Canadian Longitudinal Study on Aging: A National Platform for Research In Aging

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&

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On behalf of the CLSA Team

www.clsa-elcv.ca

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

☐ CIHR Strategic initiative

☐ Major funders:
  - CIHR and CFI
  - Provinces and universities across Canada

Support for the Platform*

Implementation: 2010-15

- CFI 2009-2014
  - CFI + Provinces + Universities and other partners
  - For infrastructure (renovations + equipment)
- CIHR 2009-2015
  - 86% of requested funds

- **No** funding for the analysis of collected data/biospecimens
  - Complete blood count only

First Follow-up: 2015-20

- CIHR 2015-2020
  - Maintaining the platform
  - Analysis of selected baseline biomarkers

*International Scientific Peer Review at every step

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Key Team Members
Local Site PIs, Leaders of Enabling Units and Working Group Leaders

Victoria: Debra Sheets, Lynne Young, Holly Tuokko
UBC: Max Cynader, Michael Kobor, Theresa Liu-Ambrose
SFU: Andrew Wister, Scott Lear
Calgary: David Hogan, Marc Poulin
Manitoba: Verena Menec, Phil St. John
McMaster: Cynthia Balion, Christopher Patterson, **Parminder Raina**, Lauren Griffith, Harry Shannon
Ottawa: Larry Chambers, Vanessa Taler
McGill: **Christina Wolfson**, Ron Postuma
Sherbrooke: Hélène Payette, Benoit Cossette
Dalhousie: **Susan Kirkland**
Memorial: Gerry Mugford, Patrick Parfrey
Waterloo: Mary Thompson, Changbao Wu, Mark Oremus

Scientific Working Groups and Co-Investigators
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The CLSA Research Platform
Vision and Scientific Aim

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

To study aging as a dynamic process, examining the inter-relationships among intrinsic and extrinsic factors from mid-life to end-of-life
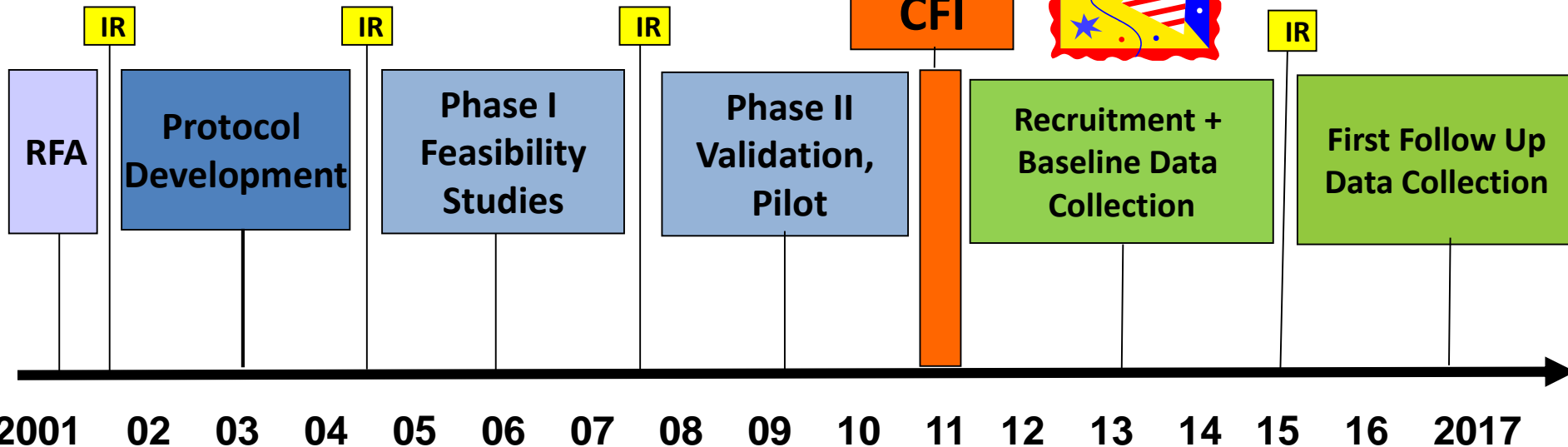
Timeline and Milestones

Team
Design
Objectives
Content

Acceptability
Bio-specimens
Recruitment
Data Linkage

Recruitment pilot
Validate measures
SOPs, TMs
Protocol pilot

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

IR **I**nternational peer **R**eview

Study Overview

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

Tracking cohort n=20,000 Randomly selected within provinces	*Comprehensive cohort* n=30,000 Randomly selected within 25-50 km of 11 sites

