Data Platforms for Investigating Built Environments and Dementia: The Canadian Longitudinal Study on Aging

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Étude longitudinale canadienne sur le vieillissement

Canadian Longitudinal Study on Aging (CLSA)

- 50,000 Participants from across Canada

- Aged 45-85 at baseline

- 20 year study with major data collection every 3 years

- More than 160 researchers in 26 institutions

- biology, genetics, medicine, psychology, sociology, demography, economics, epidemiology, nursing, nutrition, health services, biostatistics, population health

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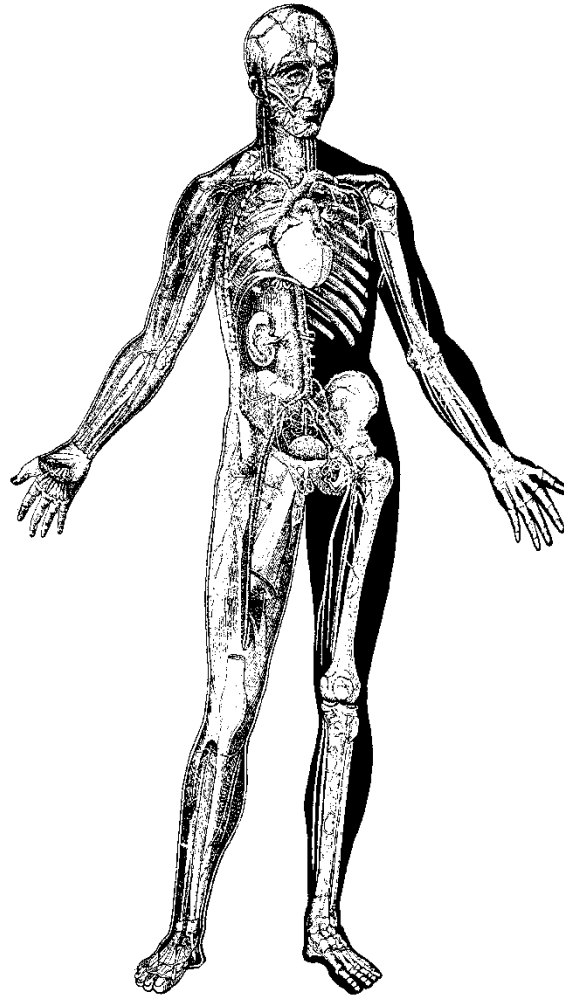Étude longitudinale canadienne sur le vieillissement

The CLSA Vision

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.

Innovation - Cell to Society

- Mid life to old age

- Quantitative traits
  - Physical
  - Social
  - Psychological

- Gene-environment interactions

- Disease, disability, psychosocial consequences

- Adaptation

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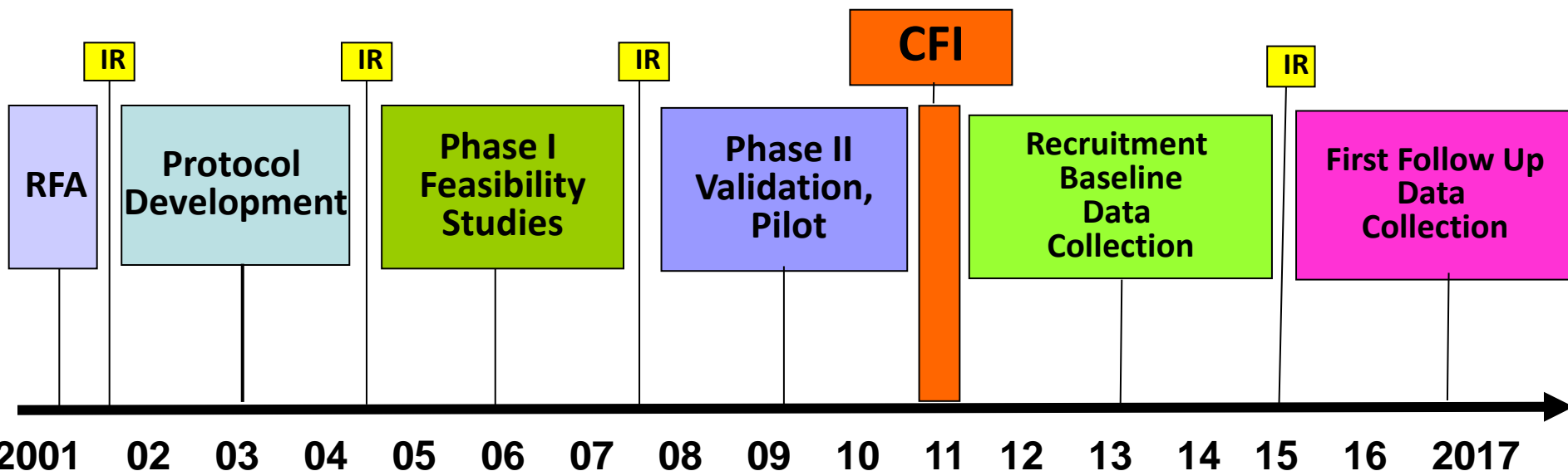Étude longitudinale canadienne sur le vieillissement

Timeline and Milestones

Team
Design
Objectives
Content

Acceptability
Bio-specimens
Recruitment
Data Linkage

Pilot recruitment
Validate measures
SOPs, TMs
Pilot protocol

Data Collection

| IR | IR | IR | CFI | IR |

| RFA | Protocol Development | Phase I Feasibility Studies | Phase II Validation, Pilot | | Recruitment Baseline Data Collection | First Follow Up Data Collection |

