



Cohort Profile

Cohort Profile: The Canadian Longitudinal Study on Aging (CLSA)

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Why was the cohort set up?

The Canadian Longitudinal Study on Aging (CLSA) was established to understand and address the needs of an aging population.^{1–3} Overall aims are to examine aging as a dynamic process; to investigate the inter-relationship among intrinsic and extrinsic factors from mid-life to older age; and to capture the transitions, trajectories and profiles of aging.⁴ A central objective in creating the CLSA was to provide national infrastructure and build capacity for state-of-the-art, interdisciplinary, population-based research and evidence-based decision-making.^{5,6}

The CLSA was designed to be a national, longitudinal research platform that includes participants from all 10 Canadian provinces, and collects comprehensive data and biological samples that will support a wide variety of aging-related research questions.³ The cohort of 51 338 participants, aged 45–85 years at enrolment, is composed of two complementary cohorts that may be studied separately or together: (1) the Tracking cohort of 21 241 participants randomly selected from within all 10 provinces who are interviewed by telephone, and (2) the Comprehensive cohort of 30 097 participants randomly selected from within 25–50 km of 11 data collection sites (DCSs) (in seven provinces) who are interviewed in person, take part in in-depth physical assessments at DCSs, and provide blood and urine samples. To support research that integrates the two cohorts, a common set of questionnaire information is being collected for both the Tracking and Comprehensive cohorts, and the same core data and data collection are planned for each future follow-up for both cohorts. All participants will be followed-up every 3 years after baseline until 2033 or until death. Recruitment and baseline data collection were completed in 2015, and the first follow-up was completed in mid-2018. [Figure 1](#)⁴ shows an overview of the CLSA design.

Who is in the cohort?

The CLSA cohort is a national stratified sample of 51 338 women and men aged 45–85 years at the time of recruitment. The inclusion of study participants as young as 45 years of age was motivated by the desire to capture

mid-life experiences, since important changes known to influence outcomes later in life occur during this period.^{7,8} The lower age limit at the baseline also allowed inclusion of a sample from the baby boom cohort (i.e. those born between 1946 and 1964) that will constitute a significant percentage of older adults in the coming years.^{9,10} The upper age limit was set to keep the focus on adults who have reached old age living in the community. One of the interests in studying the oldest age group prospectively is to examine transitions into the final years of life.

Participation in the CLSA cohort is voluntary and all individuals provided written informed consent.³ The selection and recruitment process is detailed elsewhere,^{3,11} but in brief, a random sample of eligible households was contacted, and if an eligible individual in the household was identified, they were asked to provide their information to the CLSA in order to be contacted for recruitment. Those who responded by providing their contact information were considered pre-recruits. These pre-recruits were then contacted, and those who underwent all required baseline interviews and assessments and provided written informed consent were enrolled into the cohort. The participation rate into the CLSA was about 45% with an overall response rate of 10%.

In the Tracking cohort, participants were recruited across the 10 provinces, and all questionnaire measures are collected by computer-assisted telephone interviews (CATI) administered through CLSA CATI sites established in four regions across Canada to accommodate different time zones and language (English or French) requirements for questionnaire administration.

In the Comprehensive cohort, recruits were drawn from individuals living within 25–50 km (depending on the city and accessibility) of one of eleven purpose-built DCSs located in seven provinces. DCSs are located in small, medium and large cities, and several include large rural catchment areas. Comprehensive cohort participants provide data through in-person home interview [computer-assisted personal interview (CAPI)], and additional questionnaires, tests, physical measurements and biological specimens (blood and urine) that are collected at the DCS. To participate in the Comprehensive cohort, participants had to complete an in-home interview and the visit to the

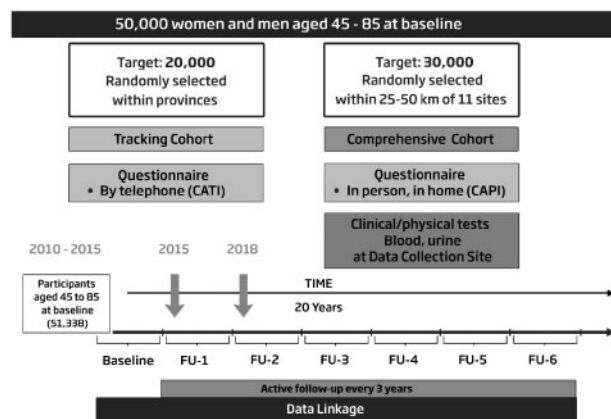


Figure 1. CLSA data collection timeline.

DCS at baseline. However, the provision of the biological specimens or their health card number for data linkage was optional.