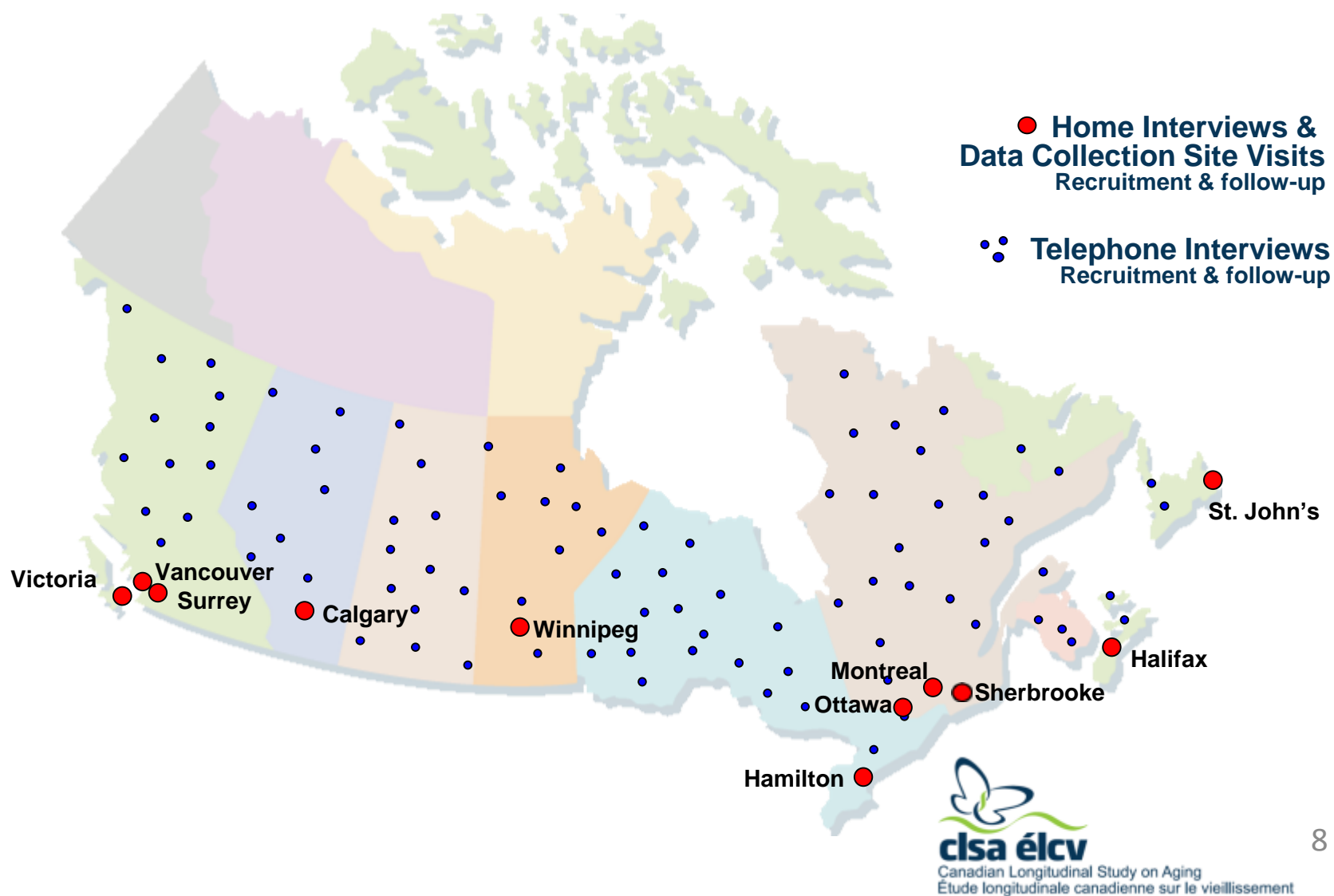**Questionnaire**
• **By telephone (CATI)**

Questionnaire
• **In person, in home (CAPI)**

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

Full follow up @ 3 years + maintaining contact call in-between

Data Linkage

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National Scope

Infrastructure
11 Data Collection Sites

Infrastructure
4 Enabling Units

National Coordinating Centre (NCC)
Director: Parminder Raina

Biorepository and Bioanalysis Centre (BBC)
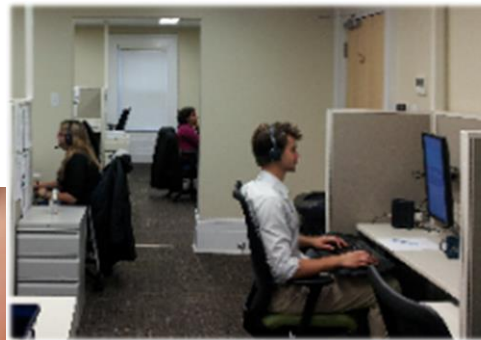**Director: Cynthia Balion**

