
Does the participant have normal or slow gait speed?	

CLINICIAN NOTES: Gait speed may be evaluated by watching the participant move around the Data Collection Site.		
CODE ONLY ONE RESPONSE		
NRM	1	Normal
SLOW	2	Slow
NOTDONE	8	Unable to assess

EXM_28	**EXM_GAIT_MSP**	
[ALWAYS ASK]		
Did you observe any gait abnormalities?		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96 ISSELECTED), CODE ALL THAT APPLY		
NO	01	No gait abnormalities
NN	02	Abnormal gait speed due to non-neurologic cause (e.g. arthritis)
ST	03	Unsteady
FR	04	Frontal
HM	05	Hemiparetic
NR	06	Neuropathic
AT	07	Ataxic
PK	08	Parkinsonian
SP	09	Spastic
NOTDONE	96	Unable to assess

EXM_29	**EXM_BALGAITNOTES_MSP**
[ASK IF EXM_TRANSF_MSP = ABNRM, OR EXM_BALANCE_MSP = ABNRM, OR EXM_GAITSPD_MSP = SLOW, OR EXM_GAITMSP = NN, ST, FR, HM, NR, AT, PK, or SP]	
Please describe any abnormalities in transferring, balance, or gait.	

EXM_30	**EXM_NOTES_MSP**	
[ALWAYS ASK]		
Do you have any additional notes to include for this module? For example, are there any other findings from the physical examination that should be taken into account when interpreting the results of the cognitive testing?		
YES	1	Yes

NO	2	No

EXM_31	**EXM_NOTES_SP_MSP**
[ASK IF EXM_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

EXM_END

Montreal Cognitive Assessment (MoCA)

*Training and certification is required by any clinical, health professional, or worker who wishes to administer, score and interpret the Montreal Cognitive Assessment (MoCA) test. The MoCA © may be used, reproduced, and distributed **WITH** permission for universities/foundations/health professionals/hospitals/clinics/public health institutes.*

Overview	The Montreal Cognitive Assessment (MoCA) was designed as a rapid screening instrument for mild cognitive dysfunction. It assesses different cognitive domains: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation. Time to administer the MoCA is approximately 10 minutes. The total possible score is 30 points; a score of 26 or above is considered normal. There is an additional point added to the obtained score if the person being tested has 12 or fewer years of formal education. For the purposes of the CLSA Memory Study, we will categorize participant that did not graduate from secondary school or those who graduated secondary school but did not complete post-secondary education as having 12 or fewer years of formal education. The MoCA memory section provides two trials to learn a word list of five nouns followed by a delay in which subjects are asked questions from other sections of the MoCA (i.e., attention, sentence repetition, letter fluency, similarities). The delay is variable, but estimated at five minutes followed by free recall of the 5-word list. This is followed by a category-cued semantic recall condition, and, finally, a multiple choice-cued recall from presentation of the correct item paired with two items within the same category but not on the list. Only the points earned in the delayed *free* recall condition of the memory section (1 point per correct word) are added to the MoCA total score. The MoCA-MIS includes points for the free recall condition and the cued conditions (3 points for each word on free recall, 2 for each on category-cued recall, 1 for each on multiple-choice recall). For those with severe visual impairment, the MoCA-BLIND can be utilized. This is scored out of 22 with normal being a score of 18 or higher. The correction for limited formal education described above is also used for the MoCA-BLIND. Clinicians are expected to complete this module using the provided script.

MOC_1	**MOC_SIGHT_MSP**	
[ALWAYS ASK]		
Does the participant have any visual impairments that would prevent them from completing the standard MoCA which requires drawing on a piece of paper?		
YES	1	Yes
NO	2	No

1. Alternating Trail Making:

Administration: The examiner instructs the subject: "*Please draw a line, going from a number to a letter in ascending order. Begin here [point to (1)] and draw a line from 1 then to A then to 2 and so on. End here [point to (E)]*."

MOC_2	**MOC_TRAIL_MSP**	
[ASK IF MOC_SIGHT_MSP = NO]		
Was the participant able to successfully complete the Alternating Trail Making task?		
CLINICIAN NOTE: Successfully completing the Alternating Trail Making task required the participant to successfully draw the following pattern: 1-A-2-B-3-C-4-D-5-E without drawing any lines that cross		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
REFUSED	9	**[DO NOT READ]** Participant refused to do task

2. Visuoconstructional Skills (Cube):

Administration: The examiner gives the following instructions, pointing to the cube: “Copy this drawing as accurately as you can, in the space below”.

MOC_3	**MOC_CUBE_MSP**	
[ASK IF MOC_SIGHT_MSP = NO]		
Was the participant able to successfully complete the cube drawing task?		
CODE ONLY ONE RESPONSE		
CLINICIAN NOTE: A successfully executed drawing must be: • Three-dimensional • All lines are drawn • No line is added • Lines are relatively parallel and their length is similar (rectangular prisms are accepted) If any of the above criteria are not met, the cube was not successfully drawn.		
YES	1	Yes
NO	2	No
REFUSED	9	**[DO NOT READ]** Participant refused to do task

3. Visuoconstructional Skills (Clock):

Administration: Indicate the right third of the space and give the following instructions: "*Draw a clock. Put in all the numbers and set the time to 10 past 11*".

MOC_4	**MOC_CLOCKCON_MSP**	
[ASK IF MOC_SIGHT_MSP = NO]		
Contour - Did the participant successfully draw the circle of the clock?		
CLINICIAN NOTE: For contour, a clock that has been correctly drawn must meet the following criteria: The clock face must be a circle with only minor distortion acceptable (e.g., slight imperfection on closing the circle).		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
REFUSED	9	**[DO NOT READ]** Participant refused to do task

MOC_5	**MOC_CLOCKNUM_MSP**	
[ASK IF MOC_SIGHT_MSP = NO]		
Numbers – Did the participant successfully draw the numbers on the clock?		
CLINICIAN NOTE: For the numbers, a clock that has been correctly drawn must meet the following criteria: All clock numbers must be present with no additional numbers; numbers must be in the correct order and placed in the approximate quadrants on the clock face; Roman numerals are acceptable; numbers can be placed outside the circle contour.		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
REFUSED	9	**[DO NOT READ]** Participant refused to do task

MOC_6	**MOC_CLOCKHAND_MSP**
[ASK IF MOC_SIGHT_MSP = NO]	

Hands - Did the participant successfully draw the hands on the clock?		
CODE ONLY ONE RESPONSE		
CLINICIAN NOTE: For the hands, a clock that has been correctly drawn must meet the following criteria: There must be two hands jointly indicating the correct time; the hour hand must be clearly shorter than the minute hand; hands must be centred within the clock face with their junction close to the clock centre.		
YES	1	Yes
NO	2	No
REFUSED	9	**[DO NOT READ]** Participant refused to do task

4. Naming:

Administration: Beginning on the left, point to each figure and say: "*Tell me the name of this animal*".

MOC_7	**MOC_ANIMALS_MSP**	
[ASK IF MOC_SIGHT_MSP = NO]		
How many animals were correctly named by the participant?		
CLINICIAN NOTES: One point is given for the following responses: (1) lion (2) rhinoceros or rhino (3) camel or dromedary.		
CODE ONLY ONE RESPONSE		
ONE	1	One
TWO	2	Two
THREE	3	Three
NONE	4	None of the animals were correctly named
REFUSED	9	**[DO NOT READ]** Participant refused to do task

5. Memory:

Administration: The examiner reads a list of 5 words at a rate of one per second, giving the following instructions: "*This is a memory test. I am going to read a list of words that you will have to remember now*

and later on. Listen carefully. When I am through, tell me as many words as you can remember. It doesn't matter in what order you say them".

"Face, velvet, church, daisy, red"

Administration: When the subject indicates that (s)he has finished (has recalled all words), or can recall no more words, read the list a second time with the following instructions: "*I am going to read the same list for a second time. Try to remember and tell me as many words as you can, including words you said the first time*."

"Face, velvet, church, daisy, red"

Administration: At the end of the second trial, inform the participant that he/she will be asked to recall these words again by saying: "*I will ask you to recall these words again at the end of the test*."

6. Attention:

Forward Digit Span: Administration: Give the following instruction: "*I am going to say some numbers and when I am through, repeat them to me exactly as I said them*". Read the five number sequence at the rate of one digit per second.

"2, 1, 8, 5, 4"

MOC_8	**MOC_NUMFORW_MSP**	
[ALWAYS ASK]		
Was the participant able to repeat the numbers "2, 1, 8, 5, 4" in the forward order?		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
REFUSED	9	**[DO NOT READ]** Participant refused to do task

Attention, Backward Digit Span: Administration: Give the following instruction: "*Now I am going to say some more numbers, but when I am through you must repeat them to me in the backwards order*.".

"7, 4, 2."

MOC_9	**MOC_NUMBACK_MSP**	
[ALWAYS ASK]		
Was the participant able to repeat the numbers "7, 4, 2" in the backward order?		
CODE ONLY ONE RESPONSE		
YES	1	Yes
NO	2	No
REFUSED	9	**[DO NOT READ]** Participant refused to do task

Vigilance: The examiner reads the list of letters at a rate of one per second, after giving the following instruction: "*I am going to read a sequence of letters. Every time I say the letter A, tap your hand once. If a say a different letter, do not tap your hand*".

"*F B A C M N A A J K L B A F A K D E A A A J A M O F A A B*"

MOC_10	**MOC_LETTER_MSP**	
[ALWAYS ASK]		
Did the participant make zero to one errors (an error is a tap on a wrong letter or a failure to tap on letter A)?		
CODE ONLY ONE RESPONSE		
YES	1	Yes, the participant made 0 or one errors
NO	2	No, the participant made two or more errors
REFUSED	9	**[DO NOT READ]** Participant refused to do task

Serial 7s: The examiner gives the following instruction: "*Now, I will ask you to count by subtracting seven from 100, and then, keep subtracting seven from your answer until I tell you to stop*". Give this instruction twice if necessary.