Sample weights and eligibility of the CLSA sample

Three sampling frames were used for recruitment into the CLSA cohort: (1) recruitment from a subset of participants in the Statistics Canada's Canadian Community Health Survey-Healthy Aging (CCHS-HA); (2) recruitment from the registries of provincial health care systems; and (3) recruitment using Random Digit Dialing (RDD) of landline telephones. Since people with less education and lower socio-economic status are often under-represented in population-based studies,¹²⁻¹⁴ efforts were made to oversample certain areas identified using census data to ensure these groups are represented in the CLSA. Sampling weights were calculated for the combined cohort, as well as for the Tracking and Comprehensive cohorts.¹¹

Since the CCHS-HA was a nationally representative sample of Canadians >45 years of age with a response rate of >80%, it was used as the first sampling frame for the selection of the CLSA cohort and therefore, the same eligibility criteria were applied to all sampling frames to ensure consistency.¹⁵ Similar to CCHS-HA, the CLSA excludes residents of the Canadian territories and some remote regions, persons on Federal First Nations reserves and other provincial First Nations settlements, full-time members of the Canadian Armed Forces, and institutionalized persons (including long-term care). In addition to these exclusion criteria, participants had to be able to complete the interviews in English or French and be physically and cognitively able to participate on their own (e.g. able to hear, able to answer).³ Participants who become institutionalized after baseline will continue to be followed until study completion, death or loss to follow-up.

Sample size and power of the cohort

Given the diversity of goals for the research platform and the statistical models used for these effects and estimates, as well as those of future (and as yet unknown) research questions, it was difficult to provide globally meaningful effect sizes for sample-size calculations. Consequently, one strategy used to determine CLSA sample size was to carry out simulations based on projected evolutions of the cohort experience over time, similar to a strategy used by the UK Biobank.¹⁶

For these simulations, the prevalence of selected exposures and the incidence of selected outcomes, such as particular chronic diseases, over the period of follow-up were used as a guide to assess the adequacy of the proposed sample size. First, the expected number of cases of an outcome was simulated for each 3-year wave of the CLSA based on sex- and age-specific incidence rates and taking into account the aging of the cohort over time. The simulations also accounted for mortality (based on age- and sex-specific annual mortality rates from Statistics Canada) and attrition due to loss to follow-up [estimated at 0.5% per year based on the attrition rates for the National Population Health Survey (1994-95 to 2000-01)].^{17,18} For example, for a condition with a high annual incidence rate, such as hypertension (sex- and age-specific incidence rates ranging from 31 to 43 cases/1000 persons per year¹⁹), we would expect almost 1516 cases from a cohort of 20 000 people and 2273 cases from a cohort of 30 000 people (at the end of baseline data collection).

We also investigated the adequacy of the power profiles for two types of outcomes: hazard ratios (for incidence studies) and odds ratios (for nested case-control studies) using an iterative simulation-based approach. Because the Comprehensive cohort includes physical measures and biological specimens that may be relevant to many analyses, we wanted to examine the power using just this cohort as well as the full CLSA sample. Simulations were undertaken to determine the minimum detectable hazard ratio (MDHR) for the Comprehensive cohort ($n = 30\ 000$) and the minimal detectable odds ratio (MDOR) for the combined cohort ($n = 50\ 000$). The results of these simulations demonstrate the robustness of the CLSA data to power a wide variety of associations.¹⁷

Generalizability

Selected weighted demographic and social characteristics of CLSA participants at baseline were compared with those of the CCHS-HA and Statistics Canada Census 2011 (see Table 1). These comparisons suggest that the weighted

Table 1. Selected socio-demographic, lifestyle and health status characteristics of CLSA participants (n, Tracking = 21 241, Comprehensive = 30 097, combined = 51 338) compared with CCHS Healthy Aging (n = 20 087) and Canadian Census 2011 data

