

Canadian Longitudinal Study on Aging (CLSA) Navigation Guide

**Laurentian Research Institute for Aging (LRIA)
August 2018**

**Meghan Forestell, LRIA Research Assistant
Ellery Veerman, LRIA Research Associate
John Lewko, PhD, LRIA and School of Rural and Northern Health**



**Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement**

Table of Contents

| | |
|---|----|
| Introduction_____ | 2 |
| <i>About the Canadian Longitudinal Study on Aging</i> | |
| <i>What was the Navigation Guide Created?</i> | |
| Protocol and Structure _____ | 3 |
| <i>Overview of CLSA Design</i> | |
| <i>Biospecimens</i> | |
| Data Collection_____ | 5 |
| <i>Data Collection Tools</i> | |
| <i>CLSA Participant Statistics</i> | |
| <i>Data Preview Portal</i> | |
| Application_____ | 11 |
| <i>General Information</i> | |
| <i>Data Access</i> | |
| Additional Information_____ | 12 |

ACKNOWLEDGEMENT

The CLSA represents a major accomplishment for research on aging in Canada. The Data Preview Portal provides researchers with access to a unique dataset that should help to advance our understanding of growing old in Canada. The Navigation Guide that follows borrowed extensively from various sources of CLSA material including the Data Preview Portal, interview documents and the study protocol. We hope that this Guide will be of some assistance to individuals who intend to pursue a line of inquiry on aging.

Introduction

About the Canadian Longitudinal Study on Aging

The Canadian Longitudinal Study on Aging (CLSA) is a large, national, long-term study that is following approximately 50,000 men and women between the ages of 45 and 85 over 20 years. It was developed in recognition of a significant knowledge gap of the combined effects of the changes that occur during the aging process over the lifecourse. Through its large sample, multidisciplinary focus and longitudinal design, the CLSA provides a unique opportunity to advance our understanding of the interplay of numerous factors involved in the aging process, as well as the complex challenges presented by the aging population in Canada. It will enable researchers to move beyond static data toward observing and understanding the evolution of function, disability and disease in response to the changing physical, psychological and social factors that frequently accompany aging.

The CLSA dates back to 2001 when a request for applications was issued by the Canadian Institutes of Health Research (CIHR) to develop a protocol for a new aging initiative. A research team led by principal investigators Dr. Parminder Raina (McMaster University), Dr. Christina Wolfson (McGill University) and Dr. Susan Kirkland (Dalhousie University) were granted the funding to begin development of the CLSA proposal. Over the course of the following decade, they led the CLSA team through feasibility and pilot studies, ethics review processes, recruitment phases and data collection. In 2009, the first article outlining the CLSA design was published in the Canadian Journal on Aging, a testament of the initiative's early momentum and success. In that same year, participant recruitment began, followed by the start of data collection in 2010. We recommend you read over that first publication, which can be accessed [here](#). Once complete, proceed through the Navigation Guide.

Why was the Navigation Guide Created?

This Navigation Guide was developed to direct the attention of graduate students, faculty members, and LRIA participants to the research opportunities available within the CLSA data. It rose out of early efforts by LRIA to identify available CLSA data that could be used in a research project on caregiving. As we focused on variables related to social identity and caregivers, we began to understand the importance of developing familiarity with the structure of the CLSA Data Preview Portal. We recognized that an individual entering the portal for the first time, for example our faculty and students, would face similar challenges to us regarding familiarization. We therefore reasoned that sharing what we learned might be of help to others who intend to explore the portal. Our collective thinking eventually brought us to decide that some form of "roadmap" might be helpful, the result of which was this Navigation Guide.

The Navigation Guide brings together critical information from the CLSA website, provides foundational information on the study and allows for familiarization of the Data Preview

Portal. It outlines how to apply for access to CLSA data, and provides researchers with a summary of pertinent CLSA information including the study design, protocols, data collection methods/tools and data access guidelines. This background knowledge is critical to enable purposeful and successful navigation of the Data Preview Portal. The portal is where researchers can explore the data sets and variables of the study to determine what available data is suitable for their research interests. Particularly useful for our purposes was the creation of Table 1, which allows for a quick comparison of the interview questionnaire variables across both the Tracking and Comprehensive cohorts. Due to the extensive nature of the study and its corresponding data portal, which is unprecedented in Canada, we hope that the Guide will streamline the process of finding and evaluating potential data quickly and effectively.