MOC_11	**MOC_SUBS_MSP**	
[ALWAYS ASK]		
How many correct subtractions did the participant make?		
CLINICIAN NOTES: This item is scored out of 3 points. Give no (0) points for no correct subtractions, 1 point for one correct subtraction, 2 points for two-to-three correct subtractions, and 3 points if the participant successfully makes four or five correct subtractions. Count each correct subtraction of 7 beginning at 100. Each subtraction is evaluated independently; that is, if the participant responds with an incorrect number but continues to correctly subtract 7 from it, give a point for each correct subtraction. For example, a participant may respond "92 – 85 – 78 – 71 – 64" where the "92" is incorrect, but all subsequent numbers are subtracted correctly. This is one error and the item would be given a score of 3.		
CODE ONLY ONE RESPONSE		
ZERO	0	Zero
ONE	1	One
TWO_THREE	2	Two or three
FOUR_FIVE	3	Four or five
REFUSED	9	**[DO NOT READ]** Participant refused to do task

7. Sentence repetition:

Administration: The examiner gives the following instructions: "*I am going to read you a sentence. Repeat it after me, exactly as I say it [pause]: I only know that John is the one to help today*.". Following the response, say: "*Now I am going to read you another sentence. Repeat it after me, exactly as I say it [*pause*]: The cat always hid under the couch when dogs were in the room*".

MOC_12	**MOC_REPET_MSP**	
[ALWAYS ASK]		
How many of the sentences did the participant correctly repeat?		
CLINICIAN NOTES: Repetition must be exact. Be alert for errors that are omissions (e.g., omitting "only", "always") and substitutions/additions (e.g., "John is the one who helped today;" substituting "hides" for "hid", altering plurals, etc.).		
CODE ONLY ONE RESPONSE		
ZERO	0	Zero
ONE	1	One
TWO	2	Two
REFUSED	9	**[DO NOT READ]** Participant refused to do task

8. Verbal fluency:

Administration: The examiner gives the following instruction: *"Tell me as many words as you can think of that begin with a certain letter of the alphabet that I will tell you in a moment. You can say any kind of word you want, except for proper nouns (like Bob or Boston), numbers, or words that begin with the same sound but have a different suffix, for example, love, lover, loving. I will tell you to stop after one minute. Are you ready?* [Pause] *Now, tell me as many words as you can think of that begin with the letter F*. [time for 60 sec]. *Stop*."

MOC_13	**MOC_WORDSF_MSP**	
[ALWAYS ASK]		
Please record the words that the participant says		
REFUSED	9	**[DO NOT READ]** Participant refused to do task

MOC_14	MOC_WORDSFNUM_MSP	
[ASK IF MOC_WORDSF ≠ REFUSED]		
How many words did the participant say in one minute that begin with the letter "F"?		
CODE ONLY ONE RESPONSE		
10_LESS	00	Less than 11 words
11_MORE	01	11 or more words
REFUSED	99	**[DO NOT READ]** Participant refused to do task

9. Abstraction:

Administration: The examiner asks the subject to explain what each pair of words has in common, starting with the example: "*Tell me how an orange and a banana are alike*". If the subject answers in a concrete manner, then say only one additional time: "*Tell me another way in which those items are alike*". If the subject does not give the appropriate response (fruit), say, "*Yes, and they are also both fruit*." Do not give any additional instructions or clarification. After the practice trial, say: "*Now, tell me how a train and a bicycle are alike*". Following the response, administer the second trial, saying: "*Now tell me how a ruler and a watch are alike*". Do not give any additional instructions or prompts.

MOC_15	MOC_WORDSIM_MSP	
[ALWAYS ASK]		
How many combinations of words did the participant identify the similarly between?		
CLINICIAN NOTES: Only the last two item pairs are scored. Give 1 point to each item pair correctly answered. The following responses are acceptable: Train-bicycle = means of transportation, means of travelling, you take trips in both; Ruler-watch = measuring instruments, used to measure. The following responses are not acceptable: Train-bicycle = they have wheels; Ruler-watch = they have numbers.		
CODE ONLY ONE RESPONSE		
NONE	0	None
ONE	1	One
TWO	2	Two
REFUSED	9	**[DO NOT READ]** Participant refused to do task

10. Delayed recall:

Administration: The examiner gives the following instruction: "*I read some words to you earlier, which I asked you to remember. Tell me as many of those words as you can remember*."

MOC_16	**MOC_MEM3_MSP**	
[ALWAYS ASK]		
.Please record which words the participant is able to spontaneously recall.		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96, OR 99ARE SELECTED), CODE ALL THAT APPLY		
FACE	01	Face
VELVET	02	Velvet
CHURCH	03	Church
DAISY	04	Daisy
RED	05	Red
NONE	96	Did not remember any of the words
REFUSED	99	**[DO NOT READ]** Participant refused to do task

10b. Delayed recall – optional component:

Administration: Following the delayed free recall trial, prompt the subject with the semantic category cue provided below for any word not recalled. Prompt all non-recalled words in this manner.

Word	**Category cue**
Face	Part of the body
Velvet	Type of fabric
Church	Type of building
Daisy	Type of flower
Red	A colour

MOC_17	**MOC_MISCUE1_MSP**

[SKIP IF MOC_MEM3_MSP = FACE AND VELVET AND CHURCH AND DAISY AND RED]		
Please indicate which words the participant produces on this third trial.		
CLINICIAN NOTE: Please select each word that the participant correctly recalled with the category cue provided. Do not select words that the participant correctly remembered spontaneously. A cue is used for clinical information purposes only and can give the test interpreter additional information about the type of memory disorder. For memory deficits due to retrieval failures, performance can be improved with a cue. For memory deficits due to encoding failures, performance does not improve with a cue.		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96 OR 99ARE SELECTED), CODE ALL THAT APPLY		
FACE	01	Face
VELVET	02	Velvet
CHURCH	03	Church
DAISY	04	Daisy
RED	05	Red
NONE	96	Did not remember any of the words
REFUSED	99	**[DO NOT READ]** Participant refused to do task

If the subject does not recall the word after the category cue, give him/her a multiple choice trial, using the following example instruction, "*Which of the following words do you think it was, NOSE, FACE, or HAND?*"

Word	**Multiple choice cue**
Face	Nose, face, hand
Velvet	Denim, cotton, velvet
Church	Church, school, hospital
Daisy	Rose, daisy, tulip
Red	Red, blue, green

MOC_18	**MOC_MISCUE2_MSP**
SKIP IF MOC_MEM3_MSP OR MOC_MISCUE1_MSP = FACE AND VELVET AND CHURCH AND DAISY AND RED]	

Please indicate which words the participant produces on this third trial.		
CLINICIAN NOTE: Please select each word that the participant correctly recalled with the category cue provided. Do not select words that the participant correctly remembered spontaneously or using the category cues.		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96 OR 99 ARE SELECTED), CODE ALL THAT APPLY		
FACE	01	Face
VELVET	02	Velvet
CHURCH	03	Church
DAISY	04	Daisy
RED	05	Red
NONE	96	Did not remember any of the words
REFUSED	99	**[DO NOT READ]** Participant refused to do task

11. Orientation:

Administration: The examiner gives the following instructions: "*Tell me the date today*". If the subject does not give a complete answer, then prompt accordingly by saying: "*Tell me the [year, month, exact date, and day of the week*]." Then say: "*Now, tell me the name of this place, and which city it is in*."

MOC_19	**MOC_ORIENT_MSP**	
[ALWAYS ASK]		
Which of the following orientation features did the participant correctly identify?		
CLINICIAN NOTES: The subject must tell the exact date and the exact place (name of hospital, clinic, office). No points are allocated if subject makes an error (even of one day) for the day and date.		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96 OR 99 ARE SELECTED), CODE ALL THAT APPLY		
DATE	01	Date
MONTH	02	Month
YEAR	03	Year
DAY	04	Day
PLACE	05	Place
CITY	06	City
NONE	96	None – the participant did not correctly identify any of the orientation features
REFUSED	99	**[DO NOT READ]** Participant refused to do task

MOC_20	**MOC_TOTALSCORE0_MSP**
[CALCULATE IF MOC_SIGHT_MSP = NO]	

The Montreal Cognitive Assessment (MoCA) is scored out of a maximum of 30 points. A final total score of 26 and above is considered normal. Total score on the MoCA: 0
CLINICIAN NOTES: One point has been added for individuals who have 12 years or fewer of formal education.
[CALCULATED VARIABLE: MOC_TRAIL + MOC_CUBE + MOC_CLOCKCON + MOC_CLOCKNUM + MOC_CLOCKHAND + MOC_ANIMALS:ONE + MOC_ANIMALS:TWO + MOC_ANIMALS:TWO + MOC_ANIMALS:THREE + MOC_ANIMALS:THREE + MOC_ANIMALS:THREE + MOC_NUMFORW + MOC_NUMBACK + MOC_LETTER:YES + MOC_SUBS:ONE + $MOC_SUBS:TWO_THREE + MOC_SUBS:TWO_THREE + MOC_SUBS:FOUR_FIVE + MOC_SUBS:FOUR_FIVE + MOC_SUBS:FOUR_FIVE + MOC_REPET:ONE + MOC_REPET:TWO + MOC_REPET:TWO + MOC_WORDSFNUM:11_MORE + MOC_WORDSIM:ONE + MOC_WORDSIM:TWO + MOC_WORDSIM:TWO + MOC_MEM3:FACE + MOC_MEM3:VELVET + MOC_MEM3:CHURCH + MOC_MEM3:DAISY + MOC_MEM3:RED + MOC_ORIENT:DATE + MOC_ORIENT:MONTH + MOC_ORIENT:YEAR + MOC_ORIENT:DAY + MOC_ORIENT:PLACE + MOC_ORIENT:CITY + 1 IF BASELINE EDUCATION WAS 12 YEARS OR LESS == 0]

VARIABLES MOC_21 TO MOC_51 SHOULD BE CALCULATED AS FOLLOWED:

VARIABLE NAME: MOC_TOTALSCORE[NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 1 TO 30.
VARIABLE DESCRIPTION: TOTAL SCORE ON MONTREAL COGNITIVE ASSESSMENT (MOCA): [NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 1 TO 30.
VARIABLE CALCULATION: THE TOTAL SCORE THAT THE VARIABLE CALCULATION EQUALS SHOULD INCREASE SEQUENTIALLY FROM 1 TO 30

