

## **CONSENT INFORMATION PACKAGE FOR DISCLOSURE TO CLSA OF PERSONAL HEALTH INFORMATION THROUGH LINKAGE TO DATABASES**

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

**Lead Principal Investigator:**

Dr. Parminder Raina, *Department of Health Research Methods, Evidence, and Impact (HEI)*,  
McMaster University

**Co-Principal Investigators (Co-PIs):**

Dr. Christina Wolfson, Research Institute, McGill University Health Centre

Dr. Susan Kirkland, *Departments of Community Health and Epidemiology and Medicine*,  
Dalhousie University

**Site Investigators:**

Dr. Vanessa Taler  
University of Ottawa

Dr. Gerry Mugford  
Memorial University of Newfoundland

Dr. Teresa Liu-Ambrose  
University of British Columbia

Dr. Benoît Cossette  
Université de Sherbrooke

Dr. David Hogan  
University of Calgary

Dr. Scott Hofer  
University of Victoria

Dr. Verena Menec  
University of Manitoba

Dr. Andrew Wister  
Simon Fraser University

Dr. Lauren Griffith  
McMaster University

**Biorepository & Bioanalysis Centre Investigator:**

Dr. Cynthia Balion  
McMaster University

**Supported by:**

Government of Canada through the Canadian Institutes of Health Research and  
the Canada Foundation for Innovation





## **Consent for Disclosure to CLSA of Personal Health Information through Linkage to Databases**

The CLSA collects data about many aspects of aging (social, physical, psychological, etc.) directly from you. Linkage with data about you from other existing databases enriches the dataset that researchers will be able to make use of for years to come. Obtaining these data held by other organizations also minimizes the burden of data collection on you.

Based on your original consent, we are able to link to data held about you in provincial healthcare databases starting from the date you began participating in the CLSA. In this document and the accompanying consent form, we are asking you to consider a few additional ways that the CLSA can link to data about you to add to the usefulness of the CLSA dataset. Please carefully read the information below and fill out the consent form that has been provided to indicate your choices about how we can collect these additional data.

### **Consent Option 1: 10-year Retroactive Data Linkage with Provincial Databases**

Your current consent, in which you give permission to use your health insurance number, allows the CLSA to link to information about you held in provincial healthcare databases starting from the date of your enrolment in the CLSA.



However, because the CLSA is looking at changes in your health over time, we are asking you to consider allowing us to link to information about you in the provincial databases starting from ten years before you joined the CLSA. These additional years of data will greatly enhance the research that can be conducted, showing the path that people's health follows as they age, and the development of various health conditions.

## **Consent Option 2: Additional Data Source: Canadian Institute for Health Information**

Currently, there are certain data that the CLSA is only able to obtain from provincial databases, which your existing consent allows us to access. However, all of the provinces share a portion of their data to be stored and managed centrally with the Canadian Institute for Health Information (CIHI). CLSA is now asking you to consider allowing the CLSA to access the data that are held by CIHI. This will allow the CLSA to obtain some of the same data we would originally have gone to the provinces for, but to access the data through a single linkage process. This means that the data will be obtained at the same time for all participants and be made available to researchers more consistently.

In order to link the data held by CIHI to your CLSA data, the CLSA will send CIHI your health insurance number, sex, and date of birth, along with a unique



ID that will be created for this purpose. This information will allow CIHI to ensure that it is definitely your data that are linked with the CLSA data. CIHI will send the data to the CLSA using the unique ID only, to avoid unnecessary exchange of your personal health information. The sharing of information between the two organizations will follow strict privacy protocols and will be shared using encrypted data exchange processes.

The Canadian Institute for Health Information (CIHI) obtains data from hospitals and other health care facilities, long-term care homes, regional health authorities, and government departments. These data include details about the use of health services, including doctor and specialist visits, diagnoses, prescriptions given, and residence in long-term care facilities and other institutions.

## **Consent Option 2a: 10-year Retroactive Data Linkage with CIHI Databases**

If you choose to allow the CLSA to link to data held in CIHI databases dating from the when you joined the CLSA, we would also like you to consider allowing the linkage to extend for 10 years before you joined the CLSA. As described in the section 10-year Retroactive Data Linkage with Provincial Databases, above, we would like to extend the retroactive linkage to CIHI databases. The data collected will be able to provide a more complete picture of your health than the CLSA data alone can.



You can consent to linkage with CIHI databases without extending the consent to 10 years before you joined the CLSA. In this instance we will complete the linkage from the date that you joined the CLSA only.

Any information from these databases that is linked to the CLSA information that you provided directly will then become part of the CLSA platform, and be retained for the length of the study (data will be collected for 20 years and then the data will be retained and used for research purposes until 2059). All data will be stored in a secure de-identified database. De-identifying the data means that even though the CLSA will store information about you, researchers will not be able to see that information while knowing who you are. Access to these de-identified data will be restricted to researchers whose applications are approved by the CLSA Data and Sample Access Committee.

You can choose whether or not to provide these additional consents. This will not affect your current participation in the CLSA, or your healthcare. If you choose not to provide this additional consent, you will still be a participant in the CLSA, and we will still link to your provincial healthcare records starting on the date of your participation in the CLSA, based on your original consent.



You can withdraw your Consent for Disclosure to CLSA of Personal Health Information through Linkage to Databases at any time. Any future linkage will be done only up to the date that you withdraw your consent; linked data prior to this date will remain part of the CLSA data.

Thank you for your participation in the CLSA!



[www.clsa-elcv.ca](http://www.clsa-elcv.ca)

For Residents of British Columbia, Alberta, Manitoba, Ontario, Quebec  
or Nova Scotia

**PLEASE CALL:**

**Toll-free: 1-866-999-8303**

For Residents of Newfoundland or Labrador

**PLEASE CALL:**

**English Toll-free: 1-888-908-4988**

**French Toll-free: 1-866-999-8303**



**a place of mind**  
THE UNIVERSITY OF BRITISH COLUMBIA