Protocol and Structure

Overview of CLSA Design

The CLSA consists of over 50,000 randomly selected men and women stratified from across Canada. The participants were between the ages of 45 and 85 at the time of recruitment. All participants in the CLSA provide a core set of information including measures of demographic, lifestyle, behavioural, social, physical/clinical, psychological, cognitive, economic and health service use factors relevant to health and aging. Data is collected in waves every three years, and participants will be followed for at least 20 years or until death. Participants belong to one of two study cohorts; either the Tracking cohort or the Comprehensive cohort.

The Tracking cohort is comprised of 20,000 study participants. These participants provide the core information set only, which is collected through a computer-assisted telephone interview (CATI). Recruitment of these participants began in 2009 from all ten provinces, and baseline data collection was conducted between early 2012 and mid-2014. Currently, data is being collected in the first follow-up phase, which will be available in the spring of 2019. Participants in this cohort are contacted by CLSA staff members working at CATI sites located in Vancouver, Winnipeg, Sherbrooke, and Halifax. The CATI takes approximately 60 minutes to complete. The following [video](#) provides more information about the Tracking cohort CATI.

The Comprehensive cohort is comprised of the remaining 30,000 CLSA participants. In addition to the core set of data, these participants provide supplementary information through direct examinations and the collection of biospecimen samples. First, these participants are visited by an in-home interviewer who collects the core information set. This interview takes approximately 90-100 minutes to complete. The interviewer then schedules a visit at a Data Collection Site (DCS). At a DCS, participants undergo additional interviews, cognitive assessments, and neuropsychological assessments. A thorough physical assessment is also completed, which includes, among others, measures of height, weight, blood pressure, lung function, electrocardiography (ECG), carotid artery wall thickness, strength, bone density, vision and hearing. With participants' consent, blood and urine samples are collected as well. The

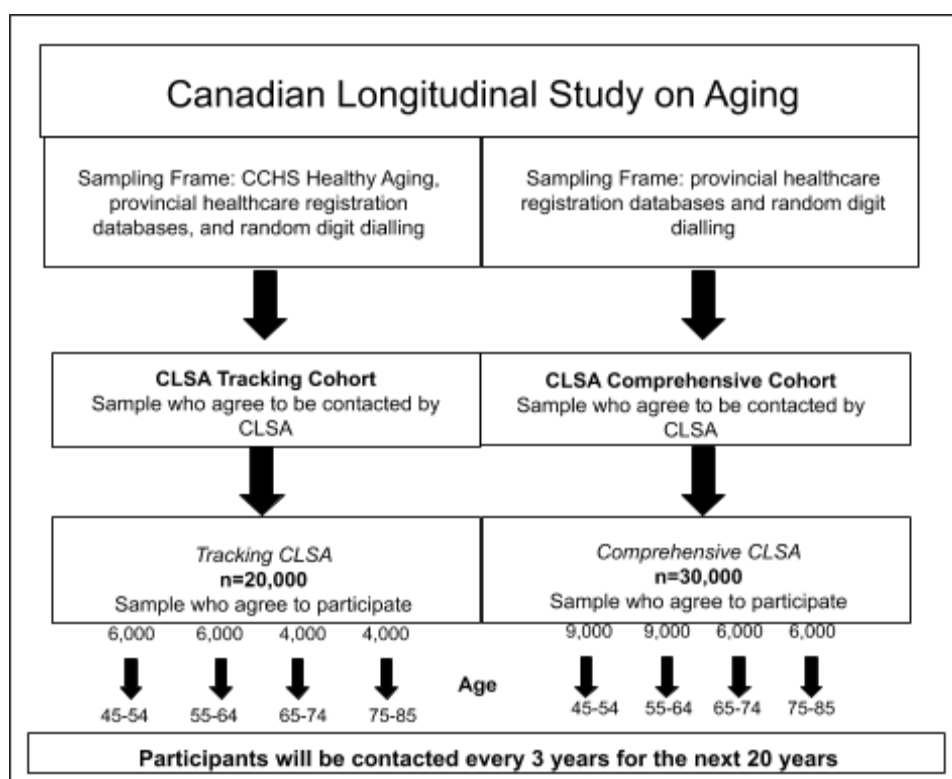
DCS visit takes approximately 2.5 hours to complete. DCSs are located in Surrey, Victoria, Vancouver, Calgary, Winnipeg, Hamilton, Ottawa, Montreal, Sherbrooke, Halifax and St. John's.

