

## CLSA Brain MRI, Memory Tests, and Stool Sample Participant Information Package

There has been very little research to date to understand why some people's brain remains healthy and others develop diseases such as dementia.

The CLSA is collecting additional information about brain health from some CLSA participants to add to the data the CLSA already collects. There are three main components that are needed to adequately study brain health: MRI of the brain, new memory tests, and stool sample collection once every three years.

There is more detail below about these measures. Please read this information carefully. At your in-home interview, you can speak with the interviewer about the information, ask any questions you might have, and decide if you wish to have these new measures collected. This information will be most useful if all components are collected on the same person. You may choose not to take part in these data collection measures and still remain in the CLSA.

### **IMPORTANT:**

It is important to note that there are a number of reasons why someone should not undergo an MRI. These reasons are called contraindications. We have listed the contraindications below.

You should not have an MRI if you have any of the following items implanted in your body:

- Cardiac pacemaker, wires, or a defibrillator
- Metal fragment in the eye or orbit
- Brain aneurysm clip
- **Stainless steel** Intrauterine Device (IUD)
- Artificial heart valve
- Eye or ear implant
- Implanted drug infusion pump
- Shunt
- Electrical stimulator for nerves or bones
- Coil, catheter or filter in any blood vessel
- Orthopedic hardware (artificial joint, plate, screws, rods)
- Other metallic prosthesis
- Shrapnel, bullets, or other metallic fragments
- Stent

You should also not have an MRI if:

- You are pregnant;
- You suffer from claustrophobia (even if this is manageable with medication).

Please know that you can always contact us with any questions by emailing us at [info@clsa-elcv.ca](mailto:info@clsa-elcv.ca) or by telephone at 1-866-999-8303.

### **What can I expect if I agree to these three new measurements?**

- 1) At your in-home interview, you will be provided with a package that will include two stool sample self-collection kits. Step-by-step instructions will be provided. You will be asked to bring the samples with you when you come for your data collection site visit.
- 2) You will complete the memory tests on an iPad at your Data Collection Site (DCS) interview. These tests involve using a smart pen to interact with images on the iPad screen, to test visual memory, learning, and attention. This will take about 20 minutes.
- 3) After your data collection site visit, you will be contacted by CLSA staff to schedule a **1 hour MRI** appointment at a MRI facility located near the CLSA DCS. You will be given \$30 in cash or by gift card in lieu of expenses such as parking or other travel-related expenses;

**You will be asked to repeat all of the measures at your next CLSA interview in 3 years.**

### **What are the possible risks and discomforts?**

There are no known medical risks to completing the stool sample collection and memory tests.

### **There are some risks in undergoing an MRI:**

- The magnetic effect of the MRI on implanted devices. The MRI could cause any metal in your body to heat up. This is because the MRI machine uses strong magnets in order to collect the scans. Every effort will be made to eliminate this risk, by asking you ahead of time about any devices or injuries from metal objects, and not running the test if you have anything in your body that will be affected by the machine.
- The brain MRI is a magnetic resonance imaging procedure to take images of your brain. This MRI procedure will have you lie on your back on a narrow table that will be moved into a circular tube. You will not be able to see outside of the tube. There will be repetitive thumping noises as the MRI scans your brain. It will take approximately 45 minutes to complete the scans. These discomforts will be mitigated in the following ways:
  - Headphones and ear plugs will be worn for ear protection.
  - Tingling sensations sometimes occur in the arms, but these can usually be prevented by keeping the hands apart.
  - The technician will maintain visual and verbal contact with you throughout the MRI scanning sessions.
  - As an extra precaution, you will be given an “emergency” button to be used if you wish to end the procedure.
- It is important to understand that participation in the MRI scans will require travel outside your home. The MRI facilities and CLSA staff will follow the required protocols for working safely during the pandemic.

### **Will I receive the results from the tests done?**

- The stool sample you provide will be stored for future research. No tests will be run on the sample at the time of collection, and no individual results will be provided from the research performed in the future.

- The additional memory tests are collected for research purposes only. No results from these tests will be provided to you.
- The MRI scan being done is designed to answer research questions, not to examine your brain medically. This MRI scan is not a substitute for one that a doctor may order for a specific reason. This research MRI may not show problems that would be picked up by a medical MRI scan. However, if we believe that we have found a medical problem in your MRI scan, we will contact you and with your permission, contact your family physician or help in getting the right medical follow-up for you. No information generated in this study will become part of your health records. However, if the study detects an abnormality in your MRI scan and further follow-up is required, then this information may become part of your health records.

### **How will my information be managed and kept safe?**

The data collected are de-identified (meaning the data are connected to an ID number, not to your name or any other personal identifying information). The MRI scans are labelled with this ID (not with your name) at the MRI facility. The data from this part of the study are kept, like all CLSA data, on secure servers located at McMaster University. The stool samples will be stored in freezers located at McMaster University.

No identifiable information will be shared with anyone outside of our established CLSA protocols. The CLSA will protect any information and images collected as we do for all other CLSA participant information.