

Transforming Everyday Life into Extraordinary Ideas





Canadian Longitudinal Study on Aging: A Research Platform for Interdisciplinary Research

Parminder Raina, PhD, McMaster University (Lead PI)

Stockholm, Sweden March 21, 2016

What is the Canadian Longitudinal Study on Aging (CLSA)?

“The Canadian Longitudinal Study on Aging is the largest most comprehensive research platform and infrastructure available in Canada for aging research with longitudinal data that will span 20 years from over 50,000 Canadians over the age of 45”

A research platform – infrastructure to enable state-of-the-art, interdisciplinary population-based *research* and *evidenced-based* decision-making that will lead to better health and quality of life for Canadians



Depth and Breadth of Baseline CLSA

PHYSICAL & COGNITIVE MEASUREMENTS

- Height & weight
- Waist and hip measurements
- Blood Pressure
- Grip strength, timed up-and-go, chair raise, 4-m walk
Standing balance
- Vision (retinal imaging, Tonometer & visual acuity)
- Hearing (audiometer)
- Spirometry
- Body composition (DEXA)
- Bone density (DEXA)
- Aortic calcification (DEXA)
- ECG
- Carotid Plaque sweep (ultrasound)
- Carotid intima-media thickness (ultrasound)
- Cognitive assessment (30 min. battery)
- Neuro-imaging (In Planning)

HEALTH INFORMATION

- Chronic disease symptoms (**disease algorithm**)
- Medication and supplements intake
- Women's health
- Self-reported health service use
- Oral health
- Preventative health
- **Administrative data linkage health services & drugs & other administrative databases**

PSYCHOSOCIAL

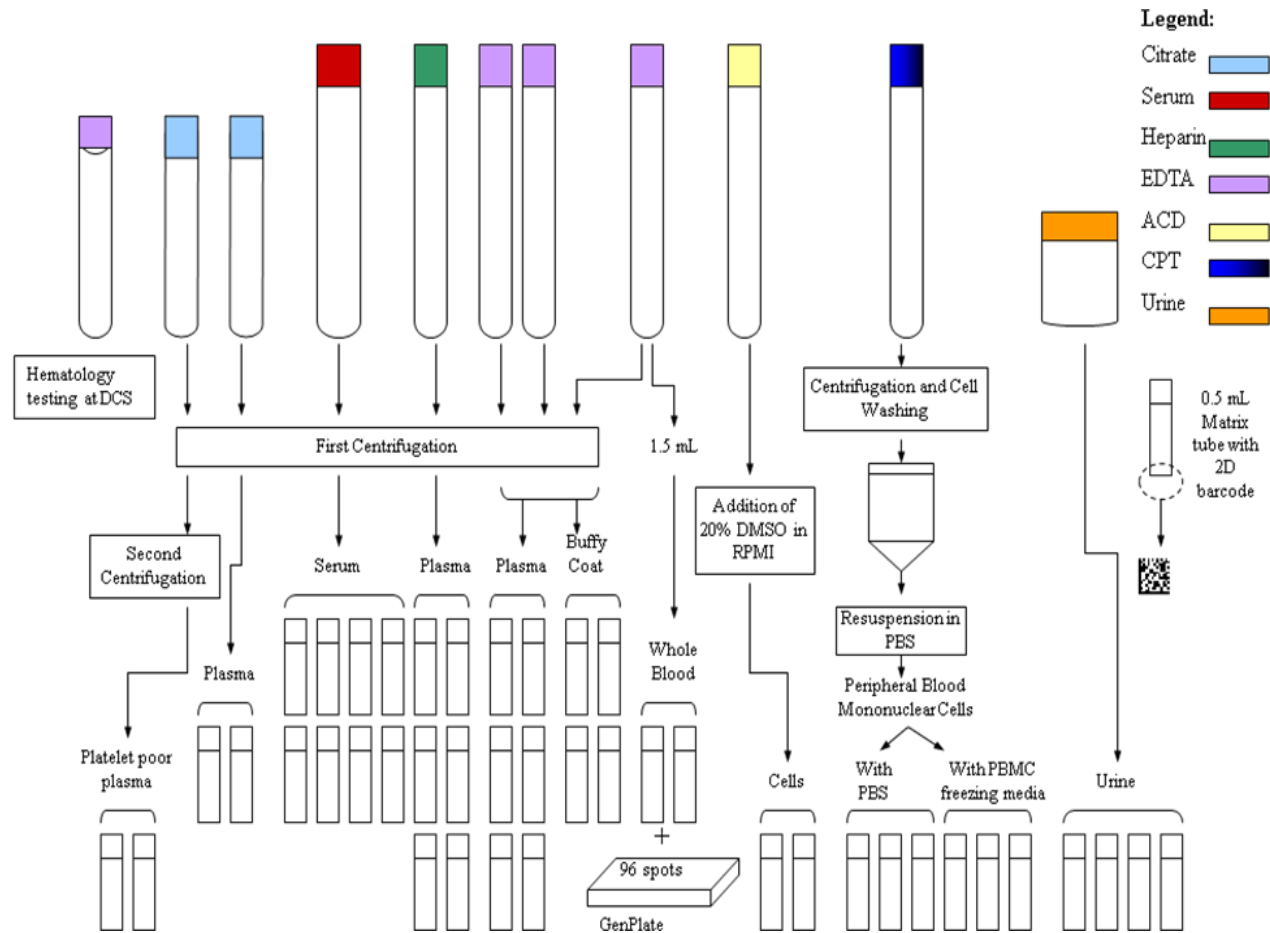
- Social participation
- Social networks and support
- Caregiving and care receiving
- Mood, psychological distress
- Veteran's Identifier & PTSD
- Coping, adaptation
- Injuries and consumer products
- Work-to-retirement transitions
- Retirement planning
- Social inequalities
- Mobility-life space
- Transportation
- Built environments & Contextual Factors
- Air Pollution
- Income, Wealth and Assets