| | Weighted CLSA-Tracking % | Weighted CLSA-Comprehensive % | Weighted CLSA-combined cohort % | Weighted CCHS-HIA ^a % | Census 2011 ^b % |
|---------------------------------|--------------------------|-------------------------------|---------------------------------|----------------------------------|----------------------------|
| Sex | | | | | |
| Female | 51.5 | 50.4 | 51.5 | 51.5 | 51.8 |
| Age (years) | | | | | |
| 45–54 | 36.7 | 42.0 | 37.6 | 39.7 | 38.2 |
| 55–64 | 30.9 | 29.8 | 30.9 | 30.4 | 31.4 |
| 65–74 | 19.6 | 17.2 | 19.2 | 18.2 | 19.0 |
| 75–85 | 12.8 | 11.1 | 12.4 | 11.8 | 11.5 |
| Marital Status | | | | | |
| Married/living with a partner | 73.3 | 75.9 | 74.7 | 73.8 | 70.6 |
| Never married | 8.2 | 8.4 | 7.9 | 7.0 | 8.6 |
| Widow | 7.5 | 5.5 | 7.2 | 8.4 | 8.0 |
| Divorce/separated | 11.0 | 10.2 | 10.2 | 10.8 | 12.8 |
| Country of birth | | | | | |
| Born in Canada | 84.2 | 82.0 | 84.7 | 74.4 | 73.3 |
| English language spoken at home | 73.5 | 68.7 | 73.2 | 66.4 | 66.0 |
| French language spoken at home | 24.3 | 28.2 | 24.6 | 23.5 | 22.8 |
| Urban–rural | | | | | |
| Urban-dwelling | 76.6 | 90.8 | 75.5 | 75.9 | 78.6 |
| <Secondary | 7.2 | 4.9 | 7.3 | 20.4 | 21.3 |
| Secondary graduate | 12.7 | 9.0 | 12.6 | 19.1 | 24.5 |
| Some post-secondary | 7.5 | 6.7 | 7.6 | 5.2 | 12.6 |
| Post-secondary education | 72.5 | 79.5 | 72.5 | 55.3 | 41.5 |
| Working status | | | | | |
| Not retired | 51.0 | 57.0 | 51.6 | 56.4 | NA |
| Retired | 39.4 | 33.5 | 38.6 | 35.7 | NA |
| Partially retired | 9.6 | 9.6 | 9.8 | 7.9 | NA |
| <\$20 000 | 5.4 | 4.7 | 5.2 | 9.0 | 9.3 |
| \$20 000–\$49 999 | 24.0 | 18.7 | 23.4 | 29.1 | 25.2 |
| \$50 000–\$99 999 | 36.0 | 33.3 | 36.1 | 36.2 | 33.9 |
| \$100 000–150 000 | 19.1 | 22.2 | 19.4 | 16.2 | 17.6 |
| ≥\$150 000 | 15.6 | 21.1 | 15.9 | 9.4 | 13.9 |
| Self-rated general health | | | | | |
| Excellent | 20.7 | 20.4 | 20.0 | 20.5 | NA |
| Very good | 38.4 | 41.0 | 39.1 | 33.8 | NA |
| Good | 28.8 | 29.8 | 29.3 | 30.4 | NA |
| Fair | 9.5 | 7.5 | 9.1 | 11.5 | NA |
| Poor | 2.6 | 1.4 | 2.5 | 3.9 | NA |
| Self-rated mental health | | | | | |
| Excellent | 32.0 | 28.1 | 30.3 | 37.6 | NA |
| Very good | 38.0 | 41.5 | 39.2 | 36.2 | NA |
| Good | 24.8 | 24.9 | 25.2 | 20.6 | NA |
| Fair | 4.5 | 4.8 | 4.6 | 4.9 | NA |
| Poor | 0.7 | 0.7 | 0.7 | 0.9 | NA |

(continued)

Table 1. Continued

| | Weighted CLSA- Tracking % | Weighted CLSA- Comprehensive % | Weighted CLSA- combined cohort % | Weighted CCHS-HA ^a % | Census 2011 ^b % |
|--------------------|------------------------------|-----------------------------------|-------------------------------------|------------------------------------|-------------------------------|
| Smoking status | | | | | |
| Current smoker | 10.6 | 9.1 | 10.6 | 19.2 | |
| Former smoker | 58.2 | 57.5 | 58.0 | 48.3 | NA |
| Never smoked | 31.1 | 33.4 | 31.4 | 32.4 | |
| Regular drinker | 72.6 | 77.5 | 74.6 | 62.1 | NA |
| Occasional drinker | 14.3 | 11.4 | 14.1 | 17.0 | |
| No drink | 11.1 | 11.1 | 11.3 | 20.9 | |

^aA subset of the CCHS-HA participants allowed contact by the CLSA for possible recruitment into the Tracking cohort. Therefore, a selection (approximately 20%) of CCHS-HA participants are also participants of the CLSA. The sensitivity analysis was done by excluding this 20% of participants from the CCHS-HA.

^bCanadian Census 2011 [in 2011, the National Household Survey (Long-form) of the Canadian Census was done on a random sample of Canadians].
CLSA, Canadian Longitudinal Study on Aging; CCHS-HA, Canadian Community Health Survey-Healthy Aging; NA, Not applicable.

CLSA data are generalizable to the comparable Canadian population on many key variables. As discussed above, the CCHS-HA (2008–09) was an initial source of participants for the CLSA Tracking cohort, with a subset of CCHS-HA participants (56%) agreeing to be contacted by the CLSA for possible recruitment.^{18,20} Approximately 20% of CCHS-HA participants were also CLSA participants. We conducted a sensitivity analysis by removing participants that overlapped between CCHS-HA and CLSA, and the results, with and without overlap, were not significantly different (data not shown). Therefore, we present only the comparison with the full CCHS-HA. It is important to note that the results presented in Table 1 are based on sampling inflation weights, and three distinct inflation sampling weights were used to calculate descriptive results for the Tracking, Comprehensive and overall cohorts respectively.

Though generalizable to the Canadian population on many important variables, some differences exist between the CLSA participants' characteristics and CCHS-HA participants (Table 1). The CLSA Comprehensive cohort, in particular, are more educated, have higher household income, have higher percentages of participants who are Canadian born and rate their general health as very good.

By design, the Comprehensive cohort was recruited from an area 25–50 km from a DCS and included small urban areas with rural populations, medium size urban areas and large cities respectively. The weighted data for the Comprehensive cohort alone, thus, reflects only these regions and not the 10 provinces of Canada. Participation in the Comprehensive cohort required a commitment to a significant amount of time and effort to provide data. These factors, along with the voluntary nature of participation in the CLSA, may have contributed to the differences between the Comprehensive cohort, CCHS-HA and Census data. The Tracking Cohort, especially with its links to the CCHS-HA, was more similar to the CCHS-HA and Census 2011.