MOC_52	**MOC_TOTALMIS0_MSP**
[CALCULATE IF MOC_SIGHT_MSP = NO]	
CLINICIAN NOTES: There were not any skipped items on the Montreal Cognitive Assessment (MoCA).	
[CALCULATED VARIABLE, ($MOC_TRAIL.refuse()$? 1 : 0) + ($MOC_CUBE.refuse()$? 1 : 0) + ($MOC_CLOCKCON.refuse()$? 1 : 0) + ($MOC_CLOCKNUM.refuse()$? 1 : 0) + $MOC_CLOCKHAND.refuse()$? 1 : 0) + ($MOC_ANIMALS.refuse()$? 1 : 0) + $MOC_ANIMALS.refuse()$? 1 : 0) + ($MOC_ANIMALS.refuse()$? 1 : 0) + ($MOC_NUMFORW.refuse()$? 1 : 0) + ($MOC_NUMBACK.refuse()$? 1 : 0) + ($MOC_LETTER.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_REPET.refuse()$? 1 : 0) + ($MOC_REPET.refuse()$? 1 : 0) + ($MOC_WORDSFNUM.refuse()$? 1 : 0) + ($MOC_WORDSIM.refuse()$? 1 : 0) + ($MOC_WORDSIM.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) == 0]	

MOC_53	**MOC_TOTALMIS1_MSP**
[CALCULATE IF MOC_SIGHT_MSP = NO]	
CLINICIAN NOTES: Not all components of the Montreal Cognitive Assessment (MoCA) may have been completed. This variable identifies the number of points out of the total score of 30 that the participant did not receive due to skipping tasks on the MoCA and should be considered when interpreting the total score of the MoCA. Number of points: 1	

[CALCULATED VARIABLE, ($MOC_TRAIL.refuse()$? 1 : 0) + ($MOC_CUBE.refuse()$? 1 : 0) + ($MOC_CLOCKCON.refuse()$? 1 : 0) + ($MOC_CLOCKNUM.refuse()$? 1 : 0) + $MOC_CLOCKHAND.refuse()$? 1 : 0) + ($MOC_ANIMALS.refuse()$? 1 : 0) + $MOC_ANIMALS.refuse()$? 1 : 0) + ($MOC_ANIMALS.refuse()$? 1 : 0) + ($MOC_NUMFORW.refuse()$? 1 : 0) + ($MOC_NUMBACK.refuse()$? 1 : 0) + ($MOC_LETTER.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_REPET.refuse()$? 1 : 0) + ($MOC_REPET.refuse()$? 1 : 0) + ($MOC_WORDSFNUM.refuse()$? 1 : 0) + ($MOC_WORDSIM.refuse()$? 1 : 0) + ($MOC_WORDSIM.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) == 1]

VARIABLES MOC_54 TO MOC_62 SHOULD BE CALCULATED AS FOLLOWED:

VARIABLE NAME: MOC_TOTALMIS[NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 2 TO 10 OR MORE.
VARIABLE DESCRIPTION: TOTAL NUMBER OF MISSING POINTS ON MONTREAL COGNITIVE ASSESSMENT (MOCA): [NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 1 TO 10 OR MORE.
VARIABLE CALCULATION: THE TOTAL SCORE THAT THE VARIABLE CALCULATION EQUALS SHOULD INCREASE SEQUENTIALLY FROM 1 TO 10 OR MORE

MOC_63	**MOC_BLINDTSCORE0_MSP**
[CALCULATE IF MOC_SIGHT_MSP = YES]	
Total score on the Montreal Cognitive Assessment (MoCA) Blind version : 0	
CLINICIAN NOTES: One point has been added for individuals who have 12 years or fewer of formal education, for a possible maximum of 22 points. A final total score of 18 and above is considered normal.	
[CALCULATED VARIABLE: MOC_NUMFORW + MOC_NUMBACK + MOC_LETTER:YES + MOC_SUBS:ONE + $MOC_SUBS:TWO_THREE + MOC_SUBS:TWO_THREE + MOC_SUBS:FOUR_FIVE + MOC_SUBS:FOUR_FIVE + MOC_SUBS:FOUR_FIVE + MOC_REPET:ONE + MOC_REPET:TWO + MOC_REPET:TWO + MOC_WORDSFNUM:11_MORE + MOC_WORDSIM:ONE + MOC_WORDSIM:TWO + MOC_WORDSIM:TWO + MOC_MEM3:FACE + MOC_MEM3:VELVET + MOC_MEM3:CHURCH + MOC_MEM3:DAISY + MOC_MEM3:RED + MOC_ORIENT:DATE + MOC_ORIENT:MONTH + MOC_ORIENT:YEAR + MOC_ORIENT:DAY + MOC_ORIENT:PLACE + MOC_ORIENT:CITY + 1 IF BASELINE EDUCATION WAS 12 YEARS OR LESS == 0]	

VARIABLES MOC_64 TO MOC_86 SHOULD BE CALCULATED AS FOLLOWED:

VARIABLE NAME: MOC_BLINDTSCORE [NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 1 TO 22.
VARIABLE DESCRIPTION: TOTAL SCORE ON MONTREAL COGNITIVE ASSESSMENT (MOCA) BLIND VERSION: [NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 1 TO 22.
VARIABLE CALCULATION: THE TOTAL SCORE THAT THE VARIABLE CALCULATION EQUALS SHOULD INCREASE SEQUENTIALLY FROM 1 TO 22

MOC_87	**MOC_BLINDMIS0_MSP**

[CALCULATE IF MOC_SIGHT_MSP = YES]
CLINICIAN NOTES: There were not any skipped items on the Montreal Cognitive Assessment (MoCA) Blind version..
[CALCULATED VARIABLE, ($MOC_NUMFORW.refuse()$? 1 : 0) + ($MOC_NUMBACK.refuse()$? 1 : 0) + ($MOC_LETTER.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_SUBS.refuse()$? 1 : 0) + ($MOC_REPET.refuse()$? 1 : 0) + ($MOC_REPET.refuse()$? 1 : 0) + ($MOC_WORDSFNUM.refuse()$? 1 : 0) + ($MOC_WORDSIM.refuse()$? 1 : 0) + $MOC_WORDSIM.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_MEM3.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) + ($MOC_ORIENT.refuse()$? 1 : 0) == 0]

MOC_88	**MOC_BLINDMIS1_MSP**
[CALCULATE IF MOC_SIGHT_MSP = YES]	
CLINICIAN NOTES: Not all components of the Montreal Cognitive Assessment (MoCA) Blind version may have been completed. This variable identifies the number of points out of the total score of 22 that the participant did not receive due to skipping tasks on the MoCA-BLIND which is administered to participants with severe visual impairment. Number of points: 1	
[CALCULATED VARIABLE, MOC_LETTER_MSP (REFUSED) + MOC_NUMFORW_MSP (REFUSED) +MOC_NUMBACK_MSP (REFUSED) + MOC_SUBS_MSP (REFUSED) + MOC_REPET_MSP (REFUSED) + MOC_WORDSFNUM_MSP (REFUSED), MOC_WORDSIM_MSP (REFUSED), MOC_MEM3_MSP (REFUSED), MOC_ORIENT_MSP (REFUSED)]	

VARIABLES MOC_89 TO MOC_98SHOULD BE CALCULATED AS FOLLOWED:

VARIABLE NAME: MOC_TOTALMIS[NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 2 TO 10 OR MORE.
VARIABLE DESCRIPTION: TOTAL NUMBER OF MISSING POINTS ON MONTREAL COGNITIVE ASSESSMENT (MOCA): [NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 1 TO 10 OR MORE.
VARIABLE CALCULATION: THE TOTAL SCORE THAT THE VARIABLE CALCULATION EQUALS SHOULD INCREASE SEQUENTIALLY FROM 1 TO 10 OR MORE

MOC_99	**MOC_MISSCORE0_MSP**
The Memory Score Index (MIS) is scored out of a maximum of 15. A score of 8 and above is considered normal. The participant's score on the MIS is: 0	
[CALCULATED VARIABLE, SUM OF (MOC_MEM3_MSP = FACE, VELVET, CHURCH, DAISY, AND/OR RED * 3) + (MOC_MISCUE1_MSP = FACE, VELVET, CHURCH, DAISY, AND/OR RED * 2) + (MOC_MISCUE2_MSP = FACE, VELVET, CHURCH, DAISY, AND/OR RED)]	

VARIABLES MOC_100 TO MOC_115 SHOULD BE CALCULATED AS FOLLOWED:

VARIABLE NAME: MOC_MISSCORE[NUMBER] SHOULD INCREASE SEQUENTIALLY FROM 1 TO 15.
VARIABLE DESCRIPTION: TOTAL SCORE MEMORY SCORE INDEX SHOULD INCREASE SEQUENTIALLY FROM 1 TO 15.
VARIABLE CALCULATION: THE TOTAL SCORE THAT THE VARIABLE CALCULATION EQUALS SHOULD INCREASE SEQUENTIALLY FROM 1 TO 15

MOC_116	**MOC_MISSCOREMIS_MSP**
CLINICIAN NOTES: Not all components of the Montreal Cognitive Assessment (MoCA) Memory Impairment Section (MIS) were completed. Please take this into consideration when interpreting the total score of the MIS.	
[CALCULATED VARIABLE, MOC_MEM3_MSP (REFUSED) OR MOC_MISCUE1_MSP (REFUSED) OR MOC_MISCUE2_MSP (REFUSED)]	

MOC_117	**MOC_NOTES_MSP**	
[ALWAYS ASK]		
Do you have any additional notes to include for this module? For example, were there any issues with the testing environment that should be taken into account when interpreting the results of the cognitive testing?		
YES	1	Yes
NO	2	No

MOC_118	**MOC_NOTES_SP_MSP**
[ASK IF MOC_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

MOC_END

Preliminary Diagnosis of Neurocognitive Disorder (NCD)

Overview	Please use this module to document your preliminary diagnosis of the participant's cognitive status based on the clinical assessment and informant interview. This module does not contain questions related to planning the care of individuals diagnosed with neurocognitive disorder.