LIFESTYLE & SOCIODEMOGRAPHIC

- Smoking
- Alcohol consumption
- Physical activity (PASE)
- Nutrition (nutritional risk and food frequency)
- Birth location
- Ethnicity/race/gender
- Marital status
- Education

Biospecimens

42 aliquots per participant



Analysis of Baseline Biomarkers

- We have completed Complete Blood Count on all fresh samples
- albumin, ALT, creatinine, CRP, ferritin, HbA1C, lipids panel, TSH, freeT4, Vitamin D on all 30,000 baseline participants
- Gene Wide Genotyping: Affymetrix UK Biobank Array on 10,000 participants (eventually on everyone)
- Whole Genome Sequencing on 500
- Methylation on 5,000 participants
- Metabolomics on 3,000 participants

Additional content 2015-2018

(collaborations & partnerships)

- Child Maltreatment and adverse events
- Elder Abuse
- Epilepsy
- Decedent Information
 - Link with provincial mortality data
 - Primary data collection for end-of-life
- Transition to Institutions
 - Primary data collection versus using InterRai or equivalent data (data linkage)
- Workability
- Subjective Cognitive Decline and Meta Memory
- Preventive Health Behaviours
- Sexual orientation and Gender Identity

Requirements for the CLSA IT Infrastructure

- Wanted to create highly integrated set of software to collect paper and pencil free data
- Cost effective data collection (e.g., VOIP)
- Build on existing sets of open source software where possible
- Integration of voice recordings in the software
 - Collection of cognitive data by recording participants responses
- Using similar platforms in Canada to facilitate harmonization of data across Cohorts
 - Common data catalogue architecture
 - Easy access to data catalogue and information about variables in each cycle of the CLSA

Quality and Data Management Needs

- Ability to implement substantial quality control as part of the data collection (e.g., elements of SOP to be integrated in the software)
- Wanted to code data in real time (e.g., Medication data)
 - Integration of Health Canada database to organize drug information by Drug Information Number (DIN)
- Verification of data from one data collection module to the next
- Minimize cleaning of data at the end
 - Lime survey versus Onyx
- Live audit of data and real time transfer of data