Genetics and Epigenetics Centre (GEC)
Directors: Michael Kobor and Michael Hayden

Statistical Analysis Centre (SAC)
Director: Christina Wolfson

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Infrastructure

4 Computer Assisted Telephone Interview Sites

UNIVERSITY OF MANITOBA

DALHOUSIE UNIVERSITY
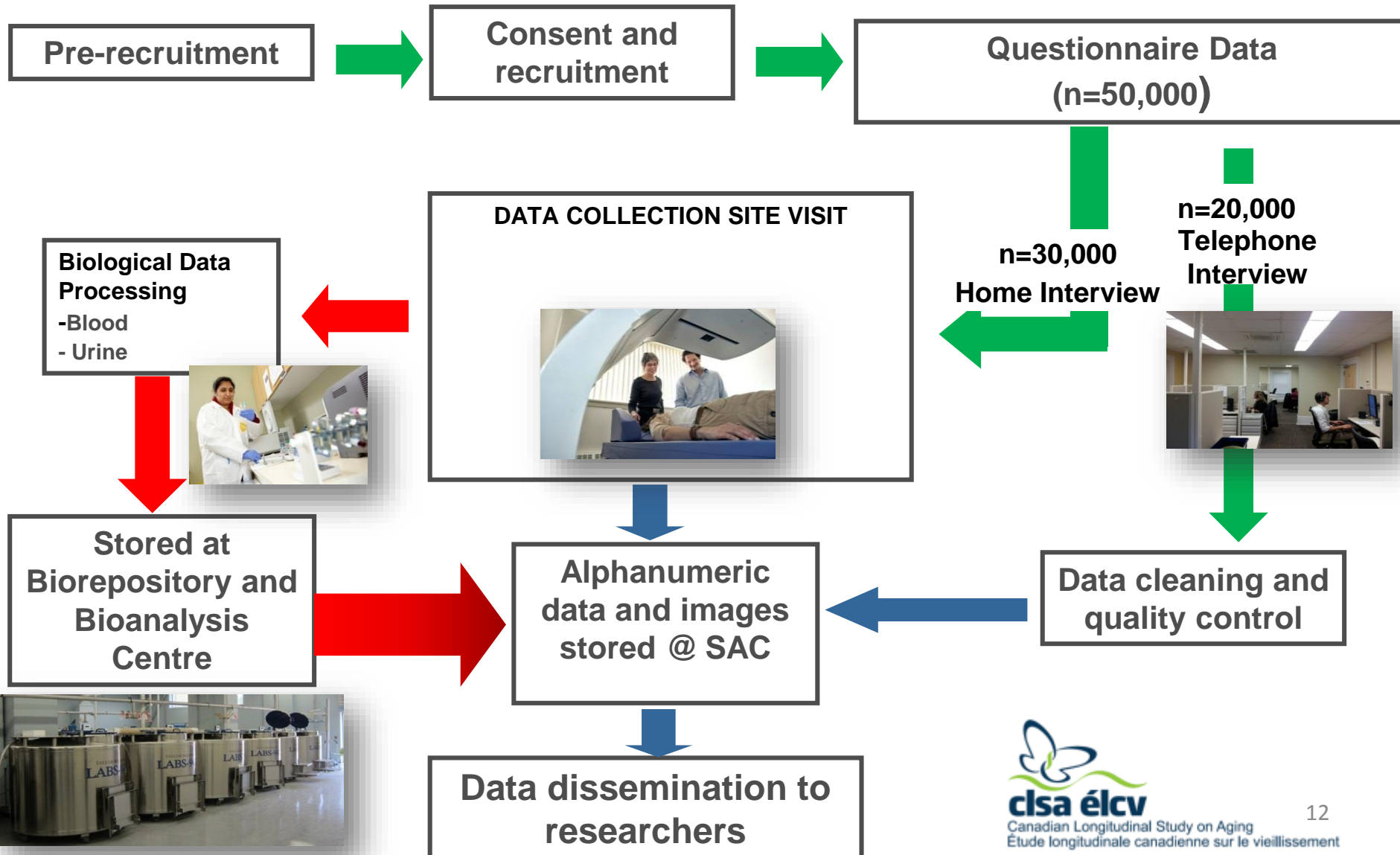*Inspiring Minds*

UNIVERSITÉ DE SHERBROOKE

SFU SIMON FRASER UNIVERSITY
ENGAGING THE WORLD

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Standardized Paperless Process

