

## **Canadian Longitudinal Study on Aging (CLSA)**

### **Privacy Policy**

November 19, 2012

The purpose of the Canadian Longitudinal Study on Aging (CLSA) Privacy Policy is twofold: (1) to provide transparency and accountability with respect to the practices around how the CLSA manages and protects your personal information; and (2) to provide you, as individual research participants, with information on your privacy and access rights.

The privacy policy reflects the principles that you reviewed when you signed the consent to participate in the CLSA. For the 20,000 who are in the Tracking (telephone interview) part of the study, the Privacy Policy refers to the safeguarding of information you provided over the telephone to a CLSA interviewer (termed information, or data). For the 30,000 who are in the Comprehensive (in-home interview and Data Collection Site visit) part of the study, the Privacy Policy refers to the safeguarding of information you provided in person and on the telephone to a CLSA interviewer (termed information, or data), the physical tests you did at the Data Collection Site (termed tests, or data) and the blood and urine samples you gave, if you chose that option (termed samples).

#### **Privacy and Confidentiality**

The Canadian Longitudinal Study on Aging (CLSA) considers the public to be its most valuable partner in research. Thus, protecting your privacy and meeting your expectations in this regard is a priority at all stages of the study. The CLSA, the different institutions involved, and the CLSA researchers and staff are all committed to ensuring that your privacy and confidentiality are always respected.

#### **Recruitment**

##### How did CLSA get my contact information?

The CLSA got your contact information in one of the following ways:

- You completed a survey by Statistics Canada in 2008-09. At that time, you gave your signed permission for your contact information to be given to the CLSA research team to contact you about seeking your consent to participate in the CLSA. With your signed consent, Statistics Canada gave us, your name, address, telephone number, alternate contact and your preferred language of interview under strict privacy and confidentiality conditions.

OR

- You received a letter from your provincial Department or Ministry of Health. At that time, you sent the CLSA your signed permission to be contacted about participating in the study. The provincial Department or Ministry sent the letter on our behalf, and we did not have access to your contact information or health card number.

OR

- You received a phone call from a marketing firm on behalf of the CLSA. If a phone call was your first contact with the study, random digit dialing was used to reach you.

#### What if I don't want the CLSA to contact me?

If you do not wish to be part of CLSA, and you inform us that you do not want to be contacted again by the study, the contact information that you provide is kept in a "Do not Contact" file for the duration of the recruitment period and then destroyed.

Since the CLSA does not have access to the contact information of people who are mailed recruitment packages by provincial Departments or Ministries of Health, there is a remote possibility that you may receive a phone call in addition to a mailed package. If this happens and you do not wish to be contacted again, please inform our [National Coordinating Centre](#).

#### **Data Collection and Data Storage**

##### How is my privacy and confidentiality protected?

Many different mechanisms are in place. Some of these are:

- All identifying information (name, telephone number, address, provincial health card number (if provided), etc.) are never linked to any collected information (questionnaire data, tests and samples). In fact, the collected data are stored using a unique code and not your name or other identifying information. The identifying information is stored at McMaster University in a secure and separate database.
- When data are collected from you, nothing is stored locally. The data are automatically encrypted and transmitted with the unique ID number through a secure network connection (called a Virtual Private Network, or VPN) to the central database at McMaster University.
- All staff involved in CLSA are bound by a strict confidentiality agreement that prohibits them from using any information for any other purpose than what is required for their specific tasks.
- Data and samples are stored in highly controlled access areas where only special card holders are able to enter and a log of all entries/exits into these restricted premises is kept.
- The workstations through which the CLSA staff are able to access the collected data (e.g. for quality control purposes) are not connected to internet, and they are password protected.
- The CLSA will only grant access to de-identified data for ethically and scientifically approved research. Approval is granted by the CLSA Data and Samples Access Committee followed by approval from a Research Ethics Board. Approved researchers must sign confidentiality and data access agreements, which bind all users to the terms and conditions set out by CLSA. The CLSA does not release any personal or identifying information to researchers.
- Once access to researchers is granted, the CLSA will to conduct random audits of research facilities and on the use of the data to ensure compliance with security requirements and reported research objectives.
- The CLSA study design has been reviewed and approved by 13 Research Ethics Boards across Canada. As part of the ethics process, any changes to the CLSA are reviewed annually.

## **Data and Sample Access**

### Who has access to my data and samples?

CLSA staff: A limited number of CLSA staff have access to your data and samples for purposes of developing the database and doing quality control tests. A more limited number of staff have access to your identifying information for purposes of contacting you in the future, for updating your information, for linking with other provincial health databases (if consent was provided) or for registering a withdrawal. Your identifying information will not be released to a non-research related third party without your consent or unless it is required by a valid court order or by law.

Researchers: Researchers in public institutions in Canada and other countries can request access to de-identified study data (but not your personal information, such as your name or address) to conduct specific research projects. Approval is granted by the CLSA Data and Samples Access Committee and must also be approved by a Research Ethics Board. Approved researchers must sign confidentiality and data access agreements, which bind all users to the terms and conditions set out by the CLSA. Researchers from private businesses will not have direct access to your data and samples, but may be part of a research team. Researchers from other countries will not be able to use your linked health care records.

You: you can always request access to your information.

Your information will not be given to non-research related third parties. In the unlikely event that we are required by law to provide your information to a third party, we would inform you first.

## **Access to provincial health databases and other health information**

### How will CLSA access my information contained in provincial health databases?

CLSA participants have the option to provide their provincial health card number so that the information contained in provincial health databases (e.g. billings for visits to doctors, hospital admissions, medication prescriptions, etc.) can be linked to study data. These databases are not the medical records kept by your doctor.

If you have given us your provincial health card number and have authorized the study to access provincial health databases, the CLSA will have an agreement with the respective organization. The terms and conditions of access to these provincial databases will depend on each province according to the organization in question, the provincial laws and the agreement with CLSA.

## **Safeguarding participant confidentiality**

### Who abides by this policy?

- a. All entities forming part of the overall governance structure of the CLSA;
- b. The principal investigators, co-investigators, institutions and all staff responsible for collecting data and/or samples for inclusion into the CLSA research platform;
- c. All researchers seeking access to CLSA data for specific research projects consistent with the mandate of the CLSA, and as approved by relevant research ethics boards and the Data and Sample Access Committee.

These individuals are held accountable for compliance either directly or indirectly (e.g. through terms and conditions in data sharing agreements, user agreements, and confidentiality agreements).

## **Changes to the CLSA Privacy Policy**

The CLSA Privacy Policy will be updated occasionally to reflect the feedback of CLSA participants and stakeholders.

If you have any questions or comments about your privacy and confidentiality within CLSA, you can contact us:

Toll-free: 1-866-999-8303

E-mail: [info@clsa-elcv.ca](mailto:info@clsa-elcv.ca)

By mail:

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