NCD_1	**NCD_DIA_MSP**	
[ALWAYS ASK]		
Based on the clinical evaluation and informant interview, what is your diagnosis of the participant?		
CLINICIAN NOTE: The category of "no significant cognitive concerns" also includes participants without any cognitive complaints that performed poorly on the Montreal Cognitive Assessment (MoCA) if confounders such as language or education are thought to explain the poor performance.		
CODE ONLY ONE RESPONSE		
NORMAL	1	No significant cognitive concerns
SUB	2	Normal cognition but with subjective cognitive decline (self-reported confusion or memory problems happening more often and getting worse over last year but not meeting the criteria for either mild or major neurocognitive disorder)
DELIRIUM	3	Delirium
MILD	4	Mild neurocognitive disorder
MAJOR	5	Major neurocognitive disorder

NCD_2	**NCD_CONF_MSP**	
[ALWAYS ASK]		
How confident are you in your diagnosis? Please rate on an 11-point scale (0-10; with the anchors of 0, indicating the lowest confidence rating, and 10, the highest confidence rating)		
NUMBER	Number	_____ **[MASK: MIN=0, MAX=10]**

NCD_3	NCD_DOM_MSP	
[ASK IF NCD_DIA_MSP = SUB, MILD ,OR MAJOR]		
What cognitive domains have been impacted by cognitive decline?		
MULTIPLE RESPONSES ALLOWED (EXCEPT IF 96 IS SELECTED), CODE ALL THAT APPLY		
AT	01	Attention
EF	02	Executive function
LM	03	Learning and memory
LG_	04	Language
PC	05	Perceptual/motor
SC	06	Social cognition
NONE	96	No cognitive domains appear to be impacted

NCD_4	NCD_INFO_MSP	
[ALWAYS ASK]		
What additional information or resources would increase your confidence in your diagnosis?		
MULTIPLE RESPONSES ALLOWED, CODE ALL THAT APPLY		
NONE	1	None
LAB	2	Laboratory investigations
IMG	3	Neuroimaging
REF	4	Referral to a consultant
TIM	5	Opportunity to follow the participant over time
OTSP	7	Other (please specify: _____)

NCD_5	NCD_TYPE_MSP	
[ASK IF NCD_DIA_MSP = MILD OR MAJOR]		
Based on the clinical evaluation and informant interview, what is your diagnosis of the participant?		
CODE ONLY ONE RESPONSE		
ALZ	1	Alzheimer's Disease
LWY	2	Lewy Body Disease
PKD	3	Parkinson's Disease
VSC	4	Vascular Cognitive Impairment
FRT	5	Frontotemporal Degeneration
TBI	6	Traumatic Brain Injury (Including Chronic Traumatic Encephalopathy)
MLT	7	Multiple (or Mixed) etiologies
OTSP	8	Other (please specify: _____)
UNK	9	Unknown

NCD_6	NCD_TYPCONF_MSP	
[ASK IF NCD_DIA_MSP = MILD OR MAJOR]		
How confident are you in your diagnosis of the underlying cause of the mild or major neurocognitive disorder? Please rate on an 11-point scale (0-10; with the anchors of 0, indicating the lowest confidence rating, and 10, the highest confidence rating)		
NUMBER	Number	_____ **[MASK: MIN=0, MAX=10]**

NCD_7	NCD_TYPINF_MSP	
[ASK IF NCD_DIA_MSP = MILD OR MAJOR]		
What additional information or resources would increase your confidence in your diagnosis?		
MULTIPLE RESPONSES ALLOWED, CODE ALL THAT APPLY		
NONE	1	None
LAB	2	Laboratory investigations
IMG	3	Neuroimaging
REF	4	Referral to a consultant
TIM	5	Opportunity to follow the participant over time
OTSP	7	Other (please specify: _____)

NCD_8	NCD_NOTES_MSP	
[ALWAYS ASK]		
Do you have any additional notes? For example, are there any other details regarding your clinical assessment with the participant that you have not previously recorded that impacted the diagnosis you provided to the participant?		
YES	1	Yes
NO	2	No

NCD_9	NCD_NOTES_SP_MSP
[ASK IF NCD_NOTES_MSP = YES]	
CLINICIAN NOTE: Please do not enter any identifying information in this section.	
Please provide any notes below:	

NCD_10	NCD_LETTER1_MSP
ALWAYS ASK	
DO NOT READ: If your clinical assessment of the participant indicates that there may be a concern about the participant's memory, please fill out the CLSA Memory Study Participant Letter Template – Potential Cognitive Concerns template with the participant's name and MoCA score. If your clinical assessment of the participant indicates that there are not any concerns about the participant's memory, please fill out the CLSA Memory Study Participant Letter Template – No Cognitive Concerns template with the participant's name and MoCA score. Give the letter to the participant and verbally discuss the content.	

NCD_11	NCD_LETTER2_MSP	
ALWAYS ASK		
Did you give the letter to the participant?		
YES	1	Yes
NO	2	No

NCD_12	NCD_LETTER3_MSP
[ASK IF NCD_LETTER_MSP = NO]	
Why did you not give the letter to the participant? _____	

NCD_END

Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

Supplementary Appendix 6 - Informant Questionnaire

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

v1.1, 2022 October 12

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clsa élcv

CLSA Memory Study Informant Questionnaire
v1.1, 2022 October 12

Relationship to Participant (INF)

Overview	This questionnaire will be completed by an informant, a family member or friend who knows the participant well and can answer questions regarding the participant's medical history, functional abilities, and overall behaviour.

First, I would like to ask you about your relationship with @first_name@.

REL_1	**INF_REL_MSI**	
[ALWAYS ASK]		
What is your relationship with @first_name@?		
CODE ONLY ONE RESPONSE		
PARTNER	1	Spouse/partner
CHILD	2	Child
SIBLING	3	Sibling
FRIEND	4	Friend
OT_SP	5	Other, specify: _____
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

REL_2	**INF_GENDER_MSI**	
[ALWAYS ASK]		
What pronoun should we use when referring to @first_name@?		
CODE ONLY ONE RESPONSE		
HIM	1	He/him/his
HER	2	She/her/hers
THEM	3	They/them/theirs
OT_SP	5	Other, specify: _____
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

REL_END

AD8 Dementia Screening Interview (AD8)

Overview	The Eight-item Informant Interview to Differentiate Aging and Dementia (AD8) was designed as a screening tool to identify early cognitive changes associated with many common subtypes of dementia including Alzheimer's Disease, vascular dementia, Lewy body dementia, and frontotemporal dementia. The informant should specifically be asked to rate changes in the participant's ability for each of the items, without attributing causality. If read aloud to the respondent, it is important for the interviewer to carefully read the phrase as worded and give emphasis to note changes due to cognitive problems (not physical problems). There should be a one second delay between individual items. There is no specific timeframe for change required to be used for this questionnaire.

For the next few questions, please think about @first_name@'s cognitive abilities in regard to thinking and memory problems.

For each question, please respond "yes" if you have noticed a change and "no" if you have not noticed a change in @first_name@ over the past several years.

AD8_1	**AD8_1_MSI**	
[ALWAYS ASK]		
Problems with judgment (e.g., problems with making decisions, bad financial decisions, problems with thinking)		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

AD8_2	**AD8_2_MSI**

[ALWAYS ASK]		
Less interest in hobbies/activities		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

AD8_3	**AD8_3_MSI**	
[ALWAYS ASK]		
Repeats the same things over and over (questions, stories, or statements)		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

AD8_4	**AD8_4_MSI**	
[ALWAYS ASK]		
Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

AD8_5	**AD8_5_MSI**	
[ALWAYS ASK]		
Forgets correct month or year		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

AD8_6	**AD8_6_MSI**

[ALWAYS ASK]		
Trouble handling complicated financial affairs (e.g., balancing check book, income taxes, paying bills)		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

AD8_7	**AD8_7_MSI**
[ALWAYS ASK]	
Trouble remembering appointments	
YES	1 Yes
NO	2 No
DK_NA	8 **[DO NOT READ]** Don't know / No answer
REFUSED	9 **[DO NOT READ]** Refused

AD8_8	**AD8_8_MSI**
[ALWAYS ASK]	
Daily problems with thinking and/or memory	
YES	1 Yes
NO	2 No
DK_NA	8 **[DO NOT READ]** Don't know / No answer
REFUSED	9 **[DO NOT READ]** Refused

AD8_9	**AD8_TOTALSCORE0_MSI**
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 0]	
Score on the AD8 Dementia Screening Interview: 0	

AD8_10	**AD8_TOTALSCORE1_MSI**
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 1]	

Score on the AD8 Dementia Screening Interview: 1

AD8_11	**AD8_TOTALSCORE2_MSI**
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 2]	
Score on the AD8 Dementia Screening Interview: 2	

AD8_12	**AD8_TOTALSCORE3_MSI**
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 3]	
Score on the AD8 Dementia Screening Interview: 3	

AD8_13	**AD8_TOTALSCORE4_MSI**
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 4]	
Score on the AD8 Dementia Screening Interview: 4	

AD8_14	**AD8_TOTALSCORE5_MSI**
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 5]	
Score on the AD8 Dementia Screening Interview: 5	

AD8_15	**AD8_TOTALSCORE6_MSI**
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 6]	
Score on the AD8 Dementia Screening Interview: 6	

AD8_16	**AD8_TOTALSCORE7_MSI**
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 7]	

Score on the AD8 Dementia Screening Interview: 7

AD8_17	**AD8_TOTALSCORE8_MSI**
[ASK IF SUM OF "YES" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 8]	
Score on the AD8 Dementia Screening Interview: 8	

This variable identifies the number of items that were not completed on the Eight-item Informant Interview to Differentiate Aging and Dementia (AD8) questionnaire and should be considered when interpreting the total score of the AD8.

AD8_18	**AD8_TOTALMIS0_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 0]	
Number of missed questions on the AD8 Dementia Screening Interview: 0	

AD8_19	**AD8_TOTALMIS1_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 1]	
Number of missed questions on the AD8 Dementia Screening Interview: 1	

AD8_20	**AD8_TOTALMIS2_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 2]	
Number of missed questions on the AD8 Dementia Screening Interview: 2	

AD8_21	**AD8_TOTALMIS3_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 3]	
Number of missed questions on the AD8 Dementia Screening Interview: 3	

AD8_22	**AD8_TOTALMIS4_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 4]	

Number of missed questions on the AD8 Dementia Screening Interview: 4

AD8_23	**AD8_TOTALMIS5_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 5]	
Number of missed questions on the AD8 Dementia Screening Interview: 5	

AD8_24	**AD8_TOTALMIS6_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 6]	
Number of missed questions on the AD8 Dementia Screening Interview: 6	

AD8_25	**AD8_TOTALMIS7_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 7]	
Number of missed questions on the AD8 Dementia Screening Interview: 7	

AD8_26	**AD8_TOTALMIS8_MSI**
[ASK IF SUM OF "DON'T KNOW/NO ANSWER OR REFUSED" RESPONSES FOR AD8_1, AD8_2, AD8_3, AD8_4, AD8_5, AD8_6, AD8_7, AD8_8 = 8]	
Number of missed questions on the AD8 Dementia Screening Interview: 8	

AD8_END

Medical History (MED)

Overview	The medical history module captures information that will assist the examining physician in determining if any observed cognitive limitations may be secondary to other diseases such as neurodegenerative diseases. This information may also increase the confidence in the physician's diagnosis based on the absence or presence of risk factors for neurocognitive disorders.