Recruitment of the Comprehensive cohort began in early 2012, and baseline data collection was completed in early July 2015. Data collection for the first follow-up began later that month and was completed in March 2018. This data will be available in the spring of 2019. The following [video](#) provides further detail about the CLSA Comprehensive cohort home interview and DCS visit.

Approximately 18 months after the completion of baseline data collection, all participants were contacted by a CLSA telephone interviewer to complete the first Maintaining Contact Questionnaire (MCQ1). The MCQ1 asked participants to confirm their address, phone number, and names of alternative contacts. It also included questions about falls, pain, health care utilization, social equality, transportation, mobility and various other health related questions. It took approximately 30 minutes to complete.

Across its scope, the CLSA collects data in 10 provinces, uses 11 data collection sites, and has more than 160 researchers from 26 Canadian universities. Though this Guide includes important information relative to its stated purpose, there is also a 135-page document that elaborates on the CLSA study design and protocol. It includes in-depth descriptions of the study content, conceptual framework, research design, research methods, data collection, data processing procedures, biospecimens, data management, quality systems, study team, ethical considerations and the CLSA Infrastructure. If interested, you may view the document [here](#).

Figure 1: CLSA Study Design (Retrieved from CLSA Protocol)

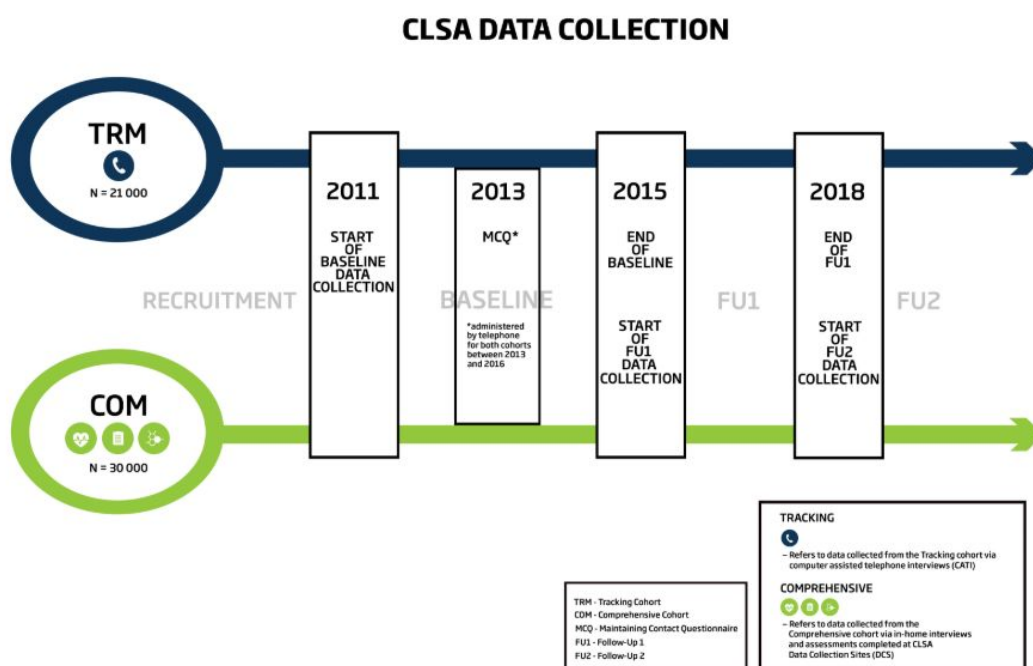


Biospecimens

Comprehensive cohort participants who consent to collection have blood and urine specimens drawn at their DCS visits. Blood specimens are non-fasting and urine samples are random in order to facilitate participant scheduling. However, researchers also collect additional information on parameters that affect the interpretation of certain biomarkers, such as when the last meal was eaten, alcohol consumption, and medication administration. Six different tube types are used to collect various samples of different blood components. After collection, the biospecimens are shipped to McMaster University where they are held in the Biorepository and Bioanalysis Centre (BBC) for long-term storage. For a complete list of the types of biological samples collected at baseline click [here](#), and for those collected at follow-up one click [here](#).

Data Collection and Access

Figure 2: CLSA Data Collection Timeline (Retrieved from CLSA Protocol)



Data Collection Tools

The CLSA collects various kinds of data using questionnaires, physical assessments and biological specimen samples. To collect baseline data from the Tracking cohort, the [telephone interview](#) questionnaire was used. For the Comprehensive cohort, baseline data was collected via the [in-home interview](#) questionnaire. Once the in-home interview was complete, participants followed up at a DCS where the [data collection site](#) questionnaire was used. This questionnaire outlines the neuropsychological and disease symptoms questions as well as the