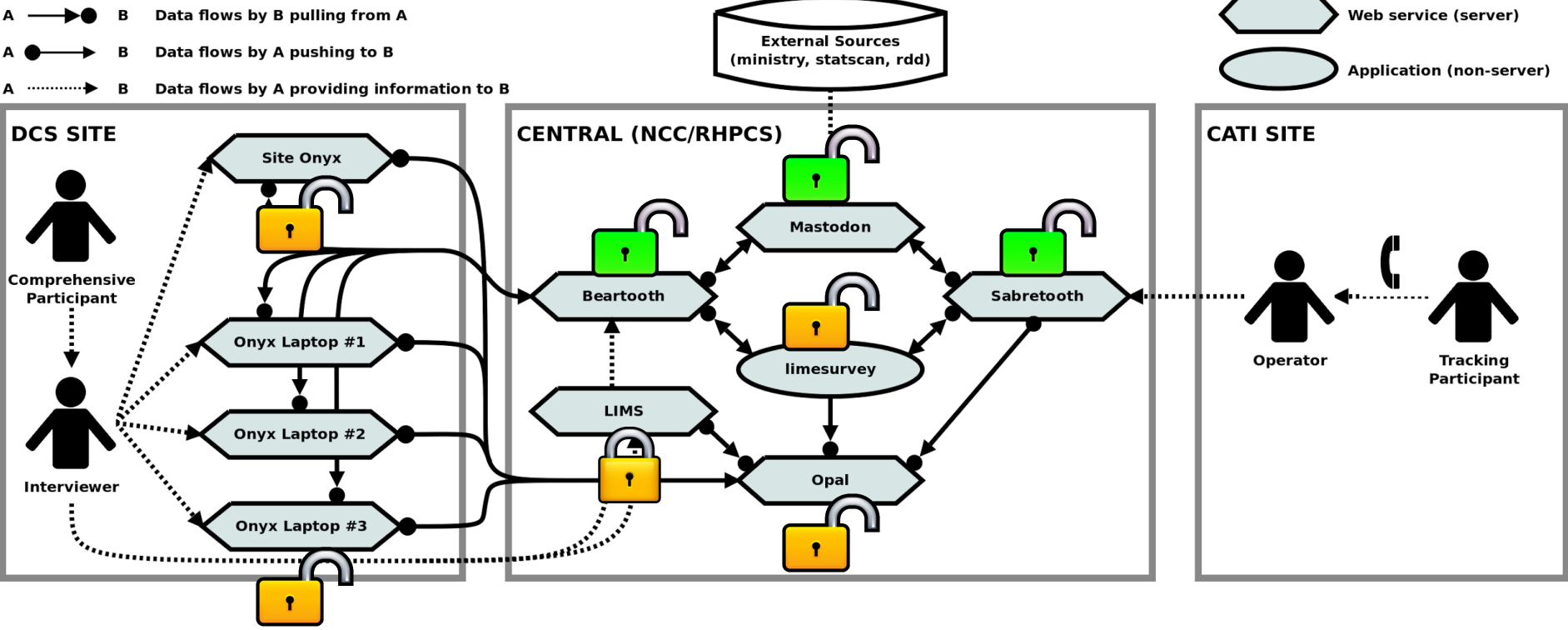
proprietary



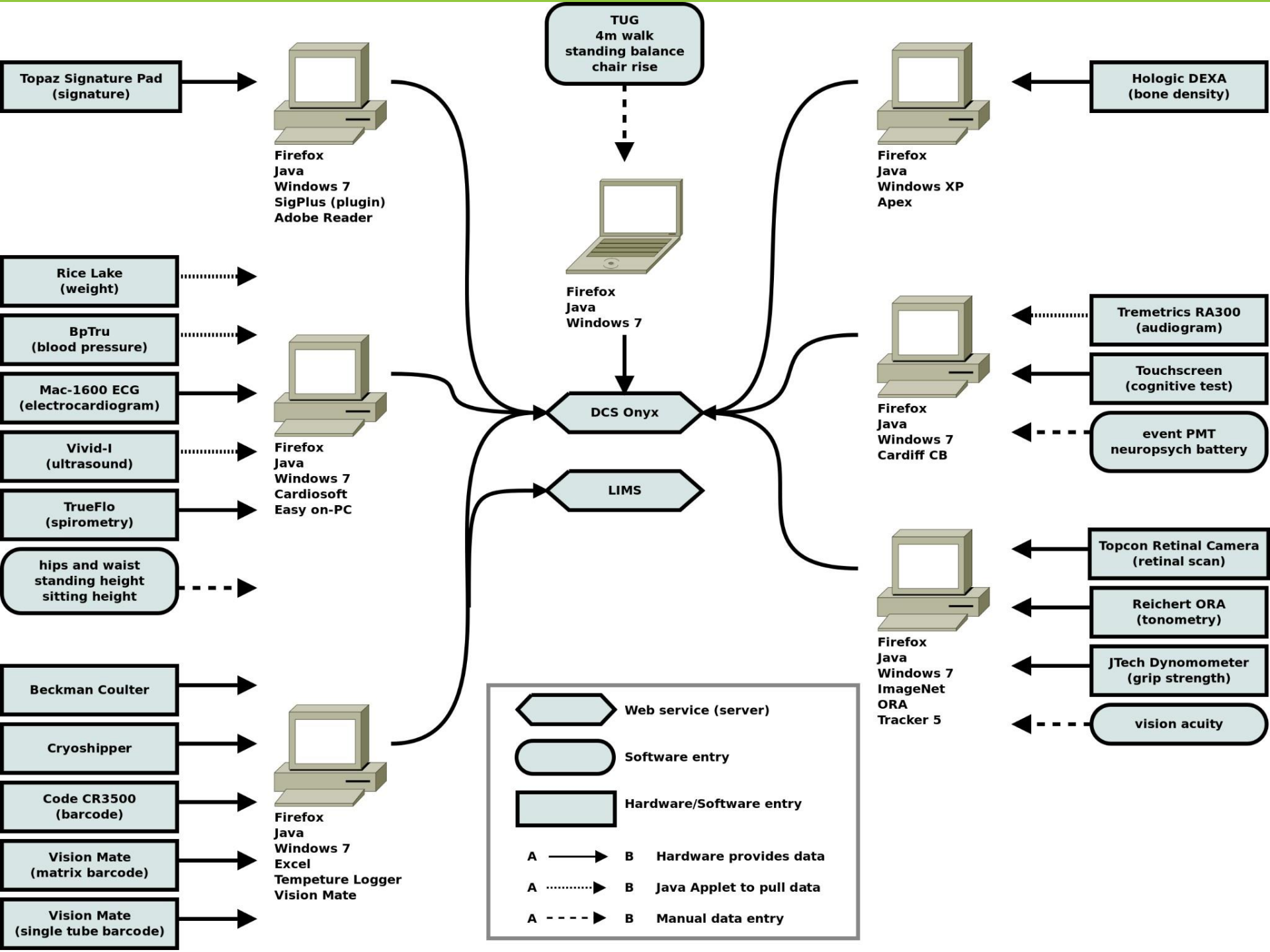
open-source

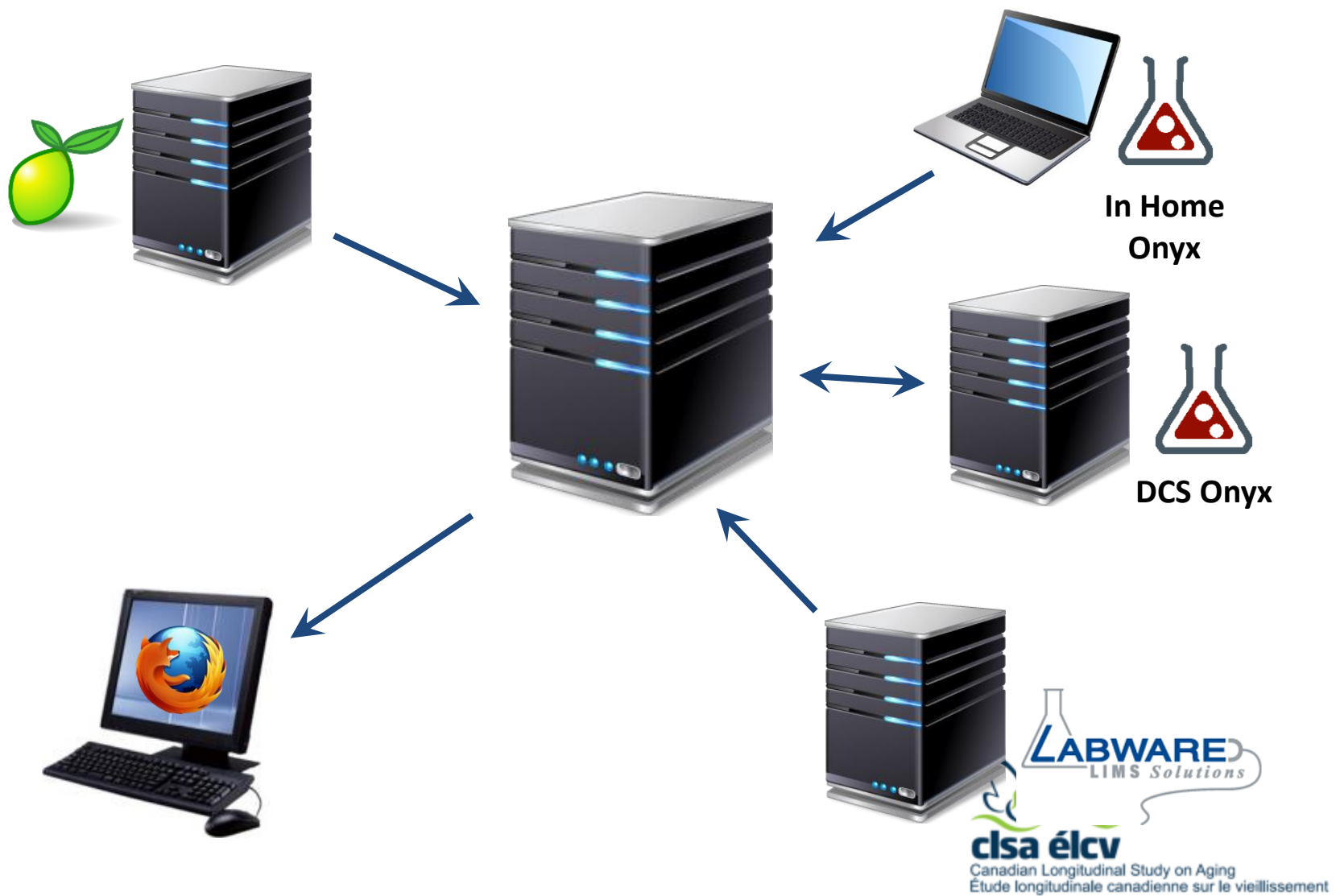


**original
open-source**



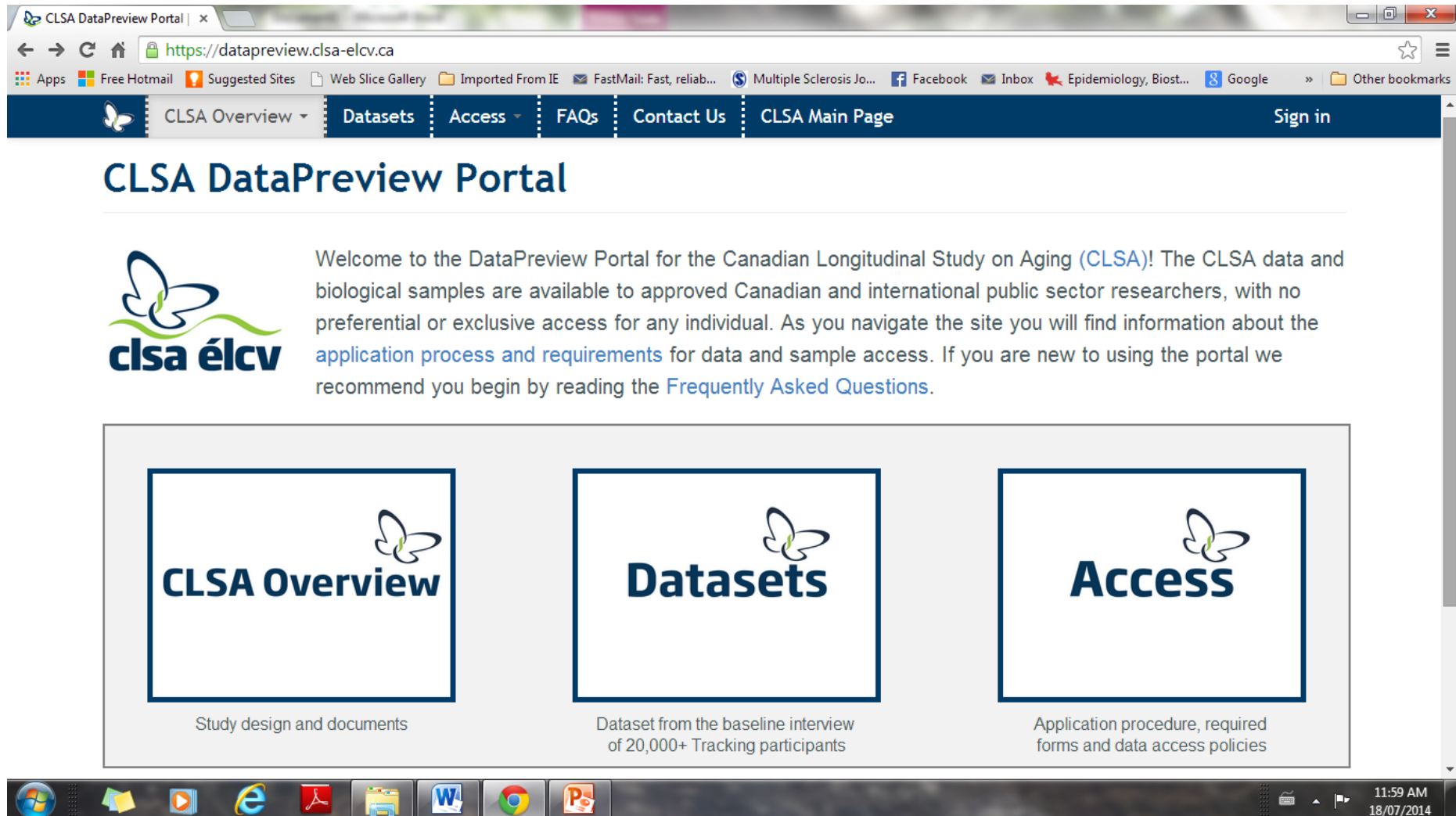
CLSA Software Architecture







<https://datapreview.clsa-elcv.ca/>



The screenshot shows a web browser window displaying the CLSA DataPreview Portal. The browser's address bar shows the URL <https://datapreview.clsa-elcv.ca/>. The page has a dark blue header with navigation links: CLSA Overview, Datasets, Access, FAQs, Contact Us, and CLSA Main Page. A 'Sign in' link is also present. Below the header, the main heading 'CLSA DataPreview Portal' is followed by a welcome message and the CLSA logo. The welcome message states that CLSA data and biological samples are available to approved researchers, with links to the 'application process and requirements' and 'Frequently Asked Questions'. Below this, three large boxes with blue borders and the CLSA logo present the main sections: 'CLSA Overview' (Study design and documents), 'Datasets' (Dataset from the baseline interview of 20,000+ Tracking participants), and 'Access' (Application procedure, required forms and data access policies). The Windows taskbar at the bottom shows various application icons and the system clock indicating 11:59 AM on 18/07/2014.