I am now going to ask you some questions regarding @first_name@'s medical history including different medical conditions he/she may have, and use of other substances. We do not expect you to know every detail about @first_name@, but ask that you answer to the best of your ability.

MED_1	**MED_CON_MSI**	
[ALWAYS ASK]		
To your knowledge, does @first_name@ have any of the following medical conditions…?		
INTERVIEWER NOTES: Psychotic illnesses include schizophrenia and other conditions which include hallucinations, delusions and disordered forms of thinking.		
READ LIST, MULTIPLE RESPONSES ALLOWED (EXCEPT IF 98 OR 99 ARE SELECTED), CODE ALL THAT APPLY		
CAD	1	Coronary artery disease
HF	2	Heart failure
AF	3	Atrial fibrillation/flutter
TIA	4	Transient ischemic attack (TIA)
STR	5	Cerebrovascular accident (stroke)
HEM	6	Intracerebral hemorrhage
HYP	7	Hypertension
DIA	8	Diabetes mellitus
DYS	9	Dyslipidemia
PKD	10	Parkinson's Disease or Parkinsonism
DEP	11	Depression
ANX	12	Anxiety disorder
PSY	13	Psychotic illness
HR	14	Hearing impairment
VS	15	Visual impairment
SM	16	Impaired sense of smell
DEM	17	Dementia
DELI	18	Suspected delirium (in the past 5 years)
IN	19	Insomnia
REM	20	REM-Sleep Behaviour Disorder
OSA	21	Obstructive Sleep Apnea
HYPT	22	Hypothyroidism
B12	23	Vitamin B12 deficiency

OTSP	24	Other conditions relevant to cognitive status (e.g. cancer and/or cancer treatments); specify _____
NONEI	25	None of the above
DK_NA	98	**[DO NOT READ]** Don't know / No answer
REFUSED	99	**[DO NOT READ]** Refused

MED_2	**MED_TBI_MSI**	
[ALWAYS ASK]		
Has @first_name@ suffered a head injury or a concussion in the past?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_3	**MED_TBI1_MSI**	
[ASK IF MED_TBI_MSI = YES]		
How many head injuries or concussions has @first_name@ had in his/her lifetime?		
INTERVIEWER NOTE: If the informant cannot remember exact number, please probe for their best estimate		
NUM	Number	_____ **[MASK: MIN=1]**
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_4	**MED_TBI2_MSI**	
[ASK IF MED_TBI_MSI = YES]		
At what age or in what year did @first_name@ have the most serious head injury?		
INTERVIEWER NOTE: If the informant cannot remember the specific year, please probe for their best estimation of when the head injury occurred.		
NB_SP	Age	_____ **[MASK: MIN=0, MAX=CURRENT AGE]**
YR_SP	Year	_____ **[MASK: MIN=BIRTH YEAR, MAX=CURRENT YEAR]**
DK_NA	9998	**[DO NOT READ]** Don't know / No answer
REFUSED	9999	**[DO NOT READ]** Refused

MED_5	MED_TBI3_MSI	
[ASK IF MED_TBI_MSI = YES]		
Did the most serious head injury result in…?		
READ LIST, MULTIPLE RESPONSES ALLOWED (EXCEP IF 8 OR 9 ARE SELECTED), CODE ALL THAT APPLY		
DZ	1	Being dazed, confused, or “seeing stars”
DRM	2	Not remembering the injury
KO	3	Losing consciousness (knocked out)
NONE	6	Head injury did not result in any of the above
DK_NA	8	**[DO NOT READ]** Don’t know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_6	MED_TBI4_MSI	
[ASK IF MED_TBI3_MSI = KO**]**		
How long did @first_name@ lose consciousness for?		
READ LIST, CODE ONLY ONE RESPONSE		
KO1	1	Less than a minute
KO20	2	1-20 minutes
K020MORE	3	Longer than minutes
DK_NA	8	**[DO NOT READ]** Don’t know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_7	MED_SMKSTATUS_MSI	
[ALWAYS ASK]		
How would you describe @first_name@’s smoking status…?		
READ LIST, CODE ONLY ONE RESPONSE		
YES	1	Yes, he/she currently smokes
NEVER	2	No, he/she does not currently smoke and never has
FORM_DAY	4	Former daily smoker (non-smoker now)
FORM_OCC	5	Former occasional smoker (non-smoker now)
DK_NA	8	**[DO NOT READ]** Don’t know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_8	MED_CAN_MSI	
[ALWAYS ASK]		
Does @first_name@ use any cannabis products?		
READ LIST, CODE ONLY ONE RESPONSE		
YES	1	Yes, he/she currently uses cannabis products
NEVER	2	No, he/she has never used cannabis products
FORMER	3	Former cannabis user, but does not use cannabis products now
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_9	MED_ALC_MSI	
[ALWAYS ASK]		
How would you describe @first_name@'s alcohol consumption?		
READ LIST, CODE ONLY ONE RESPONSE		
NEVER	1	Never drank alcohol
FORMER	2	Used to drink alcohol but does not currently drink
CURRENT	3	Currently consumes alcohol
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_10	MED_ALCNMB_MSI	
[ASK IF MED_ALC_MSI = CURRENT]		
A "standard" drink is considered 12 ounces of regular beer (~5% alcohol), 5 ounces of wine (~12% alcohol), or 1.5 ounces of distilled spirits (~40% alcohol). How many estimated standardized drinks per week does @first_name@ consume?		
ALC_NB	Number of standard drinks: _____**[MASK: MIN=0, MAX=200]**	
DK_NA	998	**[DO NOT READ]** Don't know / No answer
REFUSED	999	**[DO NOT READ]** Refused

MED_11	MED_ALCMLFQ_MSI	
[ASK IF MED_ALC_MSI = CURRENT AND AND SEX = MALE]		
In the past 12 months, has @first_name@ consumed 5 or more drinks in 2 hours or less at least once a month?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_12	MED_ALCFMFQ_MSI	
[ASK IF MED_ALC_MSI = CURRENT AND SEX = FEMALE]		
In the past 12 months, has @first_name@ consumed 4 or more drinks in 2 hours or less at least once a month?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_13	MED_FAM_MSI	
[ALWAYS ASK]		
Does the @first_name@ have a first degree relative who has been diagnosed with dementia or Alzheimer's Disease?		
INTERVIEWER NOTE: First degree relatives include biological parents, siblings, or children		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

MED_END

Basic Activities of Daily Living (ADL)

This module is a modification of the Activities of Daily Living questions of the OARS Multidimensional Assessment Questionnaire© developed by Dr. Gerda G. Fillenbaum (Duke University Medical Center). The Canadian Longitudinal Study on Aging received permission from Dr. Fillenbaum (instrument developer) for the use of this instrument.

Overview	The Activities of Daily Living (ADL) scale assesses respondents' ability to perform basic daily activities. Activities of daily living are the tasks considered vital to live independently in the community. The informant is asked if the participant requires help when feeding and dressing oneself, taking care of their appearance, walking around, getting in and out of bed, bathing, and whether the participant has incontinence problems. These basic daily activities can be difficult to perform for people with mobility restrictions or limitations. Information on activities of daily living will help provide insights into limitations that Canadians may face in day-to-day living, as well as how these limitations change as people age. It is a measure related to the need for caregivers and home care services.

Now I'd like to ask you about activities of daily living. You may feel that some of these questions do not apply to @first_name@, but it is important that we ask the same questions of everyone.

ADL_1	**ADL_ABLDR_MSI**	
[ALWAYS ASK]		
Can @first_name@ dress and undress without help (including picking out clothes and putting on socks and shoes)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_2	**ADL_HPDR_MSI**	
[ASK IF ADL_ABLDR_MSI = NO]		
Can @first_name@ dress and undress with some help?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_3	ADL_UNDR_MSI	
[ASK IF ADL_HPDR_MSI = NO]		
Is @first_name@ completely unable to dress and undress?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_4	ADL_ABLFD_MSI	
[ALWAYS ASK]		
Can @first_name@ eat without help (i.e., able to feed him or herself completely)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_5	ADL_HPFD_MSI	
[ASK IF ADL_ABLFD_MSI = NO]		
Can @first_name@ eat with some help (i.e., needs help with cutting food, etc.)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_6	ADL_UNFD_MSI	
[ASK IF ADL_HPFD_MSI = NO]		
Is @first_name@ completely unable to feed himself or herself?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_7	ADL_ABLAP_MSI	
[ALWAYS ASK]		
Can @first_name@ take care of his/her own appearance without help, for example, combing hair, shaving (if male)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_8	ADL_HPAP_MSI	
[ASK IF ADL_ABLAP_MSI = NO]		
Can @first_name@ take care of his or her own appearance with some help?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_9	ADL_UNAP_MSI	
[ASK IF ADL_HPAP_MSI = NO]		
Is @first_name@ completely unable to take care of his or her own appearance?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_10	ADL_ABLWK_MSI	
[ALWAYS ASK]		
Can @first_name@ walk without help?		
INTERVIEWER NOTE: IF PARTICIPANT WALKS WITH A CANE CODE AS YES		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_11	ADL_HPWK_MSI	
[ASK IF ADL_ABLWK_MSI = NO]		
Can @first_name@ walk with some help from a person, or with the use of a walker or crutches, etc.?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_12	ADL_UNWK_MSI	
[ASK IF ADL_HPWK_MSI = NO]		
Is @first_name@ completely unable to walk?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_13	ADL_ABLBD_MSI	
[ALWAYS ASK]		
Can @first_name@ get in and out of bed without any help or aids?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_14	ADL_HPBD_MSI	
[ASK IF ADL_ABLBD_MSI = NO]		
Can @first_name@ get in and out of bed with some help (either from a person or with the aid of some device)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_15	ADL_UNBD_MSI	
[ASK IF ADL_HPBD_MSI = NO]		
Is @first_name@ totally dependent on someone else to lift him/her in and out of bed?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_16	ADL_ABLBT_MSI	
[ALWAYS ASK]		
Can @first_name@ take a bath or shower without help?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_17	ADL_HPBT_MSI	
[ASK IF ADL_ABLBT_MSI = NO]		
Can @first_name@ take a bath or shower with some help (i.e., needs help from someone getting in and out of the tub or needs special attachments on the tub)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_18	ADL_UNBT_MSI	
[ASK IF ADL_HPBT_MSI = NO]		
Is @first_name@ completely unable to take a bath and a shower by himself/herself?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_19	ADL_BATH_MSI	
[ALWAYS ASK]		
Does @first_name@ ever have trouble getting to the bathroom in time?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_20	ADL_INCNT_MSI	
[ASK IF ADL_BATH_MSI = YES]		
How often does @first_name@ wet or soil himself/herself (either day or night)? Would you say…		
READ LIST, CODE ONLY ONE RESPONSE		
0_1_TIME_WEEK	1	Never or less than once a week
1_2_TIME_WEEK	2	Once or twice a week
3_MORE_TIMES_WEEK	3	Three times a week or more
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

ADL_END

Instrumental Activities of Daily Living (IADL)

This module is a modification of the Activities of Daily Living questions of the OARS Multidimensional Assessment Questionnaire© developed by Dr. Gerda G. Fillenbaum (Duke University Medical Center). The Canadian Longitudinal Study on Aging received permission from Dr. Fillenbaum (instrument developer) for the use of this instrument.