physical assessments conducted for this cohort. It also outlines the exclusion criteria for certain assessments. Overall, data collection at the DCS follows a systematic process, which is outlined in this [diagram](#). The CLSA team has created a [physical assessments summary table](#), along with the corresponding [Standard Operating Procedure](#) (SOP) for each physical assessment.

The [Maintaining Contact Questionnaire](#) was administered to all participants 18 months after completion of baseline data collection. Follow-up one data collection began shortly after that, in which both cohorts received an interview of longer duration compared to their respective baseline questionnaires. Click to view the Comprehensive cohort follow-up one [in-home interview](#) questionnaire; the Tracking cohort follow-up one telephone interview is not yet available. Table 1 outlines the differences between each of the data collection interviews with respect to the variables they cover at baseline (BL), maintaining contact (MCQ1), and in follow-up one (FU1) (DCS questionnaire content not included). Only small changes were made in the DCS questionnaire from baseline to follow-up one, including additional assessments of epilepsy, oral health, sleep, elder abuse, social cohesion, and a DEXA scan of the lumbar spine. It should be noted that in follow-up one, for those participants who were unable to attend a DCS visit due to a change in health status, CLSA team members used alternative protocols to collect DCS questionnaire data from these participants in their homes.

Table 1: Comparison of Variables in CLSA Interview Questionnaires

| Variable | Code | Tracking Cohort | | | Comprehensive Cohort | | |
|--|------|-----------------|-----------------|-----------------|----------------------|-----------------|-----------------|
| | | BL (60min) | MCQ1 (30min) | FU1 (100min) | BL (90min) | MCQ1 (30min) | FU1 (100min) |
| Age | AGE | ✓ | | | ✓ | | |
| Alcohol Use | ALC | ✓ | | | ✓ | | ✓ |
| Basic Activities of Daily Living | ADL | ✓ | | | ✓ | | ✓ |
| Built Environments | ENV | | ✓ | | | ✓ | ✓ |
| Care Giving | CAG | ✓ | | | ✓ | | ✓ |
| Care Receiving 1 - Formal Care | CR1 | ✓ | | | ✓ | | ✓ |
| Care Receiving 2 - Informal Care | CR2 | ✓ | | | ✓ | | ✓ |
| Childhood Maltreatment and Health x Lifespan | CEX | | | | | | ✓ |
| Chronic Conditions Tracking | CCT | ✓ | | | | | |
| Cognition | COG | ✓ | | | ✓ | | ✓ |
| Depression | DEP | ✓ | | | | | |
| Dietary Supplement Use | DSU | | ✓ | | | ✓ | |
| Education | ED | ✓ | | | ✓ | | ✓ |
| Falls and Consumer Products | FAL | ✓ | ✓ | | ✓ | ✓ | ✓ |
| Functional Status | FUL | ✓ | | | | | |
| Gender Identity | GED | | | | | | ✓ |
| General Health | GEN | ✓ | | | ✓ | | ✓ |
| Health Care Utilization | HCU | | ✓ | | | ✓ | ✓ |
| Hearing | HRG | ✓ | | | ✓ | | |