2001 02 03 04 05 06 07 08 09 10 11 12 13 14 15 16 2017

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Design Overview

50,000 women and men aged 45 - 85 at baseline

n=20,000*
Randomly selected within provinces

n=30,000
Randomly selected
within 25-50 km of 11 sites

Questionnaire
• By telephone (CATI)

Questionnaire
• In person, in home (CAPI)

Clinical/physical tests
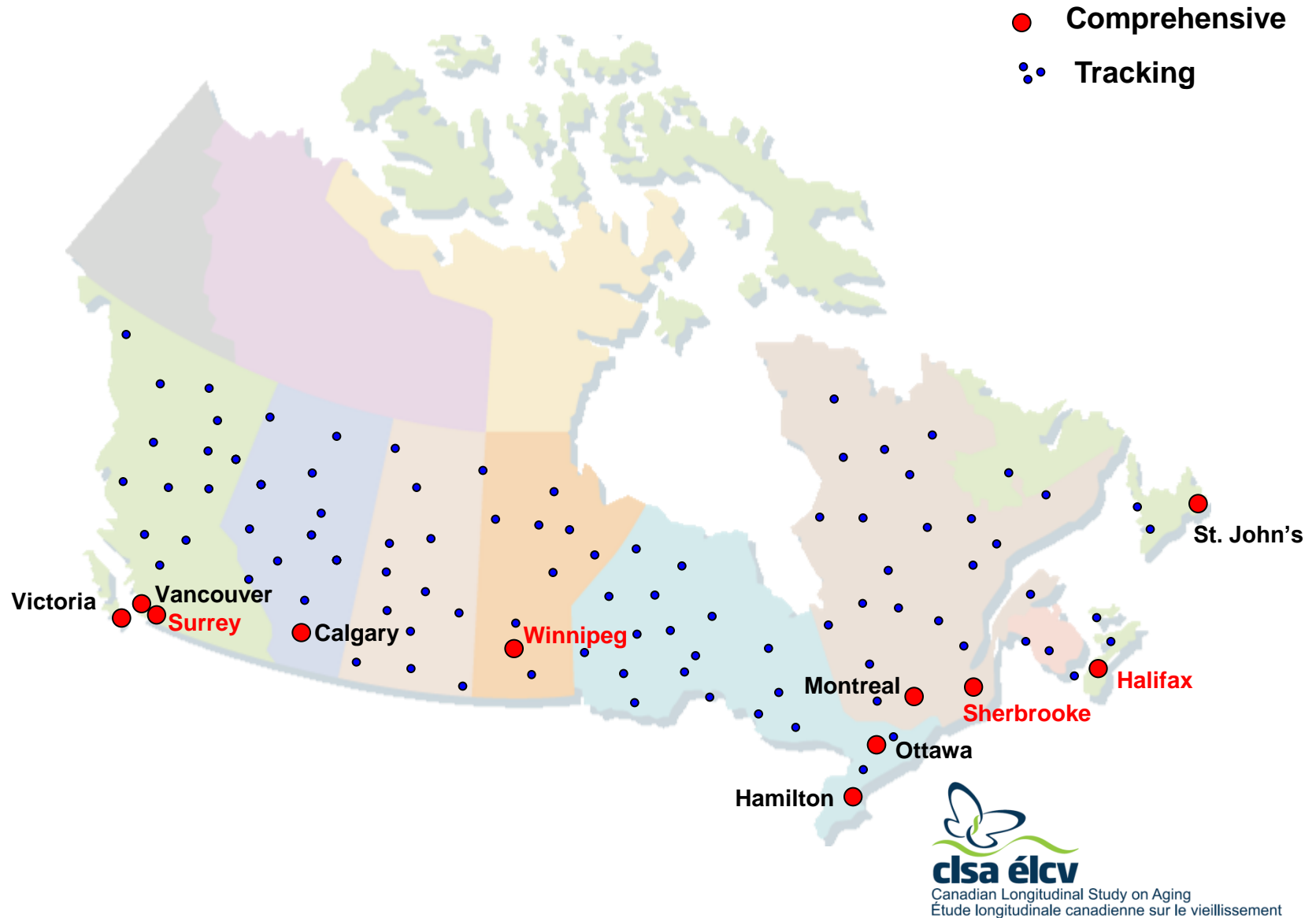**Blood, urine**
•   At Data Collection Site