Overview	The Instrumental Activities of Daily Living (IADL) scale assesses respondents' ability to independently perform a series of daily activities. The informant is asked if the participant requires help when using the telephone, traveling, shopping, cooking, doing housework, taking medicine and handling money. Information on instrumental activities of daily living will help provide insights into limitations that Canadians may face day-to-day living, as well as how these limitations change as people age. It is a measure related to the need for caregivers and home care services. This module is a companion to the ADL module.

Now I'd like to ask you about activities of daily living. You may feel that some of these questions do not apply to @first_name@, but it is important that we ask the same questions of everyone.

IAL_1	**IAL_ABLTEL_MSI**	
[ALWAYS ASK]		
Can @first_name@ use the telephone without help, including looking up numbers and dialling?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_2	**IAL_HPTEL_MSI**	
[ASK IF IAL_ABLTEL_MSI = NO]		
Can @first_name@ use the telephone with some help (i.e., can answer the phone or dial the operator in an emergency, but needs a special phone or help in getting the number or dialling)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_3	IAL_UNTEL_MSI	
[ASK IF IAL_HPTEL_MSI = NO]		
Is @first_name@ completely unable to use the telephone?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_4	IAL_ABLTRV_MSI	
[ALWAYS ASK]		
Can @first_name@ get to places out of walking distance without help (i.e., drive own car, or travel alone on buses, or taxis)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_5	IAL_HPTRV_MSI	
[ASK IF IAL_ABLTRV_MSI = NO]		
Can @first_name@ get to places out of walking distance with some help (i.e., needs someone to help him/her or go with him/her when travelling)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_6	IAL_UNTRV_MSI	
[ASK IF IAL_HPTRV_MSI = NO]		
Is @first_name@ unable to travel unless emergency arrangements are made for a specialized vehicle, like an ambulance?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_7	IAL_ABLGRO_MSI	
[ALWAYS ASK]		
Can @first_name@ go shopping for groceries or clothes without help (taking care of all shopping needs)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_8	IAL_HPGRO_MSI	
[ASK IF IAL_ABLGRO_MSI = NO]		
Can @first_name@ go shopping for groceries or clothes with some help (i.e., needs someone to go with him/her on all shopping trips)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_9	IAL_UNGRO_MSI	
[ASK IF IAL_HPGRO_MSI = NO]		
Is @first_name@ completely unable to do any shopping?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_10	IAL_ABLML_MSI	
[ALWAYS ASK]		
Can @first_name@ prepare his/her own meals without help (i.e., plan and cook full meals)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_11	IAL_HPML_MSI	
[ASK IF IAL_ABLML_MSI = NO]		
Can @first_name@ prepare his/her own meals with some help (i.e., can prepare some things but are unable to cook full meals)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_12	IAL_UNML_MSI	
[ASK IF IAL_HPML_MSI = NO]		
Is @first_name@ completely unable to prepare any meals?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_13	IAL_ABLWRK_MSI	
[ALWAYS ASK]		
Can @first_name@ do housework without help (i.e., can clean floors, etc.)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_14	IAL_HPWRK_MSI	
[ASK IF IAL_ABLWRK_MSI = NO]		
Can @first_name@ do housework with some help (i.e., can do light housework but needs help with heavy work)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_15	IAL_UNWRK_MSI	
[ASK IF IAL_HPWRK_MSI = NO]		
Is @first_name@ completely unable to do any housework?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_16	IAL_ABLMED_MSI	
[ALWAYS ASK]		
Can @first_name@ take his or her own medicine without help (in the right doses at the right time)?		
INTERVIEWER INSTRUCTIONS: IF THE PARTICIPANT OCCASIONALLY FORGETS, CODE AS 'YES'.		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

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IAL_17	**IAL_HPMED_MSI**	
[ASK IF IAL_ABLMED_MSI = NO]		
Can @first_name@ take his or her own medicine with some help (i.e., able to take medicine if someone prepares it for him/her or reminds him/her to take it)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_18	**IAL_UNMED_MSI**	
[ASK IF IAL_HPMED_MSI = NO]		
Is @first_name@ completely unable to take his/her own medicine?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_19	**IAL_ABLMO_MSI**	
[ALWAYS ASK]		
Can @first_name@ handle his/her own money without help (i.e., write cheques, pay bills, etc.)?		
INTERVIEWER INSTRUCTIONS: IF THE PARTICIPANT OCCASIONALLY FORGETS, CODE AS 'YES'.		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_20	IAL_HPMO_MSI	
[ASK IF IAL_ABLMO_MSI = NO]		
Can @first_name@ handle his/her own money with some help (i.e., manage day-to-day buying but needs help with managing chequebook or paying bills)?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_21	IAL_UNMO_MSI	
[ASK IF IAL_HPMO_MSI = NO]		
Is @first_name@ completely unable to handle his/her own money?		
YES	1	Yes
NO	2	No
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

IAL_END

Transportation (TRA)

Overview	The questions in this module ask the informant about the participant's driving status and details regarding their license status.

I will now ask you a few questions about @first_name@'s ability to use different types of transportation.

TRA_1	**TRA_DSTATUS_MSI**	
[ALWAYS ASK]		
Which of the following describes @first_name@ driving status...? (Include cars, vans, trucks and motorcycles)		
READ LIST, CODE ONLY ONE RESPONSE		
NEVER	1	Never had a driver's license
FORMER	2	Had a driver's license at one point in his or her life, but currently does not have it
CURRENT	3	Has a driver's license without restrictions (except corrective lenses)
RESTRICTED	4	Has a driver's license with restrictions on time of driving (daylight only), distance from home, type of road (no highway), or number of passengers
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

TRA_2	**TRA_STOP_MSI**	
[ASK IF TRA_STA_MSI = FORMER]		
Why did @first_name@ stop driving…?		
CODE ONLY ONE RESPONSE		
VOL_STOP	1	Voluntarily stopped driving
LICS_RESC	2	License rescinded
OT_SP	3	Other (please specify: _____)
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

TRA_3	TRA_STOPYR_MSI	
[ASK IF TRA_STA_MSI =FORMER]		
In what year or at what age did @first_name@ stop driving?		
NB_SP	Age	_____ **[MASK: MIN=00, MAX=CURRENT AGE]**
YR_SP	Year	_____ **[MASK: MIN=BIRTH YEAR, MAX=CURRENT YEAR]**
DK_NA	9998	**[DO NOT READ]** Don't know / No answer
REFUSED	9999	**[DO NOT READ]** Refused

TRA_4	TRA_TRANSIT_MSI	
[ALWAYS ASK]		
How would you describe @first_name@ use of public transit…?		
CODE ONLY ONE RESPONSE		
CURR	1	Currently uses
COULD	2	Does not use public transit, but could if they wanted to
CANNOT	3	Does not use public transit and does not think they could
DK_NA	8	**[DO NOT READ]** Don't know / No answer
REFUSED	9	**[DO NOT READ]** Refused

TRA_END

Mild Behavioural Impairment Checklist (MBI)

This module consists of the Mild Behavioural Impairment Checklist developed by Dr. Zahinoor Ismail (University of Calgary).

Overview	Mild Behavioural Impairment (MBI) refers to neuropsychiatric symptoms which are usually observed before cognitive decline and dementia in individuals aged 50 years and older. MBI describes symptoms of any severity that persist for at least six months, and occur either before or at the same time as mild neurocognitive disorder. The MBI Checklist is a 34-item instrument which can be completed by a patient/participant, close informant, or clinician. The checklist is designed to quantify the severity of behavioural symptoms in multiple domains. Global and domain-specific scores and thresholds have not yet been developed and validated for clinical diagnosis and prognosis. Ongoing validation work will identify scores and thresholds that predict an increased risk of transition to dementia.

I will now ask you some questions about @first_name@'s behaviour. For each question, please answer "yes" if you have noticed this behaviour continuously or on and off for **at least 6 months**, and if it is a **change** from her/his longstanding pattern of behaviour. Otherwise, please answer "no".

For each question you respond "yes" to indicating a change in behaviour, I will ask you to respond about the severity of the behaviour based on the following options:

1) Mild where the change in behaviour is noticeable, but not a significant change;
2) Moderate where the change in behaviour is significant, but not a dramatic change;
3) Severe where the change in behaviour is marked or prominent, a dramatic change.

If there is more than one behaviour listed in a question, please rate the most severe behavioural change.

The first domain describes interest, motivation, and drive.

MBI_1	**MBI_INTER_MSI**	
[ALWAYS ASK]		
Has the person lost interest in friends, family, or home activities?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_2	MBI_INTERSEV_MSI	
[ASK IF MBI_INTER_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_3	MBI_CURI_MSI	
[ALWAYS ASK]		
Does the person lack curiosity in topics that would usually have attracted her/his interest?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_4	MBI_CURISEV_MSI	
[ASK IF MBI_CURI_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_5	MBI_SPON_MSI	
[ALWAYS ASK]		
Has the person become less spontaneous and active – for example, is she/he less likely to initiate or maintain conversation?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_6	MBI_SPONSEV_MSI	
[ASK IF MBI_SPON_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_7	MBI_MOTI_MSI	
[ALWAYS ASK]		
Has the person lost motivation to act on her/his obligations or interest?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_8	MBI_MOTISEV_MSI	
[ASK IF MBI_MOTI_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_9	MBI_EMOT_MSI	
[ALWAYS ASK]		
Is the person less affectionate and/or lacking in emotions when compared to her/his usual self?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_10	MBI_EMOTSEV_MSI	
[ASK IF MBI_EMOT_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_11	MBI_CARE_MSI	
[ALWAYS ASK]		
Does she/he no longer care about anything?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_12	MBI_CARESEV_MSI	
[ASK IF MBI_CARE_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

The second domain describes mood or anxiety symptoms.