Retention and accommodation strategies

In longitudinal studies, one of the main challenges is participant engagement and retention.^{12,21} Barriers to participant retention include: (1) participants moving from their enrollment location; (2) participants developing health-related barriers; (3) participants experiencing cognitive decline; (4) participants entering long-term care; and (5) participants withdrawing due to study fatigue or associated reasons. In response to these barriers, CLSA accommodation and participant retention strategies were developed.

Participant moves

Every attempt is made to continue to follow each participant over time as they change geographic locations. For the Tracking cohort, this requires being able to continue to administer questionnaires by phone. For the Comprehensive cohort, those who move into an area covered by another DCS are re-assigned to the new DCS and undergo follow-up as usual. If the participant has moved out of range of all eleven DCSs, then we complete the data collection using a telephone-based survey (called the DCS by phone). Since the placement of DCSs covers many of the Canadian urban population areas, we expected to be able to re-assign many participants to a new DCS.

Participant develops health-related barriers

At the time of data collection, participants experiencing hearing impairment, speech/language problems or vision loss are offered accommodations, as required, in the interview. Procedures and processes have been developed to identify the appropriate accommodations, such as involving a helper (e.g. allowing a spouse to be present during survey questions if they can assist in enunciating or communicating for a participant with hearing loss) or declining a test for specific measures (e.g. physical function measures when a participant cannot safely stand). Under exceptional circumstances, modified interviews have been developed to facilitate participation. A 'DCS at home' interview replaces a DCS visit. This is meant to be used when a participant is physically unable to attend a DCS location. This accommodation contains as much content from a regular DCS visit as is possible. An 'in-home by phone' and 'DCS by phone' interview collects only the questionnaire content via telephone interview. These interviews are meant to accommodate participants where an in-home or DCS visit is not feasible. The proportion of participants who required accommodations at follow-up was small.

Participant develops cognitive decline

One of the potential barriers to continued participation is decline in cognitive abilities. Individuals at highest risk of cognitive decline are those ≥ 70 years of age, which allows us to identify those participants who may need a proxy decision maker and/or proxy information provider. Participants who were ≥ 70 years of age at baseline, and participants who turn 70 at each subsequent wave, are asked to indicate how they would like to participate in the CLSA in the future should they become unable to provide their own responses. If they indicate that they would like to continue participating in the CLSA, they are asked to provide consent for the CLSA to contact an identified proxy to assist in providing responses should the need arise in the future. In such cases, the contact information of a

proxy decision maker and proxy information provider, often the same person, is recorded.

Participant enters long-term care

When a CLSA participant moves into an institutional long-term care setting or nursing home, we continue to attempt to follow them using the accommodation strategies for moving, for health-related barriers or for cognitive decline, as appropriate. Participants who enter into assisted-living facilities and supported senior's housing continue to be considered community living.

Participant withdraws

Due to the longitudinal design of the CLSA, great effort has been made to continually engage participants in order to keep them motivated to continue in the study. Outreach using various media, including direct mail, newsletters, surveys, maintaining contact publications, social media posts and participant engagement events, are being managed by the CLSA Communications team and executed in partnership with the CLSA Participant Management Team, Local Site Principal Investigators and DCS staff members.

Retention rate and mortality rate

By the end of the first follow-up, 4.3% of participants had withdrawn from active data collection; however 60.8% of those withdrawn consented to continue passive data collection through data linkage. Participants who withdrew tended to be older, were more often female, had lower levels of income and education and worse self-rated general health. An additional 2.7% of participants died since their baseline assessment. This includes 4.1% in the Tracking cohort and 1.8% in the Comprehensive cohort.

Decedent questionnaire

When possible, a decedent questionnaire is administered to a close relative or friend after a participant dies. The CLSA decedent questionnaire is designed to elicit information on the date and cause of death, the trajectory of functional decline, residential transitions and health care utilization for the 3 months prior to death. Information is also sought on the decedent questionnaire respondent's perception of the quality of dying and death of the deceased participant.

What has been measured?

The CLSA was designed, in collaboration with expert working groups, to help understand the contributions of biological, clinical, health outcomes, healthcare services, lifestyle and behaviour, psychological and social measures in adult development and aging.^{3,4} Several multidisciplinary

issues critical to the understanding of the aging process were considered, focusing on questions that could only be answered with a longitudinal design.^{4,14,17,22} Feasibility and practicality were assessed when considering measures. This included consideration of administration time, psychometric properties, relevance across age groups, unique resources, or equipment required and availability of tools in English and in French. All measures are referenced on the CLSA website (<https://datapreview.clsa-elcv.ca/>). [Table 2](#) summarizes the domains and measures collected in the CLSA.

Questionnaires

There is a core set of questionnaire-based measures that are common across the Tracking cohort and the Comprehensive cohort.^{20,23} These measures cover an extensive set of domains including social and demographic measures, health status and functioning measures, psychological measures, lifestyle and behavioural measures and health care utilization. We use validated measures where available in French or English or adopt established questionnaires from other national surveys such as Statistics Canada's Canadian Community Health Survey (CCHS).