Full follow up every 3 years

Maintaining Contact in between waves

Data Linkage

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Participant Recruitment

Recruitment Sampling Frames
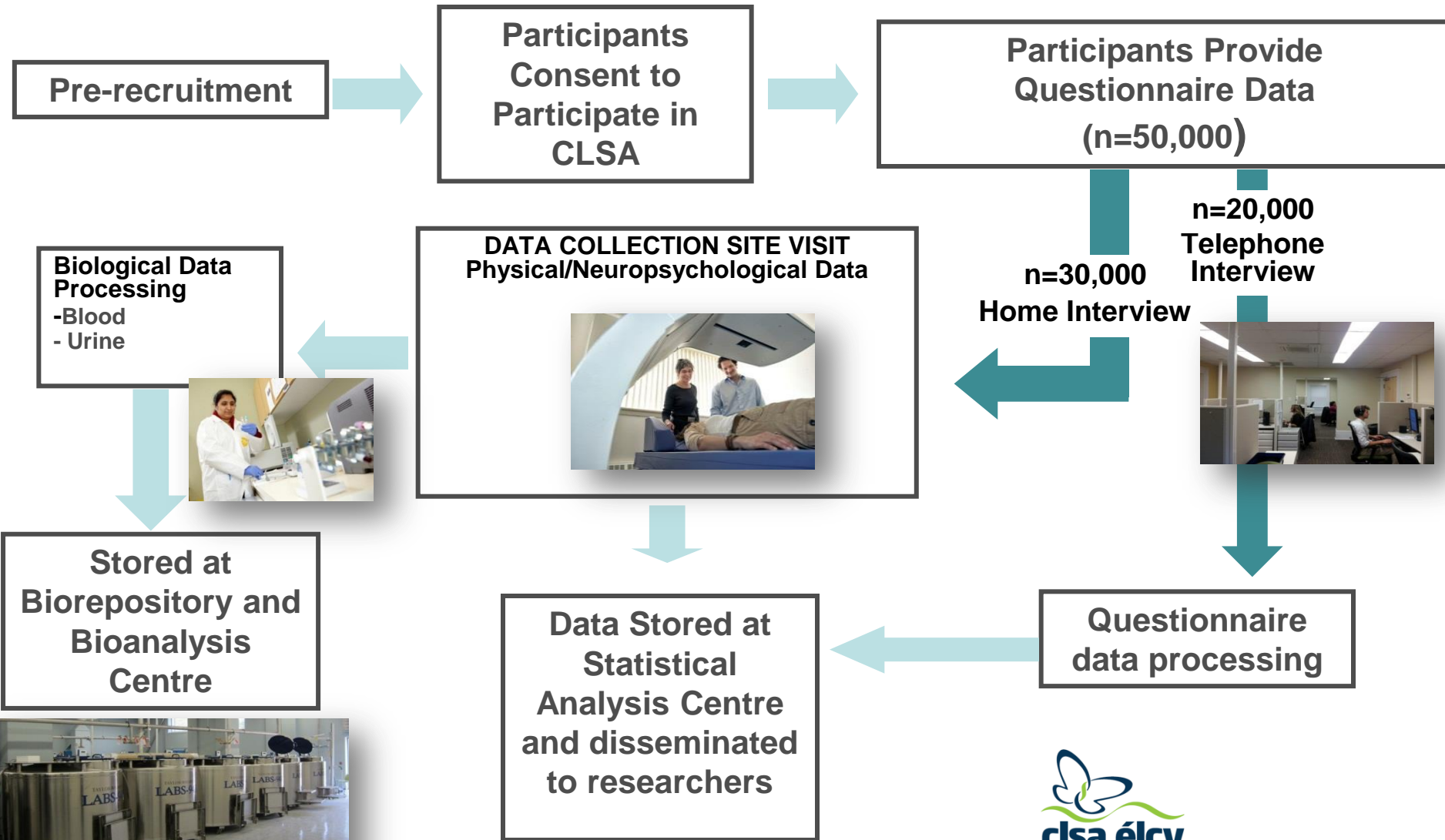
Sampling weights are available

1. ## Partnered with Statistics Canada
   - CCHS 4.2 Healthy Aging Survey
     - 2006 Census as an area frame to select households
   - Agreed to share contact information

2. ## Partnered with provincial Ministries of Health (MOH)
   - Health Card Registration databases
   - Mailouts, return Consent-to-Contact form

3. ## Random Digit Dialing
   - Pre-recruitment

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Exclusion Criteria At Baseline

Adapted from CCHS exclusion criteria

- Residents of the 3 territories
  - i.e. Northwest Territories, Nunavut, Yukon
- Living in an institution
- Living on First Nations Reserves
- Full time members of the armed forces
- Temporary visa holders
- Cognitive impairment
- Unable to communicate in French or English

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Standardized Paperless Process

Pre-recruitment → **Participants Consent to Participate in CLSA** → **Participants Provide Questionnaire Data (n=50,000)**

n=20,000 Telephone Interview

n=30,000 Home Interview

Biological Data Processing
-Blood
- Urine

DATA COLLECTION SITE VISIT Physical/Neuropsychological Data

Stored at Biorepository and Bioanalysis Centre

Data Stored at Statistical Analysis Centre and disseminated to researchers

Questionnaire data processing

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Content: Tracking Modules
60 minute Computer Assisted Telephone Interviews

- Sociodemographics
- Home ownership
- Veteran identifier
  - PTSD screen
- Lifestyle
- Health
  - General, women's, vision, hearing, chronic conditions
- Functional Status
- Cognition

- Depression
- Satisfaction with life
- Social networks/support/ participation
- Care-giving/receiving
- Injuries
- Labour Force/Retirement
- Income

Content: Comprehensive
InHome Computer Assisted Personal Interviews

The Tracking CATI plus

- Short diet questionnaire

- Sleep

- Medications

- More extensive cognition module and disease symptoms questionnaire

CLSA Data Collection
At the Data Collection Site

Physical Data Collected
- Bone Density, Body Composition
- Aortic Calcification
- ECG
- Carotid Intimal-Medial Thickness
- Pulmonary Function
- Vision and Hearing

Biological Data Collected
- Blood
- Urine

Psychological Data Collected
- Neuropsychological Battery
- Performance Testing
- Anthropometric Measures

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Content: Maintaining Contact
30 minutes CATI

- **Built Environment**
- **Transportation, migration, mobility**
- Falls
- Pain
- Oral Health
- Health Care Utilization
- Dietary Supplement Use
- Nutritional Risk
- Physical Activity
- Social Inequality
- Online social networking
- Wealth

- Parkinsonism (T)
- Medication (T)
- Psychological Distress (C)
- Personality Traits (C)