Pre-recruitment → **Consent and recruitment** → **Questionnaire Data (n=50,000)**

n=30,000 Home Interview

n=20,000 Telephone Interview

DATA COLLECTION SITE VISIT

Biological Data Processing
-Blood
- Urine

Stored at Biorepository and Bioanalysis Centre

Alphanumeric data and images stored @ SAC

Data cleaning and quality control

Data dissemination to researchers

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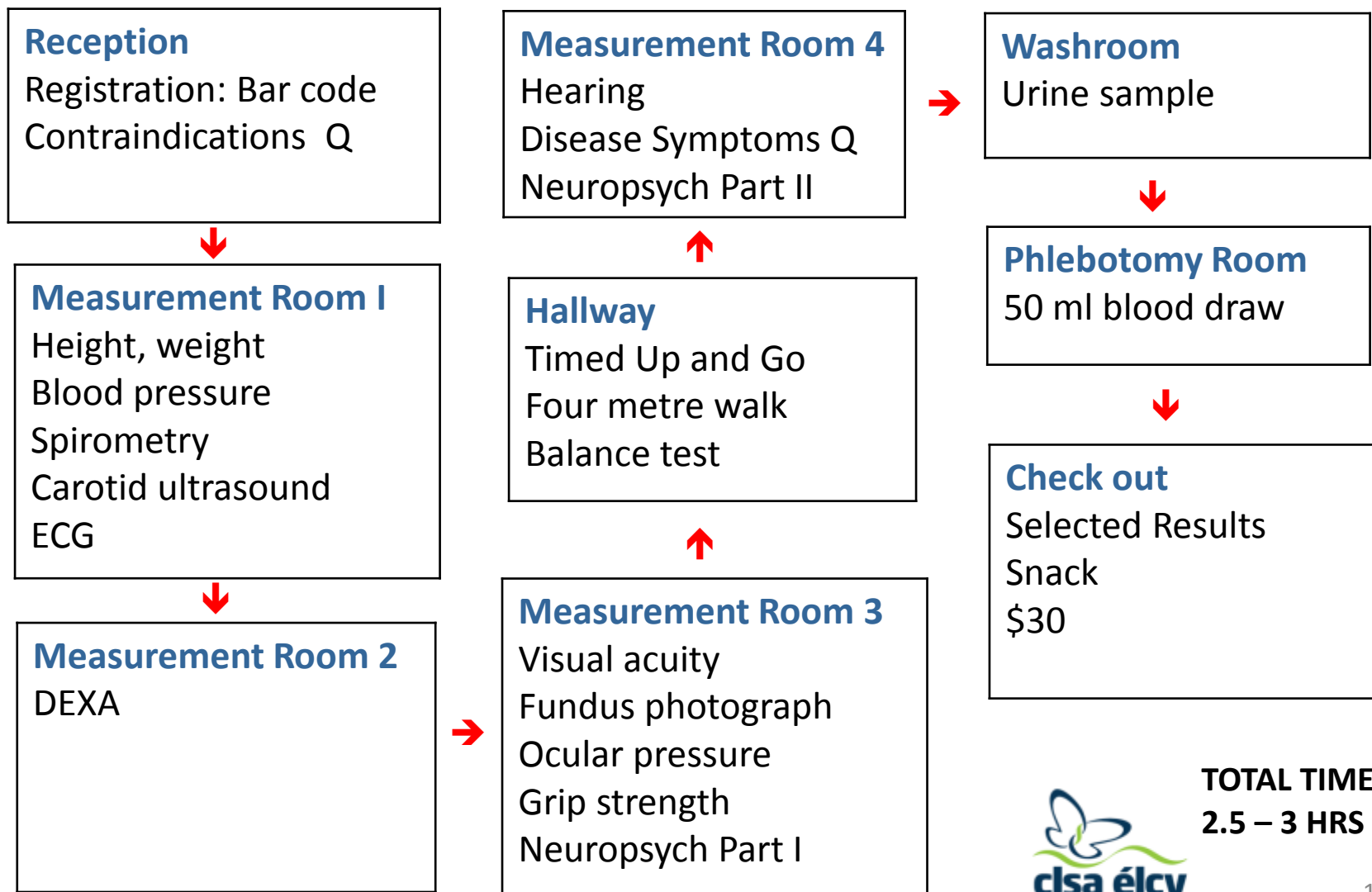
Recruitment & Data Collection Comprehensive cohort