Cognition

A number of cognitive measures to address memory and executive function are administered to all CLSA participants;^{24,25} these include the Rey Auditory Verbal Learning Test – Trial 1 and five-minute delayed recall, the Animal Fluency Test and the Mental Alternation Test. Cognitive measures that are additionally administered to the Comprehensive cohort participants are, the Controlled Oral Word Association Test, Victoria Stroop Test, Prospective Memory Test and Choice Reaction Time.

Medications

Medication and prescription drug use are part of the questionnaires for all participants, and information that is more detailed is collected from Comprehensive cohort participants, including an in-person review of medications during the in-home visit and an in-depth 'Disease Symptom Questionnaire' during the DCS visit.

Physical measures

Physical assessments are conducted only for the Comprehensive cohort, as a part of the DCS visit. They include anthropometric measures, as well as assessments for physical function, vision and hearing. In addition, participants undergo an electrocardiogram, spirometry lung-function testing, an assessment of carotid intima-media

thickness using ultrasound and a dual-energy X-ray absorptiometry (DXA) scan for hip, spine, and whole body bone density and body composition (bone, lean tissue and fat tissue mass) measurements. By design many of the physical measures deemed important for in-person assessment, including vision, hearing and physical functioning, are also collected via self-report in the questionnaires.

Biological specimens

Of the 30 097 participants in the baseline Comprehensive cohort, 27 170 (90.3%) and 28 783 (95.6%) provided blood and urine samples respectively. Approximately 60 mL of non-fasting blood is collected into six tube types to produce ten fraction types including serum, four types of plasma (citrate, platelet poor citrate, heparin and ethylenediaminetetraacetic acid (EDTA)), buffy coat, two types of peripheral blood mononuclear cells (with and without cell preservative), and three types of whole blood (acid citrate dextrose, EDTA) including dried blood spots (baseline only). Biospecimen collection and processing takes place in the purpose-built laboratory at each DCS. Blood samples are processed within 2 h of collection and up to 5 h for urine from collection for a total of 42 0.5-mL aliquots. Biospecimens are temporarily stored at -80°C before shipping weekly in cryoshippers to the CLSA Biorepository and Bioanalysis Centre (BBC) for long-term storage in cryofreezers (-190°C). The core set of biomarkers that have been analysed to date are described in [Table 3](#).

Data linkage

At the time of recruitment, participants were asked to provide their health insurance number if they consented to linkage of their CLSA data to their records in existing health care administrative databases. The purpose of these potential linkages is to collect further information on medication use, health service utilization and hospital and physician visits, as well as to ascertain deaths and causes of death. About 90% of participants provided CLSA with their health insurance number.

Key findings of CLSA research

[Table 1](#) provides an overview of socio-demographic, lifestyle and health status characteristics of the CLSA participants at baseline. Of the combined cohort, 75% were married or living with a partner, 39% are retired, and 10% partially retired, 12% self-report fair or poor general health, 5% self-report fair or poor self-rated mental health, 11% are current smokers and 75% are regular drinkers.

Table 2. Summary of measures in the CLSA Research Platform

| Measures collected by domain ^a | Baseline | | Follow-up 1 | |
|---|---|--|-----------------|----------------------|
| | Tracking cohort (<i>n</i> = 21 241) | Comprehensive cohort (<i>n</i> = 30 097) | Tracking cohort | Comprehensive cohort |
| Social and demographic measures | | | | |
| Socio-demographic characteristics | x | x | x | x |
| Social networks and social support availability | x | x | x | x |
| Social participation | x | x | x | x |
| Social cohesion | | | x | x |
| Online social networking | x | x | x | x |
| Informal/formal care giving and care receiving | x | x | x | x |
| Transitions in work and retirement | x | x | x | x |
| Work limitations | | | x | x |
| Social inequality | x | x | x | x |
| Wealth/income | x | x | x | x |
| Home ownership | x | x | x | x |
| Built environments | x | x | x | x |
| Migration, mobility, transportation | x | x | x | x |
| Life space assessment | No | x | No | x |
| Education | x | x | x | x |
| Ethnicity, language, religion | x | x | x | x |
| Family and living arrangements | x | x | x | x |
| Paid and unpaid work | x | x | x | x |
| Veteran identifier | x | x | No | No |
| Gender identity | No | No | x | x |
| Health status | | | | |
| Activities of daily living | x | x | x | x |
| Instrumental activities of daily living | x | x | x | x |
| Pain | x | x | x | x |
| Sleep | No | x | No | x |
| Women's health | x | x | x | x |
| Medications | x | x | x | x |
| Self-reported function | x | No | x | x |
| General health/healthy aging | x | x | x | x |
| Chronic conditions | x | x | x | x |
| Chronic disease symptoms | No | x | No | x |
| Injuries | x | x | x | x |
| Oral health | x | x | x | x |
| Self-reported height and weight | x | NA | x | NA |
| Self-reported vision and hearing | x | x | x | x |
| Falls | x | x | x | x |
| Falls related to consumer products | x | x | No | No |
| Physical measures | | | | |
| Weight and height | No | x | No | x |
| Hip and waist circumference | No | x | No | x |
| Pulse rate and blood pressure | No | x | No | x |
| Electrocardiogram | No | x | No | x |
| Lung function | No | x | No | x |
| Bone density (dual-energy X-ray absorptiometry) | No | x | No | x |
| Body composition (dual-energy X-ray absorptiometry) | No | x | No | x |
| Carotid intima-media thickness (cIMT) | No | x | No | x |
| Hearing | No | x | No | x |
| Timed 4-metre walk | No | x | No | x |
| Timed get up and go (TUG) | No | x | No | x |
| Standing balance | No | x | No | x |