| | | | | | | | |
|---|------|---|---|--|---|---|---|
| Height and Weight | HWT | ✓ | | | | | |
| Home Ownership | OWN | ✓ | | | ✓ | | ✓ |
| Income | INC | ✓ | | | ✓ | | ✓ |
| Injuries | INJ | ✓ | | | ✓ | | ✓ |
| Instrumental Activities of Daily Living | IAL | ✓ | | | ✓ | | ✓ |
| Labour Force | LBF | ✓ | | | ✓ | | ✓ |
| Life Space Index | LSI | | | | ✓ | | ✓ |
| Loneliness Scale | LON | | | | | | ✓ |
| Medications | MEDI | | | | ✓ | | ✓ |
| Medication Use | MED | | ✓ | | | | |
| Meta Memory | MEM | | | | | | ✓ |
| Nutrition: Short Diet Questionnaire | NUT | | | | ✓ | | ✓ |
| Nutritional Risk | NUR | | ✓ | | | ✓ | |
| Online Social Networking | INT | | ✓ | | | ✓ | ✓ |
| Oral Health | ORH | | ✓ | | | ✓ | |
| Pain and Discomfort | HUP | | ✓ | | | ✓ | |
| Parkinsonism | PKD | | ✓ | | | | |
| Personality Traits | PER | | | | | ✓ | ✓ |
| Physical Activities | PA2 | | ✓ | | | ✓ | ✓ |
| Posttraumatic Stress Disorder | PSD | ✓ | | | ✓ | | |
| Pre-Retirement Labour Force Participation | LFP | ✓ | | | ✓ | | ✓ |
| Preventive Health Behaviours | PHB | | | | | | ✓ |
| Psychological Distress | K10 | | | | | ✓ | ✓ |
| Retirement Planning | RPL | ✓ | | | ✓ | | ✓ |
| Retirement Status | RET | ✓ | | | ✓ | | ✓ |
| Satisfaction with Life | SLS | ✓ | | | ✓ | | ✓ |
| Sex | SEX | ✓ | | | ✓ | | |
| Sleep | SLE | | | | ✓ | | |
| Smoking | SMK | ✓ | | | ✓ | | ✓ |
| Snoring | SNO | | | | | ✓ | |
| Social Inequality | SEQ | | ✓ | | | ✓ | ✓ |
| Social Networks | SN | ✓ | | | | | |
| Social Participation | SPA | ✓ | | | | | |
| Social Support - Availability | SSA | ✓ | | | | | |
| Socio-Demographic Characteristics | SDC | ✓ | | | ✓ | | ✓ |
| Subjective Cognitive Decline | SCD | | | | | | ✓ |
| Transportation, Mobility, Migration | TRA | | ✓ | | | ✓ | ✓ |
| Unmet Health Care Needs | MET | | | | | | ✓ |
| Veteran Identifiers | VET | ✓ | | | ✓ | | |
| Vision | VIS | ✓ | | | ✓ | | |
| Wealth | WEA | | ✓ | | | ✓ | ✓ |
| Women's Health | WHO | ✓ | | | ✓ | | ✓ |
| Work Limitations Questionnaire | WLQ | | | | | | ✓ |

We now recommend you view the CLSA Data Checklist. Open the [CLSA website](#) to see if it is available to view, as at the time when this Guide was completed it was not. This form is used to indicate which variables in the baseline and maintaining contact datasets you would like to access, and is completed and submitted electronically in your final application to the CLSA. It outlines the data collected in all components of the interviews and DCS visits, and from which cohort(s) the data is available. The checklist should further assist you to narrow the available data for your research interests. It provides in-depth details of the parameters of each interview component compared to Table 1, which alternatively allows for the comparison of interview variables at various data collection time points across both cohorts. The Data Checklist for follow-up one is expected to be available in December 2018. The next section includes some basic statistics on the CLSA participants.