Status

As of June 12th, 2015

Recruitment & Data Collection Update
Telephone Interviews

- Recruitment of 20,000* participants, 60 minute telephone interviews every 3 years:

- Recruitment and baseline data collection are complete!
- Data available for release to researchers‡
    - MC interviews initiated 2013 (16,487 completed,~4% lost)

- First full follow-up begins end of summer 2015

*21,241 result of over sampling low SES

‡ cognition data and some open text in second release

Recruitment & Data Collection Update
Home Interviews and Data Collection Site Visits

- Recruitment of 30,000 for Home Interviews and Data Collection Site Visits:

- Baseline data collection 2012 to 2015:
    - In Home Interviews: 30,240
    - DCS visits: 29,650
    - Data release target: Spring 2016
    - MC 14,534 to date (~4% lost)

- First full follow-up begins summer 2015

Matters of Place - Transportation and the Built Environment

Built Environment

- Home ownership†
  - Current dwelling
  - Own or rent

- Problems with current home
  - e.g., noise, leaking, maintenance

- Satisfaction with current home

- How long in current community
- Reasons for moving to current location

† From Baseline Questionnaire

Matters of Place - Transportation and the Built Environment

Built Environment

11 questions regarding individuals' perceptions of their neighbourhood

- physical disorder (e.g., vandalism/graffiti, crime)
- social cohesion/social trust (e.g., feel part of this area, people will help you)

Adapted from Health and Retirement Study/English Longitudinal Study of Ageing

Matters of Place - Transportation and the Built Environment

Transportation

- Driving Status, frequency of driving
- Other forms of transportation including public transportation
- Most common form of transportation
- Driving skills (compared to 10 years ago)
- Avoidance of driving situations (e.g., unfamiliar routes, heavy traffic)
- Factors leading to stopping driving

Adapted from Older and Wiser Driver and questions from Ministry of Transportation

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Cognition and Dementia

Self-reported diagnosis by a health professional of:

- Memory problems
- Dementia or Alzheimer's disease

Neurocognitive battery

- Rey Auditory Verbal Learning Test (RAVLT)
- Verbal Fluency (Animal Naming)
- Mental Alternation Test

Comprehensive only

- Prospective memory test (event-based and time-based)
- Stroop Neuropsychological Screening Test
- Controlled Oral Word Association (F, A, S)
- Choice reaction time

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Dementia Algorithm

Algorithm created by Dr. Holly Tuokko and the Pyschological Health Working Group for Comprehensive participants

- **Uses results of cognitive tests to classify participants wrt cognitive impairment/dementia**
- **Currently being validated**

Dementia Algorithm

Memory Domain Score

Rey 1
Normal	= 0
MCI	= 1
Impaired	= 2

Executive fn Domain Score

MAT
Normal	= 0
MCI	= 1
Impaired	= 2

PMT
Normal	= 0
MCI	= 1
Impaired	= 2

Stroop
Normal	= 0
MCI	= 1
Impaired	= 2

COWAT
Normal	= 0
MCI	= 1
Impaired	= 2

ANIMAL
Normal	= 0
MCI	= 1
Impaired	= 2

Psychomotor Speed Domain

SCRT
Normal	= 0
MCI	= 1
Impaired	= 2

STEP 1

Use comparative norm to establish whether individuals were impaired on each of the 7 neuropsychological tests

SCALED = (RAW | Age, Edu, Gender)

How many SD below the mean?

If < 2 SD = Impaired
If $1 \leq SD \leq 2$ = MCI
Else = Normal

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Dementia Algorithm

Memory Domain Score

Clinician Judgement

Normal	= 0
MCI	= 1
Impaired	= 2

Executive fn Domain Score

Clinician Judgement

Normal	= 0
MCI	= 1
Impaired	= 2

Psychomotor Speed Domain

Clinician Judgement

Normal	= 0
MCI	= 1
Impaired	= 2
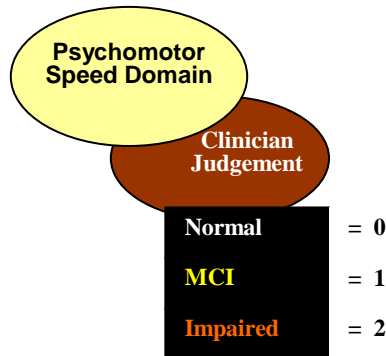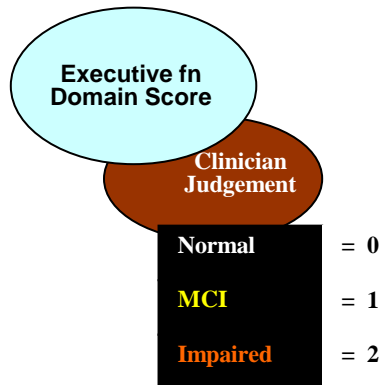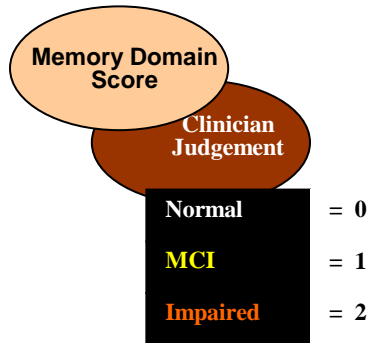
STEP 2

Create composite domain scores using the highest score across the tests in that domain. Such that, if any test score is 2, the domain score take a score of 2. If the next highest on any test is 1, then the domain score take a score of 1. Domain score will only equal 0 if all tests have a score of 0.

A set of parallel clinician's judgements can also be used to examine correspondence.