(continued)

Table 2. Continued

| Measures collected by domain ^a | Baseline | | Follow-up 1 | |
|---|---------------------------------|--------------------------------------|-----------------|----------------------|
| | Tracking cohort (n = 21 241) | Comprehensive cohort (n = 30 097) | Tracking cohort | Comprehensive cohort |
| Chair rise: balance and coordination | No | x | No | x |
| Visual acuity | No | x | No | x |
| Tonometry | No | x | No | x |
| Retinal scan | No | x | No | x |
| Grip strength | No | x | No | x |
| Biological specimens | | | | |
| Blood | No | x | No | x |
| Urine | No | x | No | x |
| Cognition | | | | |
| Executive function | x | x | x | x |
| Memory | x | x | x | x |
| Reaction time | No | x | No | x |
| Prospective memory | No | x | No | x |
| Subjective cognitive decline/meta memory | No | No | x | x |
| Psychological function | | | | |
| Depression | x | x | x | x |
| Satisfaction with life | x | x | x | x |
| Personality traits | No | x | No | x |
| Posttraumatic stress | x | x | No | No |
| Psychological distress | No | x | No | x |
| Loneliness | No | No | x | x |
| Abuse and maltreatment | | | x | x |
| Childhood maltreatment and health across the lifespan | No | No | x | x |
| Elder abuse | No | No | x | x |
| Lifestyle/behaviour | | | | |
| Alcohol use | x | x | x | x |
| Tobacco use | x | x | x | x |
| Diet questionnaire | No | x | No | x |
| Nutritional risk | x | x | x | x |
| Dietary supplement use | x | x | x | x |
| Physical activity | x | x | x | x |
| Health care use | | | | |
| Health/social service provider visits | x | x | x | x |
| Unmet health care needs | No | No | x | x |
| Preventive health services | No | No | x | x |
| Data linkage | x | x | x | x |
| Decedent questionnaire | No | No | x | x |

^aFor a detailed explanation of specific measures and the tools and instruments used, please visit the CLSA website at www.clsa-elcv.ca

Source: Adapted from Raina P, Wolfson C, Kirkland S, Griffith L. The Canadian Longitudinal Study on Aging (CLSA) Report on Health and Aging in Canada: Findings from Baseline Data Collection 2010–2015. Available from: <https://www.CLSA-ELCV.ca> (1 August 2018, date last accessed).

The CLSA Report on Health and Aging in Canada, Findings from Baseline Data Collection 2010–2015, provides a detailed description of the key finding of the CLSA.⁴

The goal of the CLSA is to facilitate important and impactful research on health and aging, and to direct health evidence and policy to improve the lives of aging Canadians.³ Baseline data are currently available for researchers and partners through a formal data access request. Data from the first follow-up was made available in Spring of 2019. Lay summaries of all ongoing projects are available on the CLSA website

(available at <https://www.clsa-elcv.ca/>). Numerous studies have already resulted in publications in a variety of areas, and links to published works can be found on the CLSA website (available at <https://www.clsa-elcv.ca/>).

What are the main strengths and weaknesses?

The size, depth and breadth of data in the CLSA enable the investigation of various understudied and novel areas that

Table 3. List of biomarkers in the CLSA Research Platform

| Category | N | Biomarkers |
|--------------------------|--------|---|
| Hematology ^a | 25 427 | Erythrocytes Granulocytes Hematocrit Hemoglobin Lymphocytes Platelets |
| Chemistry ^a | 27 012 | Albumin C-reactive protein (CRP) Creatinine Cholesterol Ferritin Free T4 (Thyroxine) Triglycerides Non-HDL |
| Epigenetics ^a | 1488 | DNA methylation DNA extracted from PBMCs 850K Infinium Methylation EPIC BeadChip (Illumina) |
| Genetics ^{b,d} | 19 663 | Genome-wide genotyping DNA extracted from buffy coat (<i>n</i> = 26 855) 820K UK Biobank Axiom Array (Affymetrix) |

^aRepeated at each wave of the study.

^bBaseline only.

^cNew for follow-up.

^dAll 26 855 will be completed by 2020.