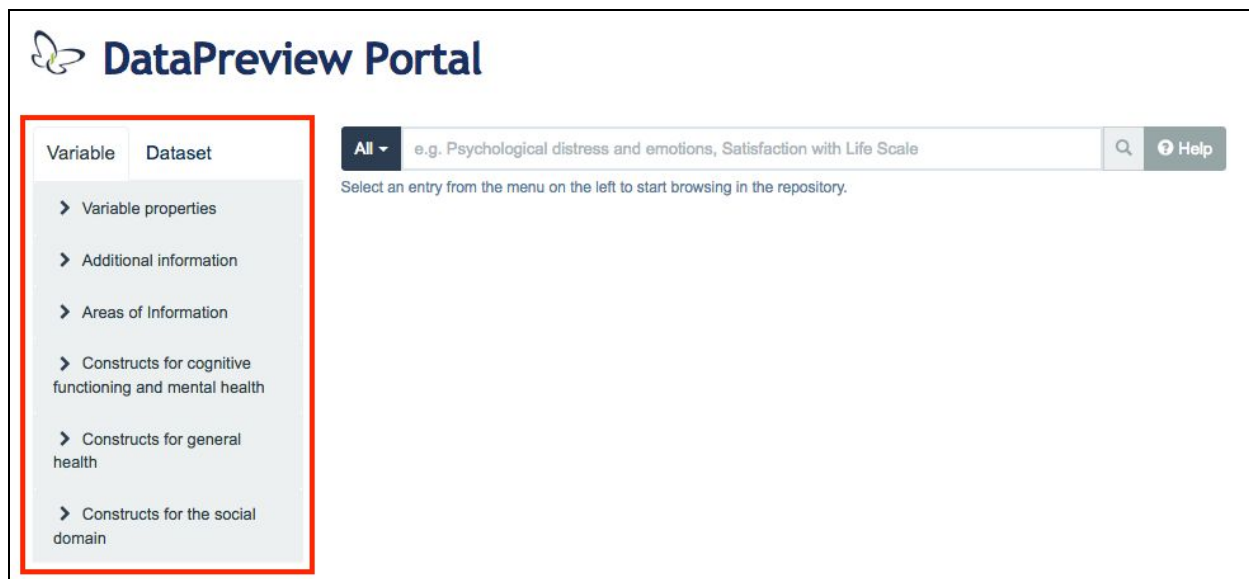
CLSA Participant Statistics (Retrieved from the Data Preview Portal)

| | | Tracking Cohort | Comprehensive Cohort |
|----------------------------|--|-----------------|----------------------|
| Age | Minimum | 44.00 | 45.00 |
| | Maximum | 63.00 | 63.00 |
| | Standard deviation | 10.70 | 10.30 |
| | Total | 21,241 | 30,097 |
| Sex | Male | 10,306 (49.00%) | 14,777 (49.10%) |
| | Female | 10,835 (51.00%) | 15,320 (50.90%) |
| Marital/Partner Status | Single, never married or lived with partner | 1,698 (8.00%) | 2,654 (8.80%) |
| | Married/living with partner in common law | 14,602 (68.70%) | 20,651 (68.60%) |
| | Widowed | 2,360 (11.10%) | 2,809 (9.30%) |
| | Divorced | 1,995 (9.40%) | 3,185(10.60%) |
| | Separated | 580 (2.70%) | 790(2.60%) |
| | Refused | 6 (0.00%) | 8 (0.00%) |
| Highest Level of Education | Grade 8 or lower | 539 (2.50%) | 454 (1.50%) |
| | Grade 9-10 | 897 (4.20%) | 704 (2.30%) |
| | Grade 11-13 | 550 (2.60%) | 485 (1.60%) |
| | Secondary school graduate, no post-secondary | 2,882 (13.60%) | 2,839 (9.40%) |
| | Some post secondary education | 1,623 (7.60%) | 2,238 (7.40%) |
| | Trade certificate or diploma from apprenticeship | 2,574 (12.10%) | 3,318 (11.00%) |
| | Non-university certificate or diploma from community college | 3,958 (18.60%) | 5,147 (17.10%) |
| | University certificate below bachelor's level | 864 (4.10%) | 1,256 (4.20%) |
| | Bachelor's degree | 4,231 (19.90%) | 7,073 (23.50%) |
| | University degree or certificate above bachelor's degree | 2,856 (13.40%) | 6,494 (21.60%) |
| | Other post-secondary education | 184 (0.90%) | 39 (0.10%) |
| | Question not answered | 83 (0.40%) | 50 (0.20%) |