CLSA DataPreview Portal | x

← → ↻ 🏠 <https://datapreview.clsa-elcv.ca/> ☆ ☰


Apps Free Hotmail Suggested Sites Web Slice Gallery Imported From IE FastMail: Fast, reliab... Multiple Sclerosis Jo... Facebook Inbox Epidemiology, Biost... Google » Other bookmarks

CLSA Overview Datasets Access FAQs Contact Us CLSA Main Page Sign in

CLSA DataPreview Portal




Welcome to the DataPreview Portal for the Canadian Longitudinal Study on Aging (CLSA)! The CLSA data and biological samples are available to approved Canadian and international public sector researchers, with no preferential or exclusive access for any individual. As you navigate the site you will find information about the [application process and requirements](#) for data and sample access. If you are new to using the portal we recommend you begin by reading the [Frequently Asked Questions](#).




CLSA Overview

Study design and documents



Datasets

Dataset from the baseline interview of 20,000+ Tracking participants

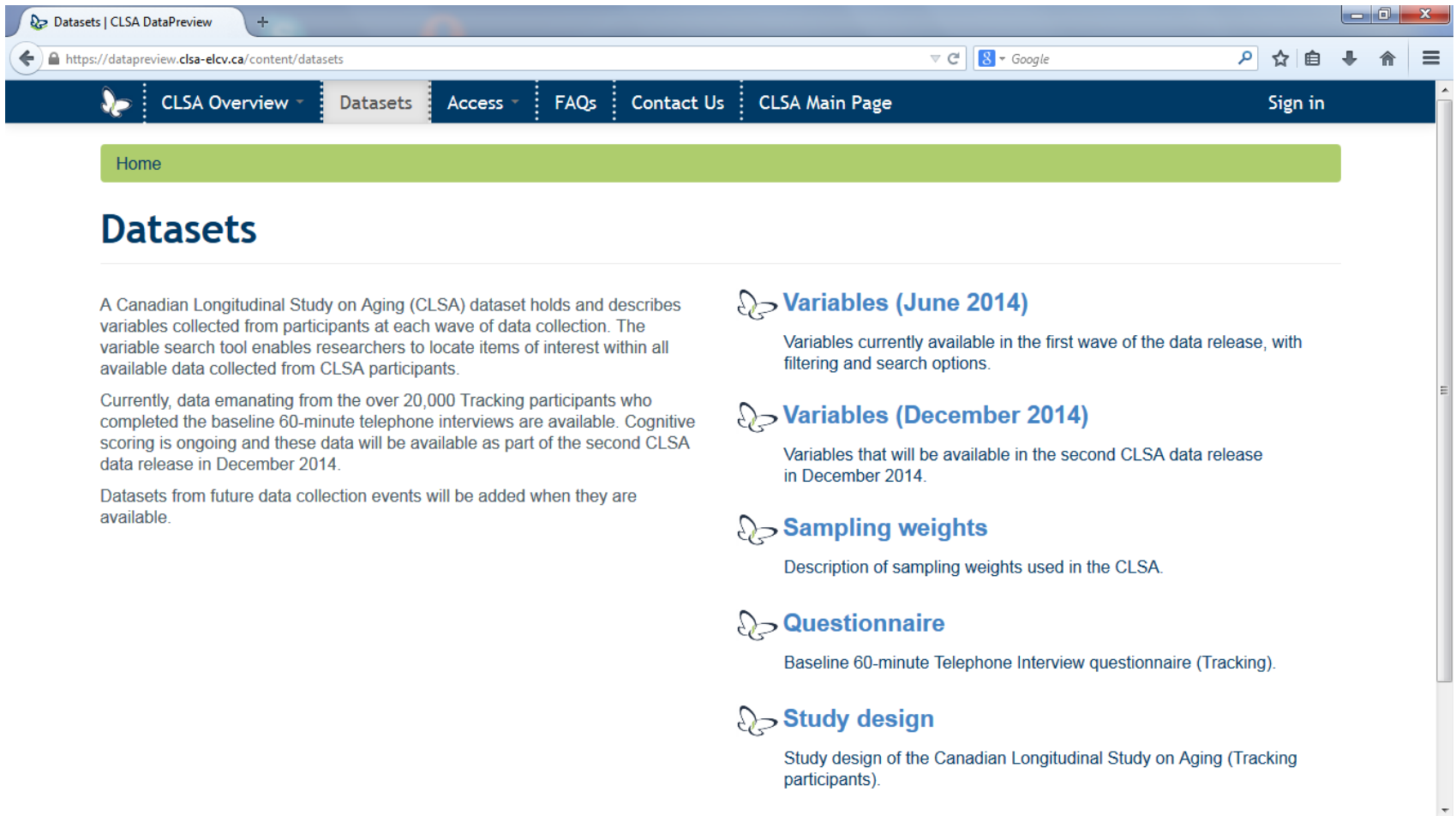


Access

Application procedure, required forms and data access policies

Windows taskbar: 11:59 AM 18/07/2014

DataPreview Portal (MICA)