Interviewer note, remind the respondent if required: For each questions you respond "yes" to indicating a change in behaviour, I will ask you to respond about the severity of the behaviour based on the following options:

1) Mild where the change in behaviour is noticeable, but not a significant change;
2) Moderate where the change in behaviour is significant, but not a dramatic change;
3) Severe where the change in behaviour is marked or prominent, a dramatic change.

If there is more than one behaviour listed in a question, please rate the most severe behavioural change.

MBI_13	MBI_SAD_MSI	
[ALWAYS ASK]		
Has the person developed sadness or appear to be in low spirits? Does she/he have episodes of tearfulness?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_14	MBI_SADSEV_MSI	
[ASK IF MBI_SAD_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_15	MBI_PLES_MSI	
[ALWAYS ASK]		
Has the person become less able to experience pleasure?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_16	MBI_PLESSEV_MSI	
[ASK IF MBI_PLES_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_17	MBI_DISC_MSI	
[ALWAYS ASK]		
Has the person become discouraged about their future or feel that she/he is a failure?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_18	MBI_DISCSEV_MSI	
[ASK IF MBI_DISC_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_19	MBI_BURD_MSI	
[ALWAYS ASK]		
Does the person view herself/himself as a burden to family?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_20	MBI_BURDSEV_MSI	
[ASK IF MBI_BURD_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_21	MBI_ANX_MSI	
[ALWAYS ASK]		
Has the person become more anxious or worried about things that are routine (e.g. events, visits, etc.)?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_22	MBI_ANXSEV_MSI	
[ASK IF MBI_ANX_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_23	**MBI_TENSE_MSI**	
[ALWAYS ASK]		
Does the person feel very tense, having developed an inability to relax, or shakiness, or symptoms of panic?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_24	**MBI_TENSESEV_MSI**	
[ASK IF MBI_TENSE_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

The third domain describes the ability to delay gratification and control behaviour, impulses, oral intake and/or changes in reward.

Interviewer note, remind the respondent if required: For each questions you respond "yes" to indicating a change in behaviour, I will ask you to respond about the severity of the behaviour based on the following options:

1) Mild where the change in behaviour is noticeable, but not a significant change;
2) Moderate where the change in behaviour is significant, but not a dramatic change;
3) Severe where the change in behaviour is marked or prominent, a dramatic change.

If there is more than one behaviour listed in a question, please rate the most severe behavioural change.

MBI_25	**MBI_AGGR_MSI**	
[ALWAYS ASK]		
Has the person become agitated, aggressive, irritable, or temperamental?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_26	MBI_AGGRSEV_MSI	
[ASK IF MBI_AGGR_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_27	MBI_ARGU_MSI	
[ALWAYS ASK]		
Has she/he become unreasonably or uncharacteristically argumentative?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_28	MBI_ARGUSEV_MSI	
[ASK IF MBI_ARGU_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_29	MBI_IMPU_MSI	
[ALWAYS ASK]		
Has the person become more impulsive, seeming to act without considering things?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_20	MBI_IMPUSEV_MSI	
[ASK IF MBI_IMPU_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_31	MBI_DISI_MSI	
[ALWAYS ASK]		
Does the person display sexually disinhibited or intrusive behaviour, such as touching (themselves/others), hugging, groping, etc., in a manner that is out of character or may cause offense?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_32	MBI_DISISEV_MSI	
[ASK IF MBI_DISI_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_33	MBI_FRUS_MSI	
[ALWAYS ASK]		
Has the person become more easily frustrated or impatient? Does she/he have troubles coping with delays, or waiting for events or for their turn?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_34	MBI_FRUSSEV_MSI	
[ASK IF MBI_FRUS_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_35	MBI_DRIVE_MSI	
[ALWAYS ASK]		
Does the person display a new recklessness or lack of judgement when driving (e.g. speeding, erratic swerving, abrupt lane changes, etc.)?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_36	MBI_DRIVESEV_MSI	
[ASK IF MBI_DRIVE_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_37	MBI_STUB_MSI	
[ALWAYS ASK]		
Has the person become more stubborn on rigid, i.e., uncharacteristically insistent on having their way, or unwilling/unable to see/hear other views?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_38	MBI_STUBSEV_MSI

[ASK IF MBI_STUB_MSI = Yes]

How would you describe the severity of this behaviour…?

CODE ONLY ONE RESPONSE

MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_39	MBI_FOOD_MSI

[ALWAYS ASK]

Is there a change in eating behaviours (e.g., overeating, cramming the mouth, insistent on eating only specific foods, or eating the food in exactly the same order)?

YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_40	MBI_FOODSEV_MSI

[ASK IF MBI_FOOD_MSI = Yes]

How would you describe the severity of this behaviour…?

CODE ONLY ONE RESPONSE

MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_41	MBI_APP_MSI	
[ALWAYS ASK]		
Does the person no longer find food tasteful or enjoyable? Are they eating less?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_42	MBI_APPSEV_MSI	
[ASK IF MBI_APP_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_43	MBI_HOARD_MSI	
[ALWAYS ASK]		
Does the person hoard objects when she/he did not do so before?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_44	MBI_HOARDSEV_MSI

[ASK IF MBI_HOARD_MSI = Yes]

How would you describe the severity of this behaviour…?

CODE ONLY ONE RESPONSE

MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_45	MBI_REP_MSI

[ALWAYS ASK]

Has the person developed simple repetitive behaviours or compulsions?

YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_46	MBI_REPSEV_MSI

[ASK IF MBI_REP_MSI = Yes]

How would you describe the severity of this behaviour…?

CODE ONLY ONE RESPONSE

MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_47	MBI_REGU_MSI	
[ALWAYS ASK]		
Has the person recently developed trouble regulating smoking, alcohol, drug intake or gambling, or started shoplifting?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_48	MBI_REGUSEV_MSI	
[ASK IF MBI_REGU_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

The next domain describes following society norms and having social graces, tact, and empathy.

Interviewer note, remind the respondent if required: For each questions you respond "yes" to indicating a change in behaviour, I will ask you to respond about the severity of the behaviour based on the following options:

1) Mild where the change in behaviour is noticeable, but not a significant change;
2) Moderate where the change in behaviour is significant, but not a dramatic change;

Severe where the change in behaviour is marked or prominent, a dramatic change. If there is more than one behaviour listed in a question, please rate the most severe behavioural change.

MBI_49	MBI_INSEN_MSI	
[ALWAYS ASK]		
Has the person become less concerned about how her/his words or actions affect others? Has she/he become insensitive to others' feelings?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_50	MBI_INSENSEV_MSI	
[ASK IF MBI_INSEN_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_51	MBI_OPEN_MSI	
[ALWAYS ASK]		
Has the person started talking openly about very personal or private matters not usually discussed in public?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_52	MBI_OPENSEV_MSI	
[ASK IF MBI_OPEN_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_53	MBI_RUDE_MSI	
[ALWAYS ASK]		
Does the person say rude or crude things or make lewd sexual remarks that she/he would not have said before?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_54	MBI_RUDESEV_MSI	
[ASK IF MBI_RUDE_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_55	MBI_JUDGE_MSI	
[ALWAYS ASK]		
Does the person seem to lack the social judgement she/he previously had about what to say or how to behave in public or private?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_56	MBI_JUDGESEV_MSI

[ASK IF MBI_JUDGE_MSI = Yes]

How would you describe the severity of this behaviour…?

CODE ONLY ONE RESPONSE

MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_57	MBI_TALK_MSI

[ALWAYS ASK]

Does the person now talk to strangers as if familiar, or intrude on their activities?

YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_58	MBI_TALKSEV_MSI

[ASK IF MBI_TALK_MSI = Yes]

How would you describe the severity of this behaviour…?

CODE ONLY ONE RESPONSE

MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

This last domain describes strongly held beliefs and sensory experiences.

Interviewer note, remind the respondent if required: For each questions you respond "yes" to indicating a change in behaviour, I will ask you to respond about the severity of the behaviour based on the following options:

1) Mild where the change in behaviour is noticeable, but not a significant change;
2) Moderate where the change in behaviour is significant, but not a dramatic change;
3) Severe where the change in behaviour is marked or prominent, a dramatic change.

If there is more than one behaviour listed in a question, please rate the most severe behavioural change.

MBI_59	**MBI_HARM_MSI**	
[ALWAYS ASK]		
Has the person developed beliefs that they are in danger, or that others are planning to harm them or steal their belongings?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_60	**MBI_HARMSEV_MSI**	
[ASK IF MBI_HARM_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_61	**MBI_SUSP_MSI**	
[ALWAYS ASK]		
Has the person developed suspiciousness about the intentions or motives of other people?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_62	MBI_SUSPSEV_MSI
[ASK IF MBI_SUSP_MSI = Yes]	
How would you describe the severity of this behaviour…?	
CODE ONLY ONE RESPONSE	

MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_63	MBI_UNRL_MSI
[ALWAYS ASK]	
Doe she/he have unrealistic beliefs about her/his power, wealth, or skills?	

YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_64	MBI_UNRLSEV_MSI
[ASK IF MBI_UNRL_MSI = Yes]	
How would you describe the severity of this behaviour…?	
CODE ONLY ONE RESPONSE	

MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_65	**MBI_VOICE_MSI**	
[ALWAYS ASK]		
Does the person describe hearing voices or does she/he talk to imaginary people or “spirits”		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don’t know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_66	**MBI_VOICESEV_MSI**	
[ASK IF MBI_VOICE_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don’t know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_67	**MBI_IMAG_MSI**	
[ALWAYS ASK]		
Does the person report or complain about, or act as if seeing things (e.g. people, animals, or insects) that are not there, i.e., that are imaginary to others?		
YES	1	Yes
NO	2	No
DK_NA	8	**DO NOT READ]** Don’t know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_68	MBI_IMAGSEV_MSI	
[ASK IF MBI_IMAG_MSI = Yes]		
How would you describe the severity of this behaviour…?		
CODE ONLY ONE RESPONSE		
MILD	1	Mild
MOD	2	Moderate
SEVERE	3	Severe
DK_NA	8	**DO NOT READ]** Don't know / No answer
REFUSED	9	**DO NOT READ]** Refused

MBI_END

Supplementary Appendix 7 – Letter for participants with potential concerns about their cognition

clsa élcv
Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

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Date

Dear [Participant name],

During your Data Collection Site visit for the Canadian Longitudinal Study on Aging (CLSA) Memory Study, our assessment identified a potential concern about your memory. We encourage you to discuss these results with your family physician. Please find below information that may be given to a physician to provide context for the examination result.