Data Preview Portal

The [Data Preview Portal](#) holds all of the data collected from CLSA participants at each wave of data collection. It functions as a variable search tool, allowing users to explore, examine and compare variables across all CLSA questionnaires and collected data. Currently, baseline and MCQ1 data from over 51,000 Tracking and Comprehensive participants is available to search. Datasets from future waves of data collection will be added as they become available.

With the Portal open in a separate internet window on your computer, first familiarize yourself with its overall layout. Begin to explore the “Variable” and “Dataset” tabs located on the left hand side of the main page, as shown in the image below. Clicking on the individual items under each tab will reveal their respective subcategories, which may also have further subdivisions. Hovering your cursor over titles in these tabs will reveal additional information about the particular title and its content.



These tabs allow you to refine and view specific data available in the portal. Under the variables tab you are able to select specific variable(s), whereas the dataset tab allows you to select specific dataset(s). When the desired options are selected, the data items meeting those criteria will appear in a results list. By default, the results list is categorized by variable, but this can be switched to be categorized by dataset. In the resultant list of data items, each is listed by name, label and dataset of origin. Clicking on the name of a data item will allow you to view detailed information about that particular item, including the exact wording of the question that generated the data item, possible answers to the question, and cumulative statistics.

Each data item has a unique name comprised of numerous codes. The first code indicates the variable category the data item belongs to, and the last code indicates from which cohort the data was obtained. For example, the variable named SPA_EDUC_TRM is from the

variable category of social participation (SPA) and was obtained from the Tracking cohort (TRM). The code(s) in the middle of the name refer to the specific question asked. Refer back to Table 1 where the codes for the interview variables are identified. It may be helpful to be know that a specific code can be searched using the “Name” search bar under “Variable properties” as shown in the image below. For example, to search for available data on the variable category of social participation, one would input “SPA” in the search bar.

The screenshot shows the DataPreview Portal interface. At the top, there is a 'SMART TIPS' section with three bullet points:

- Click the 'Help' button on the right to see a step-by-step guide to using the DPP
- Use the main Search Bar on this page to search for predetermined **Areas of Information** or **Scales** only
- For a more detailed search, select 'Variable Properties' under the 'Variable' tab on the left. Expand 'Name' and 'Label' to view search boxes

Below the tips, there is a navigation bar with 'Variable' and 'Dataset' tabs. A search bar is present with the text 'e.g. Psychological distress and emotions, Satisfaction with Life Scale'. Under the 'Variable properties' section, there is a 'Name' search bar with a red box around it and a callout box that says: 'Search for a specific variable by its name, or "code" as we have defined it.' To the right of the search bar, there is a filter for 'CMCQ | COM | TMCQ | TRM'. Below the search bar, there is a table with columns 'Name' and 'Label'. The first row shows 'ADL_ABLAP_COM' and 'OARS scale: Able to take care of appearance'. There is also a 'Datasets (4)' indicator and a '10' dropdown menu.

There are currently four codes to distinguish between datasets: TRM for Tracking cohort baseline assessment; COM for Comprehensive cohort baseline assessment; TMCQ for Tracking cohort maintaining contact questionnaire 1; and CMCQ for Comprehensive cohort maintaining contact questionnaire 1. As you further explore the portal, it will be helpful to identify if you need data from the Tracking cohort, Comprehensive cohort or both for your research. This will allow you to refine your searches by dataset and isolate the variables and data items relative to your research area in an efficient manner.