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:
    - **Recruitment & Data collection almost completed**
    - **Data release – Late Spring 2016**
    - Maintaining Contact >10,000 to date
- First full follow-up begins summer 2015

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@ the Data Collection Site

Reception
Registration: Bar code
Contraindications Q

⬇

Measurement Room I
Height, weight
Blood pressure
Spirometry
Carotid ultrasound
ECG

⬇

Measurement Room 2
DEXA

➡

Measurement Room 3
Visual acuity
Fundus photograph
Ocular pressure
Grip strength
Neuropsych Part I

⬆

Hallway
Timed Up and Go
Four metre walk
Balance test

⬆

Measurement Room 4
Hearing
Disease Symptoms Q
Neuropsych Part II

➡

Washroom
Urine sample

⬇

Phlebotomy Room
50 ml blood draw

⬇

Check out
Selected Results
Snack
$30

TOTAL TIME
2.5 – 3 HRS

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Recruitment & Data Collection
Tracking cohort -Telephone Interviews

- **Recruitment of 20,000+ participants, 60 minute telephone interviews every 3 years:**
  - Recruitment and baseline data collection are complete!
  - 21,241 actually recruited
- **Data now available for release to researchers**
  - Maintaining contact interviews initiated 2013 (>14,000 completed, 98% response)
- **First full follow-up begins summer 2015**

Analysis of baseline biomarkers (new funding)
Biomarker and epigenetic analyses
Goal: to repeat (as appropriate) over time

- **Panel of biomarkers:** albumin, ALT, creatinine, CRP, ferritin, hemoglobin A1C, lipids (cholesterol, HDL, Triglycerides, LDL, non-HDL), thyroid stimulating hormone, free T4*, 25-hydroxyvitamin D
  - ➢ ~28,000 participant samples (Calgary Laboratory Services)
- **Genotyping:** Affymetrix UKBiorepository array assay 820,967 SNPs
  - ➢ n=10,000 (McGill Genome Centre))
- **Epigenetic analysis:** targeted age-associated CpG methylation using pyrosequencing and Sequenom EpiTyper
  - ➢ n=5,000 (UBC Genetics and Epigenetics Centre, Mike Kobor)
- **Metabolomics:** working on a strategy to do metabolomics on a sub sample of participants (Brent Richards & Mark Lathrop)

*for those with abnormal TSH

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Clinical Aspects of the CLSA

Clinical aspects of the CLSA

CLSA clinical Working Group activities:

- Scientific guidance on content in the CLSA at baseline

- Quality control throughout baseline data collection

- Troubleshooting clinical issues arising during recruitment and baseline data collection

- Modifications for first follow up (deletions, additions)

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CLSA clinical Working Group

Other working groups:

- Psychological Health

- Lifestyle and nutrition

- Social health

- Health care

- Biomarker/genetic/epigenetic

- Methodology

Composition of Clinical Working Group

Member	Role	Expertise
Christopher Patterson	CWG lead	Geriatric Medicine
Matthias Friedrich	Heart diseases	Cardiology, imaging
David Hogan	Cognition, function Lead as of July 2015	Geriatric Medicine, cognition, frailty
Yaping Jin	Vision	Ophthalmology
Susan Kirkland	Women's health	Women's health, epidemiology
Jacek Kopec	Arthritis	Rheumatology
Bill Leslie	Osteoporosis	Osteoporosis
Maureen MacDonald		Vascular physiology & metabolism
Michael Macentee	Oral health	Oral health, dentistry
Gerry Mugford		Clinical epidemiology, psychology
Harriet MacMillan	Child maltreatment, elder abuse	Pediatrics, psychiatry

Composition of Clinical Working Group

Member	Role	Expertise
Gary Naglie	Function, ADL, diseases	Geriatric medicine
Alexandra Papaioannou	Osteoporosis	Osteoporosis, geriatric medicine, frailty
Kathy Pichora-Fuller	Hearing and cognition	Audiology, cognition
Jenny Ploeg	Elder abuse	Nursing, community health
Ron Postuma	CVA, sleep	Neurology, movement disorders, sleep
Malcolm Sears	Airflow limitation	Respirology, asthma
Debra Sheets		Nursing, gerontology
Eric Smith	Cognition, neurological conditions, epilepsy, CVA	Neurology, cognition
Koon Teo	Heart diseases	Cardiology
Graham Trope	Vision	Ophthalmology