Source: Adapted from Raina P, Wolfson C, Kirkland S, Griffith L. The Canadian Longitudinal Study on Aging (CLSA) Report on Health and Aging in Canada: Findings from Baseline Data Collection 2010–2015. Available from: <https://www.CLSA-ELCV.ca> (1 August 2018, date last accessed).

are not currently addressed in ongoing or proposed studies of aging in Canada or elsewhere.³ The CLSA includes participants from age 45 at baseline, younger than those typically included in aging studies. This affords the advantage of prospectively capturing middle life-course experiences that may be associated with changes in health later in life. At the other end of the age spectrum, the CLSA includes participants at baseline aged ≤ 85 years. One of the interests in studying the oldest age group prospectively is to examine transitions into and in the final years of life.

The CLSA was designed as a platform to build capacity for research on the many interrelated factors that affect healthy aging over the life course.³ The longitudinal design of the CLSA enables the interdisciplinary and transdisciplinary study of health transitions and trajectories.⁵ A primary goal of the CLSA is to support research into the identification and understanding of the complex interplay of modifiable risk factors, which will lead to interventions that improve people's health as they age.⁶

Although sampling may be random, it is acknowledged that due to self-selection cohort studies tend to recruit

healthier and wealthier participants. To be enrolled in the CLSA, participants had to provide written consent. The participants were required to complete French or English language interviews by telephone and Comprehensive cohort participants were required to have an in-home visit and a DCS visit. This may have resulted in a cohort that under-represents people with lower levels of literacy in French or English (e.g. recent migrants), with health problems, such as hearing problems, memory impairment and mobility issues.⁴ This and the response rates at baseline (comparable with other large cohort studies but still low) limit the representativeness of the CLSA; however, key CLSA measures for the entire cohort are comparable with estimates generated from Canadian census data and other nationally representative surveys like CCHS-HA with high response rates (Table 1). Although our weighted prevalence estimates for chronic conditions are in line with these nationally representative sources, caution is still warranted especially when presenting prevalence estimates for subgroups (e.g. high income vs low income), but exposure-disease and other complex relationships can be validly tested using CLSA data.^{12,16}

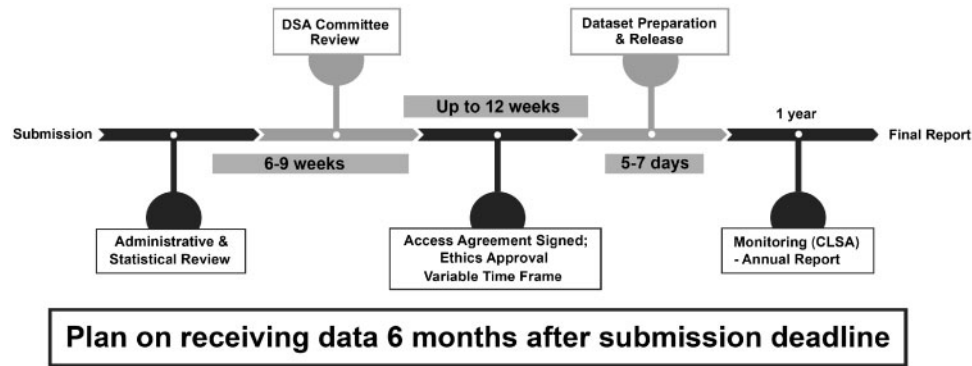


Figure 2. CLSA data access timeline.

Is the CLSA data available for use?

A fundamental principle of the CLSA is to make data and biospecimens available to the research community while protecting the privacy and confidentiality of study participants. This principle is specified in the CLSA Data and Biospecimen Access Policy and Guiding Principles. To date, more than 133 applications to access the data have been approved by the CLSA since 2016, more than 175 researchers and partners are using the CLSA platform and more than 15 research papers have been published using CLSA data. Special consideration is given to applications supporting the training of highly qualified health researchers.

Currently, there are three deadlines each year for submission of applications to access CLSA data. The applications are reviewed by the CLSA Data and Sample Access Committee. The data access process is shown in Figure 2.⁴ Data access information, including an overview of the Data Preview Portal, data release timelines, the data application process and documents, application deadlines, the data and biospecimen review process and data access FAQs are available on the CLSA website at www.clsa-elcv.ca²⁶

Profile in a nutshell

The CLSA is one of the most comprehensive research platforms for aging research

- The recruitment and baseline data collection on 51 338 men and women aged 45–85 occurred between 2011 and 2015.
- Continuous data collection occurs, producing a new wave of follow-up data every 3 years.
- The CLSA collects information on the changing biological, medical, psychological, social, lifestyle and economic aspects of people's lives. These factors are being studied to understand how, individually and in combination, they impact both the maintenance of health and the development of disease and disability as people age.
- Data collected includes survey information on social

and demographic measures, health status, cognition and psychological function on all participants, and physical measures and imaging for over 30 000 of the participants as part of the Comprehensive cohort.