The following image shows key information about searches and search results in the portal. You will see that there is a search bar available to conduct unique searches. Using this search option requires a high degree of specificity, and, if used, it is recommended to search multiple words related to your area of interest or concept. In an example of caregivers, searching the word “caregiver” does not reap any results, but a search of the word “care” produces multiple results: care services, care assistance and medical care. A guiding recommendation is to first use the variable tabs on the left to search for data items, as they have already been organized into categories, and the unique search bar second if necessary.

DataPreview Portal

Search bar: e.g. Psychological distress and emotions, Satisfaction with Life Scale

Variable: Social participation 37

Dataset: (1)

| Name | Label | Dataset |
|-------------------------------|--|---------------------|
| SPA_CHRCH_TRM | Frequency of participation in religious activities (past 12 months) | TRM |
| SPA_CLUB_TRM | Frequency of participation in clubs or fraternal organization activities (past 12 months) | TRM |
| SPA_EDUC_TRM | Frequency of participation in educational or cultural activities (past 12 months) | TRM |
| SPA_MORAC_TRM | Desire to participate in more activities (past 12 months) | TRM |
| SPA_NEIBR_TRM | Frequency of participation in association activities (past 12 months) | TRM |
| OTACT_TRM | Frequency of participation in other recreational activities (past 12 months) | TRM |
| OUTS_TRM | Frequency of participation in family/ friends activities out of household (past 12 months) | TRM |

Annotations:

- Search bar: Shows the variables included in result list
- Variable selection: Blue check mark indicates selected variable(s)
- Dataset list: Shows which datasets are included in result list
- Table header: Options to organize data by variable or dataset

Application

General Information

- At this point you should be familiar with the study design, protocol, data collection methods and tools. Review any details if necessary.
- Before starting your application you may want to consult the following:
 - [Data and Biospecimen Access Policy and Guiding Principles](#)
 - [Data Access Process](#)
- Applications for data access are submitted electronically via the CLSA's online data access application system called [Magnolia](#). In order to gain access to the system you need to email access@clsa-elcv.ca to request a user account. You must provide your full name, institution email, title and institution in your request. The online application contains two parts: General Project Information and the Data Checklist. Click [here](#) for more information.
- The CLSA has three annual submission [deadlines](#), which are announced on the website.
- CSLA biospecimen are expected to be released in 2019 and will have one application deadline per year, which has yet to be determined.
- Ethics approval is not required at the time of application, but access to data will not be granted without it.
- In general, applicants should be prepared for the application process to take six months from the date of the submission deadline to the receipt of data.

- The base cost to access data is \$3,000 for an individual. Additional fees may be applied for data sets that require more complex customization. Click [here](#) for more information.
- Graduate students and postdoctoral fellows are permitted to use CLSA data through a trainee application at no cost, but a supervisor is required. Click [here](#) for more information.
- Click [here](#) for more information on the data access application process.
- Click [here](#) for additional FAQs.

Data Access

All requests to access CLSA data are reviewed by the Data and Sample Access Committee (DSAC). Once an application has been reviewed, the DSAC will make a recommendation to the Scientific Management Team (SMT). If the SMT approves the project, data is released once the CLSA access agreement is signed and proof of ethics has been provided to the CLSA. The requested data is sent through an electronic, downloadable link to the primary applicant. The link can be shared by the primary applicant to the project team members listed on the application. The provided link is active for seven days. Researchers who are granted access to CLSA data have a specified time frame in which the proposed analysis must be completed. If the analysis cannot be completed in that timeframe, an extension must be requested. Investigators, students, and project team members may be added to a project as long as there is a valid CLSA access agreement.

Additional Information

[*Approved CLSA Project Summaries*](#)

[*CLSA Publications*](#)

[*Data Support Documentation*](#)

Includes data dictionaries, derived variables documents, and other support materials.

[*CATI Sites Contact Information*](#)

CLSA Contact Information

Telephone (Toll-Free): 1-866-999-8303

Email: info@clsa-elcv.ca

Mailing Address: CLSA National Coordinating Centre

1280 Main St. W., MIP-300A

Hamilton ON, L8S 4K1