Preparing for CLSA Baseline

- Selection of domains and conditions

- Literature reviews of longitudinal studies

- Selection of ascertainment algorithms

- Finalizing content for comprehensive cohort, including physical measures

Examples of clinical conditions
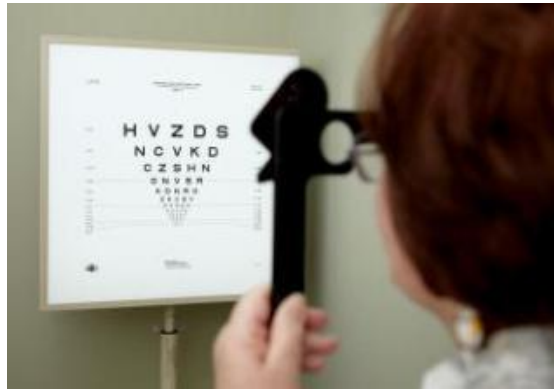
- Cardiovascular (HTN, MI, angina)
- Cerebrovascular (CV events)
- Neurological (Dementia, Parkinson's)
- Respiratory (Asthma, COPD)
- Vision and Hearing
- Function (disability)
- Renal

- Endocrine (DM, thyroid)
- Metabolic
- Musculoskeletal
- Osteoporosis
- Osteoarthritis (Hand, hip, knee)
- Depression
- Malignancy

Depth and Breadth of CLSA

Neuropsychological

- Mood
- Psychological distress (K10)
- Depression (CES-D)
- PTSD screen
- Memory
  - Rey Auditory Verbal Learning Test
- Executive Function
  - Mental Alternation Test
  - Animal Naming

Depth and Breadth of CLSA

PSYCHOSOCIAL

- Social participation
- Social networks and support
- Caregiving and care receiving
- Mood, psychological distress
- Satisfaction with life
- Wealth
- Personality traits

- Work-to-retirement transitions
- Veteran identifier/PTSD
- Retirement planning
- Social inequalities
- Mobility-lifespace
- Built environments

Photo: Health Canada

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Depth and Breadth of CLSA

HEALTH INFORMATION

- Chronic disease and symptoms
- Medication and supplement use
- Women's health
- Self-reported health service use
- Oral health
- Administrative data linkage health services and drugs
- Other administrative databases
- General health
- Injuries
- Pain/discomfort
- Functional status
- Activities of daily living (ADL)
- ADL impairment

Photo: Health Canada

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Depth and Breadth of CLSA

Photo: Health Canada

Photo: Health Canada

Photo: Health Canada

LIFESTYLE & SOCIODEMOGRAPHIC

- Smoking
- Alcohol consumption
- Physical activity
- Nutrition
- Birth location
- Ethnicity/race/gender
- Marital status
- Education
- Income
- Transportation
- Home ownership

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Some issues identified during baseline

- Carotid intimal thickness: variation in length of scan; some issues with plaque measurement
- Sitting height more susceptible to error than standing height (height of chair and person sometimes inverted) different heights of chairs
- Standing balance potentially incorrect
- Grip strength had lower threshold values in some sites
- Timing of measures sometimes high
- Quality control for DEXA
- Quality control for retinal photographs
- Thanks to Sarah Youssef, Mark Oremus

Planning for the first follow up

- **Items for inclusion suggested by CWG members, other researchers and several agencies**

- **Items for deletion were debated within CWG**

- **For each suggested item, justification required:**

- **Statement of the issue: what is novel about it?**

- **A short literature review**

- **Examples of inclusion in other longitudinal studies**

- **The question or test**

- **Estimated cost (time, resources)**

First Follow Up (2015-2018)
New Content

- Child maltreatment*

- Elder Abuse*

- Transportation*

- Epilepsy

- Hearing

- Arterial stiffness

- Decedent information

- Workability

- Subjective cognitive decline

- Health care use

- Preventive health behaviours

*external funding obtained

First Follow Up (2015-2018)
Accommodations for changing circumstances

- Change in residence
  - ➤ Transfer to another DCS, telephone follow up

- Institutionalization
  - ➤ Home interview protocol, telephone follow up, proxy

- Mobility challenges
  - ➤ Data collection at home, special consideration at DCS

- Sensory challenges
  - ➤ Hearing loss—interviewer, technology, proxy, self administered questionnaire

- Cognitive challenges
  - ➤ Use of proxies, selected assessments

Incidental findings

- Challenging to develop this SOP

	Title:	Communication of Incidental Findings to the DCS Participant		
clsa élcv Canadian Longitudinal Study on Aging Étude longitudinale canadienne sur le vieillissement	Version Date:	2014-NOV-11	Document Number:	SOP_DCS_0071
	Effective Date:	2014-		
Data Collection Site (DCS)	Version:	1.0	Number of Pages:	3

1.0   Purpose: This document describes the procedure for communicating confirmed incidental findings with a DCS participant.