The screenshot shows a web browser window with the address bar displaying <https://datapreview.clsa-elcv.ca/content/datasets>. The page has a dark blue navigation bar with links: CLSA Overview, Datasets (active), Access, FAQs, Contact Us, and CLSA Main Page. A 'Sign in' link is on the right. Below the navigation bar is a green 'Home' button. The main content area is titled 'Datasets' and contains a paragraph about the CLSA dataset, a paragraph about the current data release (December 2014), and a paragraph about future data collection events. To the right of the main text are five links, each preceded by a butterfly icon: 'Variables (June 2014)', 'Variables (December 2014)', 'Sampling weights', 'Questionnaire', and 'Study design'. Each link has a brief description below it.

Datasets

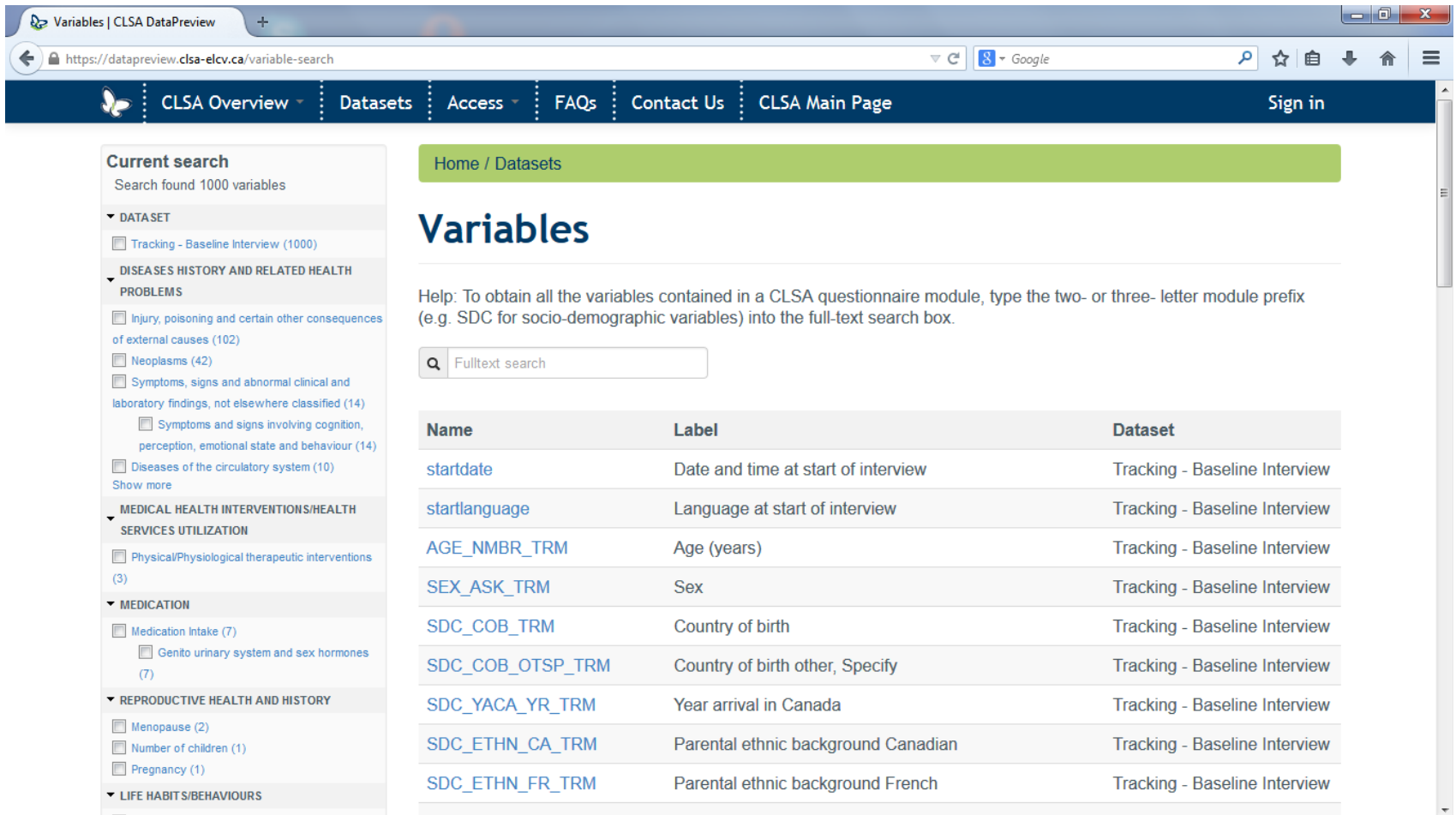
A Canadian Longitudinal Study on Aging (CLSA) dataset holds and describes variables collected from participants at each wave of data collection. The variable search tool enables researchers to locate items of interest within all available data collected from CLSA participants.