- The data collection for the first follow-up wave was completed in February 2019 and the second follow-up wave began in April 2018.
- Information on the CLSA platform, and on how to access the data, is available on the CLSA website at www.clsa-elcv.ca

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References

1. Statistics Canada. *An Aging Population*. Ottawa: Statistics Canada, 2010.
2. Cheal D. Aging and demographic change. *Can Public Policy* 2000;26:S109–122.
3. Raina PS, Wolfson C, Kirkland SA *et al*. The Canadian longitudinal study on aging (CLSA). *Can J Aging* 2009;28:221–29.
4. Raina P, Wolfson C, Kirkland S, Griffith L. The Canadian Longitudinal Study on Aging (CLSA) Report on Health and

- Aging in Canada: Findings from Baseline Data Collection 2010–2015. Available from: <https://www.CLSA-ELCV.ca> (1 August 2018, date last accessed).
5. Kirkland SA, Griffith LE, Menec V *et al.* Mining a unique canadian resource: the canadian longitudinal study on aging. *Can J Aging* 2015;**34**:366–77.
 6. Orton L, Lloyd-Williams F, Taylor-Robinson D, O’Flaherty M, Capewell S. The use of research evidence in public health decision making processes: systematic review. *PLoS One* 2011;**6**: e21704.
 7. MIDUS. Midlife in the *United States (MIDUS) Study: Home*, 2014. <http://midus.wisc.edu/> (8 August 2019, date last accessed).
 8. HRS. *The Health and Retirement Study: Home*. <http://hrsonline.isr.umich.edu/index.html> (8 August 2019, date last accessed).
 9. Raina PS, Kirkland SA, Wolfson C *et al.* Accessing health care utilization databases for health research: A Canadian Longitudinal study on Aging feasibility study. *Can J Aging* 2009;**28**:287–94.
 10. Wolfson C, Raina PS, Kirkland SA *et al.* The Canadian community health survey as a potential recruitment vehicle for the Canadian longitudinal study on aging. *Can J Aging* 2009;**28**:243–49.
 11. Canadian Longitudinal Study of Aging (2017). *Sampling and Computation of Response Rates and Sample Weights for the Tracking (Telephone Interview) Participants and Comprehensive Participants*. <https://www.clsa-elcv.ca>.
 12. Fry A, Littlejohns TJ, Sudlow C *et al.* Comparison of sociodemographic and health-related characteristics of UK biobank participants with those of the general population. *Am J Epidemiol* 2017;**186**:1026–034.
 13. Oremus M, Postuma R, Griffith L *et al.* Validating chronic disease ascertainment algorithms for use in the Canadian longitudinal study on aging. *Can J Aging* 2013;**32**:232–39.
 14. Raina PS, Wolfson C, Kirkland SA *et al.* Ascertainment of chronic diseases in the Canadian longitudinal study on aging (CLSA), systematic review. *Can J Aging* 2009;**28**:275–85.
 15. Statistics Canada. Surveys and Statistical Programs—Canadian Community Health Survey—Healthy Aging (CCHS), 2018. <http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=5146&lang=en&db=imdb&adm=8&dis=2>.
 16. Sudlow C, Gallacher J, Allen N *et al.* UK biobank: an open access resource for identifying the causes of a wide range of complex diseases of middle and old age. *PLoS Med* 2015;**12**:e1001779.
 17. Ma J, Thabane L, Beyene J, Raina P. Power Analysis for population-based longitudinal studies investigating gene-environment interactions in chronic diseases: a simulation study. *PLoS One* 2016;**11**:e0149940.
 18. National Population Health Survey. National Population Health Survey-Household Component, Cross-Sectional, 2003. <https://www12.statcan.gc.ca/census-recensement/2011/ref/92-135/surveys-enquetes/nationalhealth-nationalesante-eng.cfm> (8 August 2019, date last accessed).
 19. Robitaille C, Dai S, Waters C *et al.* Diagnosed hypertension in Canada: incidence, prevalence and associated mortality. *CMAJ* 2012;**184**:E49–56.
 20. Canadian Longitudinal Study on Aging. *Canadian Longitudinal Study on Aging: Data Support Documentation*, 2018. <https://www.clsa-elcv.ca/>.
 21. Abshire M, Dinglas VD, Cajita MI, Eakin MN, Needham DM, Himmelfarb CD. Participant retention practices in longitudinal clinical research studies with high retention rates. *BMC Med Res Methodol* 2017;**17**:30.
 22. Balion CM, Raina P, Wolfson C *et al.* Feasibility of biological specimen collection for the Canadian Longitudinal Study on Aging (CLSA) Biorepository. *Can J Aging* 2009;**28**:251–59.
 23. Canadian Longitudinal Study on Aging. *Canadian Longitudinal Study on Aging; Data Collection*, 2018. <https://www.clsa-elcv.ca>.
 24. Canadian Longitudinal Study on Aging. *Canadian Longitudinal Study on Aging: Comprehensive Baseline Cognition Measurements Portal Dataset Overview*. <https://www.clsa-elcv.ca>.
 25. Canadian Longitudinal Study on Aging. *Canadian Longitudinal Study on Aging: Tracking Baseline Cognition Measurements*. <https://www.clsa-elcv.ca>.
 26. Canadian Longitudinal Study on Aging. *Canadian Longitudinal Study on Aging: Data Access*. <https://www.clsa-elcv.ca>.