2.0   Scope: The DCS Coordinator will consult with the local responsible investigator (LRI) of their site, and the designated physician co-investigator. Incidental findings that are deemed relevant will be communicated to the DCS participant.

3.0   Responsibilities:
- The DCS Staff are responsible for bringing any suspected incidental findings from the DCS measurements to the attention of the DCS Coordinator.
- The DCS Coordinator is responsible for consulting with the local responsible investigator (LRI) regarding the suspected incidental finding.
- Once it is established that the results may be an incidental finding, the LRI, or if unavailable, the DCS Coordinator, is responsible for communicating with the physician co-investigator regarding the suspected incidental finding. It will then be decided who is the most appropriate person to convey information to the participant.
- The DCS Coordinator, LRI or physician co-investigator will then be responsible for communicating any confirmed incidental finding with the participant in a timely manner.
- The DCS Coordinator is responsible for communicating with the NCC as to the process followed.

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How to manage serious events at the DCS visit

From time to time, serious events will occur or will appear during the comprehensive assessment of CLSA participants. This outline aims to assist Site PIs and DCS study teams to anticipate such findings and develop a plan to deal with them.

Each DCS should have a co investigator physician with whom to discuss concerns such as those outlined below. Each site will determine the protocol for contact with the physician, usually through the local Site PI.

If it is necessary for information to be conveyed to physicians who are outside of the study, a letter will be provided to the participant. The letter will be addressed to the participant but will contain information that may be relevant to a treating physician; please see samples of letter below.

1. Medical Emergencies

DCS staff will need to exercise judgment in deciding how to respond to these potentially serious situations. Actions can include providing first aid; calling emergency medical services if a life threatening situation is present; contacting the person's relative with the participant's permission; and, discussion with local PI and/or designated physician as per DCS-specific protocol.

Following is a partial listing of potential medical emergencies which require immediate attention:

- Bleeding that will not stop
- Breathing problems (difficulty getting breath, shortness of breath)
- Change in mental status (unusual behaviour, confusion, difficulty in arousing)
- Chest pain or discomfort
- Choking
- Coughing up or vomiting blood
- Fainting or loss of consciousness
- Seizures (epileptic fits)
- Severe abdominal pain
- Severe or persistent vomiting
- Sudden change in vision, dizziness, inability to speak, or weakness
- Sudden severe bodily pain

Clinical issues with participants

Examples:

- Dense plaque on carotid image
- A possible adverse effect of retinal photography
- Possible suicidal intent

The Data

The success of the CLSA will be determined, in large part, by the research community's interest in and use of the collected data and biospecimens

"You better hurry. Management wants the data cleaned up by tomorrow morning."

Data <u>and</u> Biospecimen Access

- Data and biospecimens 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 must be used optimally to support research to benefit all Canadians.