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Dementia Algorithm

Normal

All domain scores = 0

Multiple Domain CI – not dementia

At least 2 of 3 domain scores = 1 or 2, but does not meet dementia criteria below

Amnesic CI

Memory domain score = 1 or 2, all else = 0

Single Domain Non-Memory

Memory domain score = 0, one other domain score = 1 or 2

Dementia

Memory domain score = 2 & one other domain = 2
The higher the number of impaired domains, the more confident the diagnosis

STEP 3

Classify individuals into five categories using specific criteria depending on the combination of domain scores
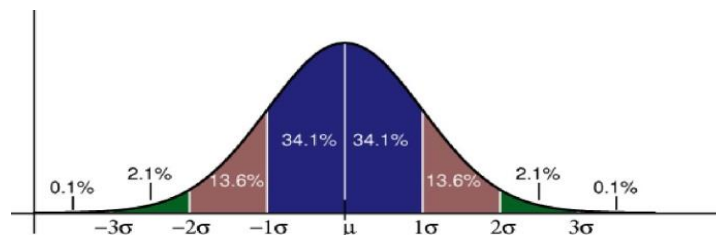
Richness of CLSA Data
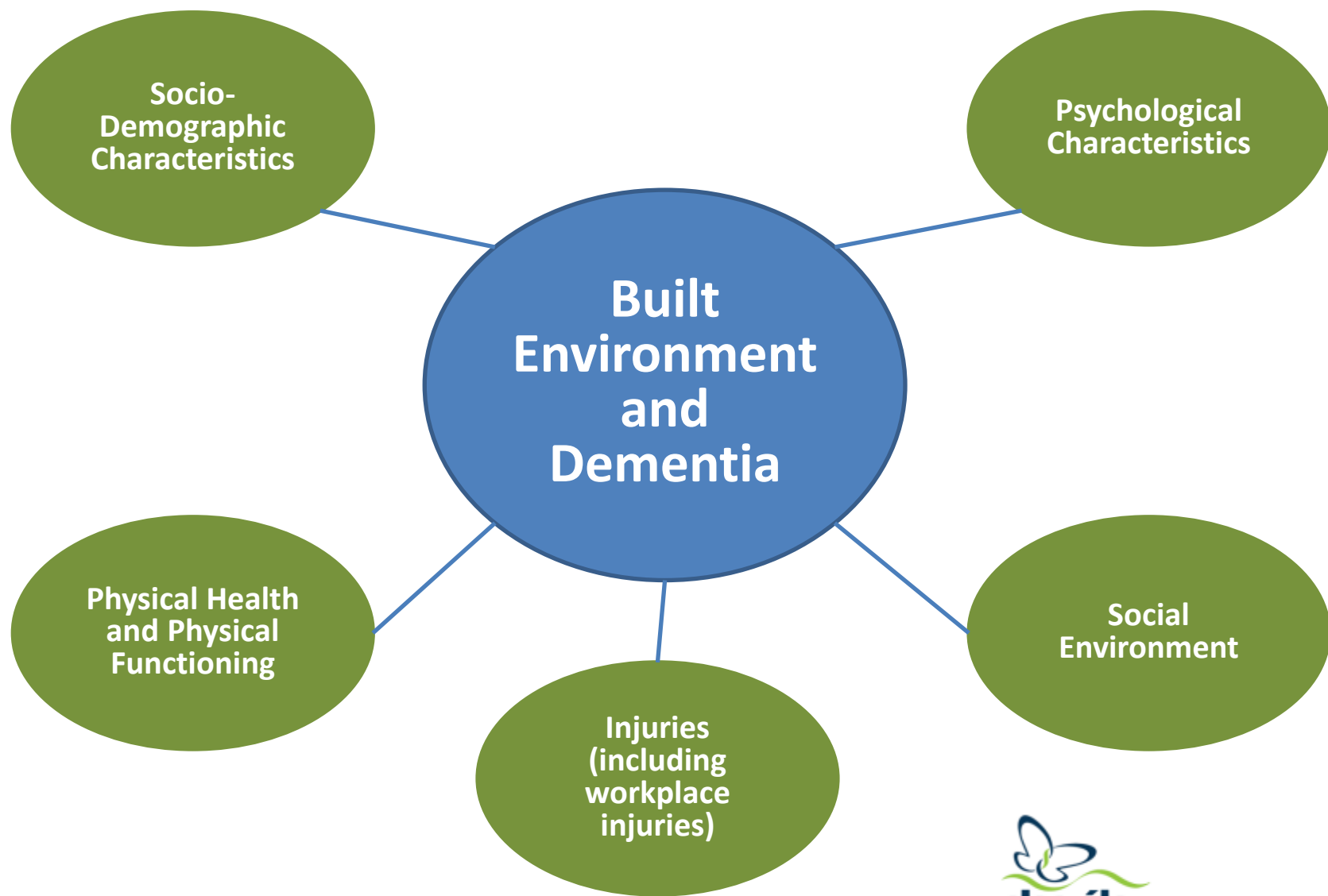
Access