Currently, data emanating from the over 20,000 Tracking participants who completed the baseline 60-minute telephone interviews are available. Cognitive scoring is ongoing and these data will be available as part of the second CLSA data release in December 2014.

Datasets from future data collection events will be added when they are available.

- Variables (June 2014)**
Variables currently available in the first wave of the data release, with filtering and search options.
- Variables (December 2014)**
Variables that will be available in the second CLSA data release in December 2014.
- Sampling weights**
Description of sampling weights used in the CLSA.
- Questionnaire**
Baseline 60-minute Telephone Interview questionnaire (Tracking).
- Study design**
Study design of the Canadian Longitudinal Study on Aging (Tracking participants).

DataPreview Portal(MICA)



Variables | CLSA DataPreview

https://datapreview.clsa-elcv.ca/variable-search

CLSA Overview Datasets Access FAQs Contact Us CLSA Main Page Sign in

Current search
Search found 1000 variables

DATASET

- ☐ Tracking - Baseline Interview (1000)

DISEASES HISTORY AND RELATED HEALTH PROBLEMS

- ☐ Injury, poisoning and certain other consequences of external causes (102)
- ☐ Neoplasms (42)
- ☐ Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (14)
 - ☐ Symptoms and signs involving cognition, perception, emotional state and behaviour (14)
- ☐ Diseases of the circulatory system (10)
[Show more](#)

MEDICAL HEALTH INTERVENTIONS/HEALTH SERVICES UTILIZATION

- ☐ Physical/Physiological therapeutic interventions (3)

MEDICATION

- ☐ Medication Intake (7)
 - ☐ Genito urinary system and sex hormones (7)

REPRODUCTIVE HEALTH AND HISTORY

- ☐ Menopause (2)
- ☐ Number of children (1)
- ☐ Pregnancy (1)

LIFE HABIT S/BEHAVIOURS

Home / Datasets

Variables

Help: To obtain all the variables contained in a CLSA questionnaire module, type the two- or three- letter module prefix (e.g. SDC for socio-demographic variables) into the full-text search box.

Q Fulltext search

Name	Label	Dataset
startdate	Date and time at start of interview	Tracking - Baseline Interview
startlanguage	Language at start of interview	Tracking - Baseline Interview
AGE_NMBR_TRM	Age (years)	Tracking - Baseline Interview
SEX_ASK_TRM	Sex	Tracking - Baseline Interview
SDC_COB_TRM	Country of birth	Tracking - Baseline Interview
SDC_COB_OTSP_TRM	Country of birth other, Specify	Tracking - Baseline Interview
SDC_YACA_YR_TRM	Year arrival in Canada	Tracking - Baseline Interview
SDC_ETHN_CA_TRM	Parental ethnic background Canadian	Tracking - Baseline Interview
SDC_ETHN_FR_TRM	Parental ethnic background French	Tracking - Baseline Interview





SDC_MRTL_TRM

What is your current marital/partner status?

Description

Label:

Marital/partner status

Dataset:

Tracking - Baseline Interview

Value Type:

Text

Studies:

[Canadian Longitudinal Study on Aging](#)

Repeatable:

No

Categories

Name	Label	Missing
1	Single, never married or never lived with a partner	
2	Married/Living with a partner in a common-law relationship	
3	Widowed	
4	Divorced	
5	Separated	
9	[DO NOT READ] Refused	✓

Domains

Data Source:

Questionnaire

Sociodemographic/Socioeconomic Characteristics:

Marital/Partner status

Statistics

Value	CLSA
Single, never married or never lived with a partner	1698 (8%)
Married/Living with a partner in a common-law relationship	14601 (68.8%)
Widowed	2361 (11.1%)
Divorced	1995 (9.4%)
Separated	580 (2.7%)
[DO NOT READ] Refused	6
All	21241

Opportunities and Challenges

Maelstrom Suite of Software

- Opportunities
 - Cost effective solution
 - (\$5 million versus \$500,000)
 - Each new implementation costs less
 - Able to implement in a very short period of time
 - Support from Maelstrom Team
 - Scientific collaboration versus Service
 - Designing for future data harmonization with other cohorts around the world

Challenges

- Limited expertise in Java language to maintain software internally within CSA team
 - Heavy reliance on Maelstrom team to solve problems
- Limited documentation available on Maelstrom software
 - Getting better
- Version upgrades pose challenges
 - Specifically for ONYX
 - Need further testing before released



Contact:

Parminder Raina (Principal Investigator): praina@mcmaster.ca

CLSA funded by the Government of Canada through CIHR and CFI, and provincial governments and universities

www.clsa-elcv.ca