This person is a participant in the Canadian Longitudinal Study on Aging (CLSA) (www.clsa/elcv.ca). The study is funded by the Canadian Institutes of Health Research (CIHR) and will involve 50,000 participants aged 45 to 85 years from across Canada who will be followed for up to 20 years.

The CLSA is conducting a substudy on the topic of memory funded by the Public Health Agency of Canada (PHAC). Participants in this study complete a clinical assessment done by a clinician specializing in geriatric psychiatry, neurology, or psychiatry with experience in cognitive assessment. The clinical assessment includes questions about the participant's medical history, a brief cognitive test, a neurocognitive examination, and observation of mobility. A family member or friend who knows the participant well answered questions regarding the participant's cognitive health, ability to complete daily tasks, and behaviour.

The clinical assessment was completed for research purposes only and was not intended for clinical use. One component of the clinical assessment was the administration of the Montreal Cognitive Assessment (MoCA) which is used to screen for potential cognitive problems. The participant score on the MoCA was _____. The interpretation of a MoCA score requires judgement by an experienced clinician who is aware of other aspects of the participant's health. A score itself does not indicate a specific diagnosis.

If you have any questions, please feel free to contact [*Site Coordinator name or Site PI name as per DCS-specific protocol*] at [*phone number*].

Sincerely,

[Clinician name]

Supported by the **Government of Canada** through the **Canadian Institutes of Health Research** and the **Canada Foundation for Innovation**.

Appuyée par le **gouvernement du Canada** par l'entremise des **Instituts de recherche en santé du Canada** et de la **Fondation canadienne pour l'innovation**.

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Supplementary Appendix 8 – Letter for participants without potential concerns about their cognition

clsa élcv
Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

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Department of Community Health & Epidemiology and Department of Medicine
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Date

Dear [Participant name],

During your Data Collection Site visit for the Canadian Longitudinal Study on Aging (CLSA) Memory Study, our assessment did not identify any concerns about your memory. Please find below information that may be given to a physician to provide context for the examination result.

This person is a participant in the Canadian Longitudinal Study on Aging (CLSA) (www.clsa/elcv.ca). The study is funded by the Canadian Institutes of Health Research (CIHR) and will involve 50,000 participants aged 45 to 85 years from across Canada who will be followed for up to 20 years.

The CLSA is conducting a substudy on the topic of memory funded by the Public Health Agency of Canada (PHAC). Participants in this study complete a clinical assessment done by a clinician specializing in geriatric psychiatry, neurology, or psychiatry with experience in cognitive assessment. The clinical assessment includes questions about the participant's medical history, a brief cognitive test, a neurocognitive examination, and observation of mobility. A family member or friend who knows the participant well answered questions regarding the participant's cognitive health, ability to complete daily tasks, and behaviour.

The clinical assessment was completed for research purposes only and was not intended for clinical use. One component of the clinical assessment was the administration of the Montreal Cognitive Assessment (MoCA) which is used to screen for potential cognitive problems. The participant score on the MoCA was _____. The interpretation of a MoCA score requires judgement by an experienced clinician who is aware of other aspects of the participant's health. A score itself does not indicate a specific diagnosis.

If you have any questions, please feel free to contact [*Site Coordinator name or Site PI name as per DCS-specific protocol*] at [*phone number*].

Sincerely,

[Clinician name]

Supported by the **Government of Canada** through the **Canadian Institutes of Health Research** and the **Canada Foundation for Innovation**.

Appuyée par le **gouvernement du Canada** par l'entremise des **Instituts de recherche en santé du Canada** et de la **Fondation canadienne pour l'innovation**.

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Supplementary Appendix 9, Table 1 – DSM-5 Diagnostic criteria mapped on to CLSA data for mild NCD

DSM-5 Diagnostic Criteria	Components of algorithm in the CLSA	Operationalization	Limitations
A - Modest cognitive decline in one or more cognitive domains based on: **1) concern about mild decline, expressed by individual or reliable informant, or observed by clinicians**	Subjective cognitive decline	Responds "yes" to "Do you feel like your memory is becoming worse" and if yes, responds "strongly agree" or "agree" to "does this worry you?"	Questions not available at baseline
	Physician diagnosis of memory problem	Responds "yes" to "Has a doctor ever told you that you have a memory problem"	Underestimates burden of memory problems
	Multifactorial Memory Questionnaire	Individual participant t-scores will be derived and interpreted based on the recommendations of the developer. Participants categorized as "low" or "very low" based on their t-score will be classified as having mild decline	Questions not available at baseline
2) AND/OR modest impairment documented by objective cognitive assessment	Performance on the Rey Auditory Verbal Learning Test (REY1 and REY2), the Animal Fluency Test (AFT2), and the Mental Alternation Test (MAT)	Mean Z score of >-2.0 but <1.5 on two or more cognitive tests	• CLSA cognitive tests not designed to detect mild/major NCD • Missing data due to participant refusing test, technology issues, and other non-participant related factors
B - The cognitive deficits do not interfere with capacity for independence in everyday activities	Instrumental Activities of Daily Living (IADL)	Participant reports doing the following activities independently; grocery shopping, money management, housework, preparing meals, medication management, preparing meals, using telephone, getting to places out of walking distance	• Self-reported, ideal to have informant reported IADLs • Mobility, hearing, visions, and physical limitations may explain inability to complete IADLs independently. Basic Activities of Daily Living, self-rated and measured hearing/vision, and

			physical function tests such as gait speed, the Timed Up and Go, Chair Rise test, balance, and grip strength will be explored to determine if reasons other than problems with cognition may explain the presence of IADL limitations.
C- The cognitive deficits do not occur exclusively in the context of a delirium	Assumed to not be present - participants being seen for a scheduled data collection visit are unlikely to have delirium		The CLSA does not collect this information
D - The cognitive deficits are not better explained by another mental disorders (e.g., major depressive disorder, schizophrenia)	The Centre for Epidemiological Studies Depression Scale (CESD-10)	Exclude participants who have a score of ≥ 10 indicating the presence of significant depressive symptoms	May have both a cognitive disorder and a current mood disorder
	Physician diagnosis of a mood disorder	Responds "yes" to "Has a doctor ever told you that you have a mood disorder such as depression (including manic depression), bipolar disorder, mania, or dysthymia? " Responds "yes" to "Has a doctor ever told you that you suffer from major depression?"	• Without data on current mood (e.g., CESD-10 score), unclear if mood disorders are historic or active • Self-reported data may underestimate • May have both a cognitive disorder and a history of mood disorders.

Supplementary Appendix 9, Table 2 – DSM-5 Diagnostic criteria mapped on to CLSA data for major NCD

DSM-5 Diagnostic Criteria	Components of algorithm in the CLSA	Operationalization	Limitations
A – Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition) based on: **3) Concern of the individual, knowledgeable informant, or the clinician** **4) AND/OR substantial impairment in cognitive performance, preferably documented by standardized neuropsychological testing**	Physician diagnosis of dementia or Alzheimer's disease	Responds "yes" to "Has a doctor ever told you that you have dementia or Alzheimer's disease?	Underestimates burden of memory problems
		Prescription for dementia-specific medication including cholinesterase inhibitor, or memantine	Only aware of the medications provided to interviewer by participant
	All participants - Performance on the Rey Auditory Verbal Learning Test (REY1 and REY2), the Animal Fluency Test (AFT2), and the Mental Alternation Test (MAT) Comprehensive cohort participants - the Stroop test, Controlled Oral Word Association Test, and Miami Prospective Memory Tests will additionally be used.	Mean Z score of ≤-2.0 on two or more cognitive tests	• CLSA cognitive tests not designed to detect mild/major NCD • Missing data due to participant refusing test, technology issues, and other non-participant related factors
B - The cognitive deficits interfere with capacity for independence in everyday activities	Instrumental Activities of Daily Living (IADL)	Participant or proxy reports requiring assistance with one or more of the following activities; grocery shopping, money management, housework, preparing meals, medication management, preparing meals, using	• Self-reported, ideal to have informant reported IADLs • Mobility, hearing, visions, and physical limitations may explain inability to complete IADLs independently. Basic Activities of Daily Living, self-rated and

		telephone, getting to places out of walking distance.	measured hearing/vision, and physical function tests such as gait speed, the Timed Up and Go, Chair Rise test, balance, and grip strength will be explored to determine if reasons other than problems with cognition may explain the presences of IADL limitations.
C- The cognitive deficits do not occur exclusively in the context of a delirium	Assumed to not be present - participants being seen for a scheduled data collection visit are unlikely to have delirium		The CLSA does not collect this information
D - The cognitive deficits are not better explained by another mental disorders (e.g., major depressive disorder, schizophrenia)	The Centre for Epidemiological Studies Depression Scale (CESD-10)	Participant has a score of ≥ 10 indicating the presence of depressive symptoms	May have both a cognitive disorder and a current mood disorder
	Physical diagnosis of a mood disorder	Responds "yes" to "Has a doctor ever told you that you have a mood disorder such as depression (including manic depression), bipolar disorder, mania, or dysthymia? "	• Without data on current mood (e.g., CESD-10 score), unclear if mood disorders are historic or active • Self-reported data may underestimate • May have both a cognitive disorder and a current or history of mood disorder
		Responds "yes" to "Has a doctor ever told you that you suffer from major depression?"	

Supplementary Appendix 10 – Locally responsible research ethics boards

- Université de Sherbrooke (Project ID 2009-18)
- Hamilton Integrated Research Ethics Board (Project ID 14406)
- Dalhousie University (Project ID 2010-2336)
- University of Manitoba (Project ID H2010:330), McGill University (Project ID A05-E59-10A)
- McGill University Health Centre Research Institute (Project ID: 2018-3497)
- Memorial University of Newfoundland (Project ID 11.003)
- University of Victoria (Project ID 11-320-C)
- Élisabeth Bruyère Research Institute of Ottawa (Project ID M16-10-023)
- University of British Columbia (Project ID H10-02143)
- Island Health (Formerly the Vancouver Island Health Authority, Project ID C2010-80)
- Simon Fraser University (Project ID 2010s0527)
- Calgary Conjoint Health Research Ethics Board (Project E-23489).