Alphanumeric data from 21,241 CLSA participants who completed 60 minute CATIs

Data and Biospecimen Access
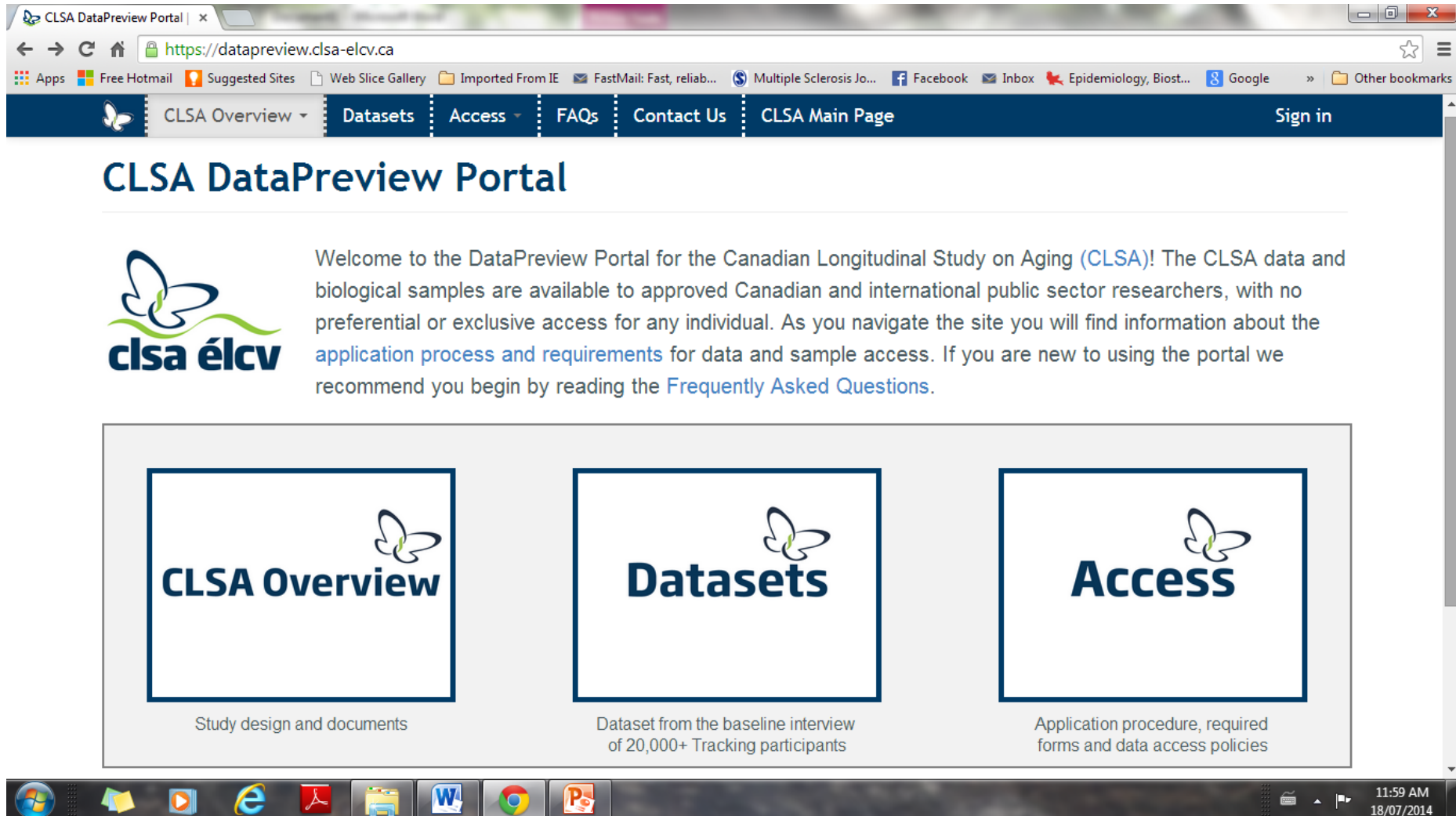
- Data and biospecimens will be available to the research community

- Fundamental tenets:

  - The *rights*, *privacy* and *consent* of participants must be protected and respected at all times

  - The *confidentiality* and *security* of data and biospecimens must be safeguarded at all times

  - CLSA data and biospecimens are unique resources that must be used optimally to support research to benefit all Canadians.

Data Access Continued

- Costing
- Cost Recovery
  a. $1,000 for a straightforward dataset
  b. No cost for data for graduate student theses

- DSAC Meetings 2015
  - February, April, June, September, December

- Application deadlines
  - March 23rd, May 15th, August 14th, November 16th

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DataPreview Portal
https://datapreview.clsa-elcv.ca/

Funded by the Government of Canada through the CIHR and CFI, and by Provincial Governments

Transforming Everyday Life
into Extraordinary Ideas

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Questions? Comments?

Matters of Place - Transportation and the Built Environment

<u>Built Environment</u>

Does your home have any of the following problems:
- Problems with noise
- Problems with leaking
- Problems with condensation
- Problems with electrical wiring or plumbing
- Problems with heating
- Problems with maintenance or repair
- Problems with infestations
- Other problems (specify)

I am satisfied with my current housing

Agree, neither agree or disagree, disagree

Matters of Place - Transportation and the Built Environment

Built Environment

- I really feel a part of this area
- Vandalism and graffiti are a big problem in this area
- I often feel lonely living in this area
- Most people in this area can be trusted
- People would be afraid to walk alone after dark in this area
- Most people in this area are friendly
- People in this area will take advantage of you
- This area is kept very clean
- If you were in trouble, there are lots of people in this area who would help you

Strongly agree, agree or disagree

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Biological Samples

BIOCHEMICAL & HEMATOLOGICAL ANALYSIS (50 ml Blood; Urine)

General Hematology

- Basophils
- Eosinophils
- Neutrophils
- Lymphocytes
- Monocytes
- White blood count
- Red blood cells
- Hemoglobin
- Platelets

Lipid Profile

- HDL-cholesterol
- LDL-cholesterol
- Tryglycerides
- Glucose
- Fasting blood sugar

Genetic and Epigenetic Markers

Hematology tests performed at the DCS

First Centrifugation

2 mL

Centrifugation and Cell Washing

Second Centrifugation

Serum

Plasma

Plasma

Buffy Coat

Addition of DMSO

Plasma

Whole Blood

Resuspension in PBS

Platelet poor plasma

+

96 spots

GenPlate

Cells

Mononucleocytes

Urine
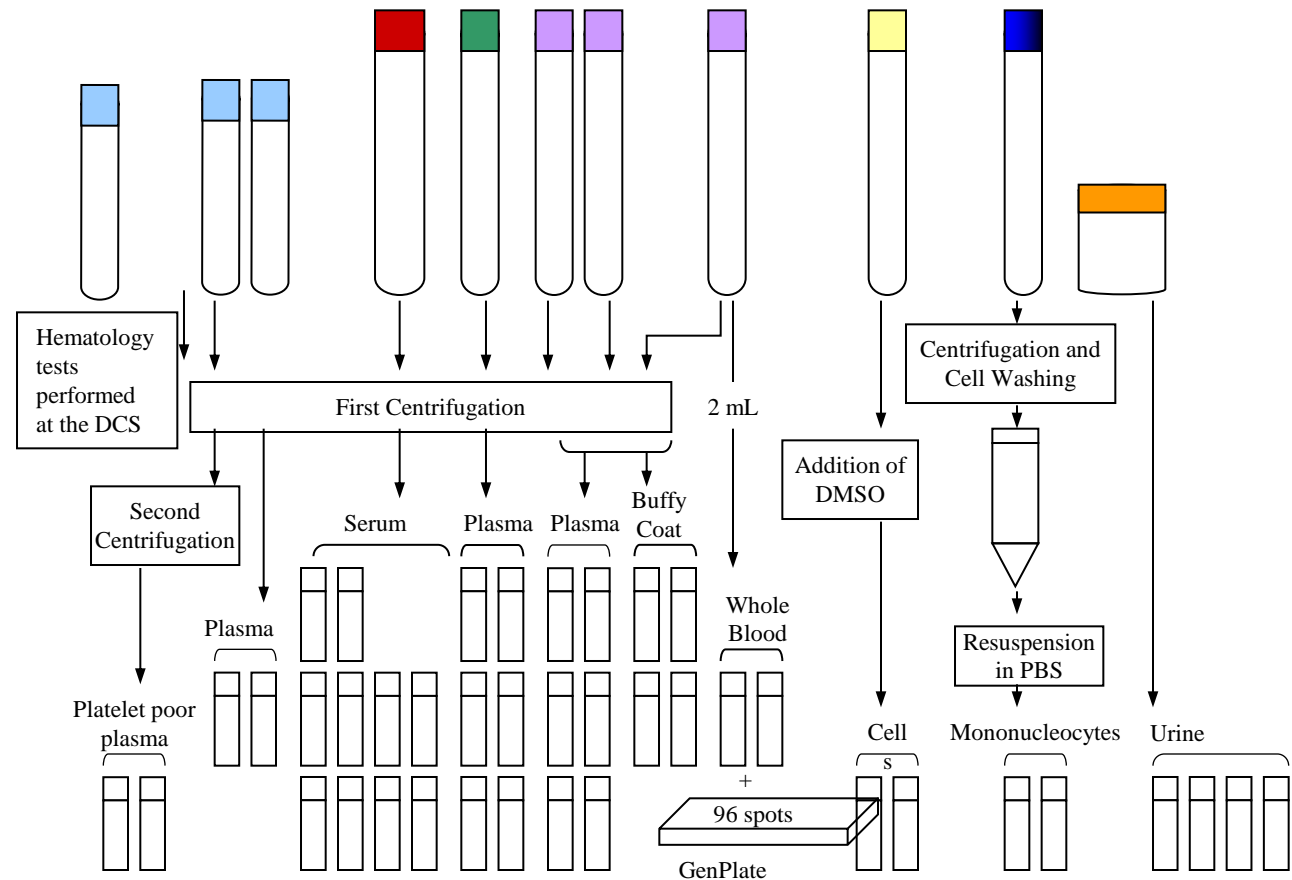
Data Access Steps
Tracking Data Only

Application process via CLSA **DataPreview** portal
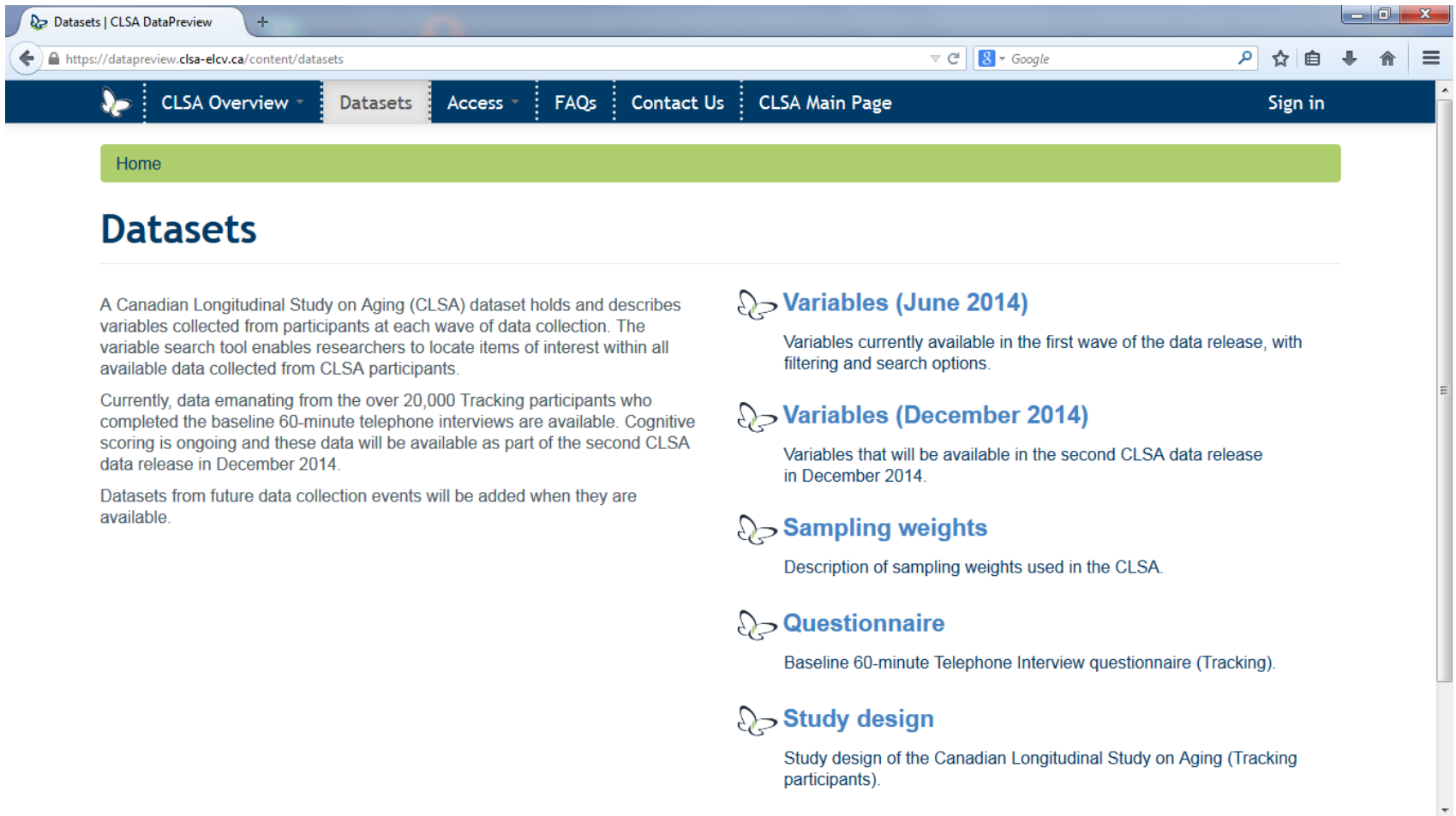
1. Administrative Review

2. Data and Sample Access Committee Review

3. Recommendation to Scientific Management Team

4. Notification of applicant

   – Steps 1 to 4 take 3-4 weeks

5. CLSA Access Agreement preparation and signatures

   – Institutional review/signature timing is unpredictable

6. Raw data provided to approved investigator

   – Step 6 takes 5 working days following completion of step 5

acces@clsa-elcv.ca

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DataPreview Portal

DataPreview Portal

Approved Applications

Applicant Title	Location
Consumer Product related senior falls and injury risk assessment	Ontario
CLSA Neurological conditions initiative (CLSA-NCI)	Quebec
The association between hearing loss and social function in older Canadians	British Columbia
The Veterans' Health Initiative within the CLSA (CLSA-VHI)	Quebec
Labour force participation: Retirement Transitions, Expectations and Planning	Ontario Student application
Who is at risk of social isolation and loneliness?	Manitoba
Companion animals and the aging population: Exploring relationships, contexts, and opportunities to contribute to health equity	Alberta Student application
Factorial invariance of the CES-D	Saskatchewan
The development of normative data and comparison standards for the cognition measures employed in the CLSA	British Columbia

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Linking CLSA Data

- Linkage is key to CLSA research strategy
  - Enormous potential for collection of information that is difficult to get from participants due to time, accuracy limitations; unknown to participants

- Types of databases
  - Individual level administrative provincial health databases (priority)
  - Disease registries
  - Population level databases of community characteristics, climate, pollution
  - Individual level economic characteristics

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First Follow Up (2015-2018)

- 1st follow up Tracking (September 2015)
  - ➢ Re-contacting 21,242 participants for their follow up telephone interviews

- 1st follow up Comprehensive (July 2015)
  - ➢ Re-contacting 30,000 participants for their follow up in-home interviews and DCS visits

First Follow Up
New Content

– Child maltreatment

– Elder Abuse

– Epilepsy

– Hearing handicap

– Arterial stiffness

– Workability

– Subjective cognitive decline

– Transportation

– Health care use

– Preventive health behaviours

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Analysis of baseline biomarkers
Biomarker and epigenetic analyses repeated over time

- Panel of biomarkers: albumin, ALT, creatinine, CRP, ferritin, hemoglobin A1C, lipids (cholesterol, HDL, Triglycerides, LDL), thyroid stimulating hormone, free T4, 25-hydroxyvitamin D
  - n=28,000 (Calgary Laboratory Services)
- Proposed genotyping: Affymetrix UKBiorepository array assay 820,967 SNPs
  - n=10,000 (McGill Genome Centre)
- Proposed epigenetic analysis: targeted age-associated CpG methylation using pyrosequencing and Sequenom EpiTyper
  - n=5,000 (UBC Genetics and Epigenetics Centre)
- Proposals submitted to do miRNA and metabolomics
- Requires isolation of DNA from PBMCs

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