*The process to access alphanumeric data
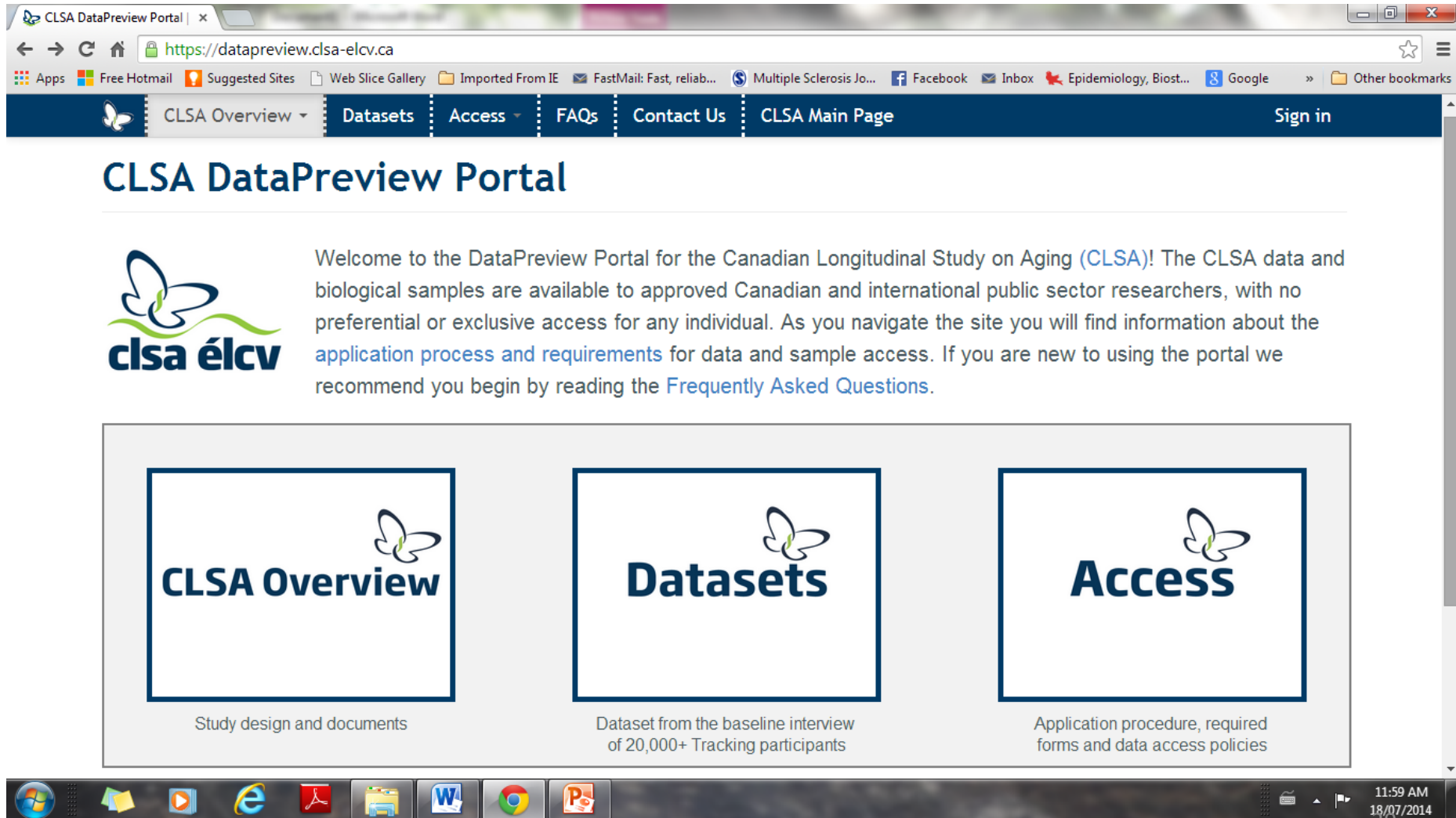
- via CLSA **DataPreview** portal
  - https://datapreview.clsa-elcv.ca/
- **Review**: Administrative → Data and Sample Access Committee → Scientific Management Team
- **Approval:** Preparation of CLSA access agreement, verification of ethics approval, cost recovery
- **Release:** Raw data provided to approved investigator
- **Enhance:** Return of derived variables to CLSA dataset as appropriate

*For 21,241 Tracking participants only

Access to the Comprehensive Data and Biospecimens

- Data Collection, quality control, data cleaning are ongoing

- Estimated availability: Late Spring 2016

- Cost recovery model

- Accepting applications for access to Comprehensive data and biospecimens beginning in January 2016

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

CLSA Data Request Applications

Title of Selected Applications	Location
Consumer product related senior falls and injury risk assessment	Ontario
CLSA Neurological Conditions Initiative (NCI)	Quebec
The association between hearing loss and social function in older Canadians	British Columbia
The Veterans' Health Initiative within the CLSA (VHI)	Quebec
Labour force participation: Retirement Transitions, Expectations & Planning	Ontario/Student
Describing dementia in Nova Scotia	Nova Scotia
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
Factorial invariance of the Centre of Epidemiologic Studies Depression Scale	Saskatchewan
The development of normative data and comparison standards for the cognition measures employed in the CLSA	British Columbia
Long term exposure to ambient air pollution and effects on cardiovascular, respiratory and neurocognitive health	Ontario
additional applications under review (April 20th meeting)	

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Other initiatives

- Canadian Consortium on Neurodegeneration in Aging (CCNA)
  - Use of the CLSA infrastructure to support CCNA research
    - In particular use of CLSA biospecimen protocol and BBC for storage of specimens
  - Access to data (alphanumeric, vascular and retinal imaging, and biospecimens) from CLSA participants for CCNA studies that require a normative comparison
  - Harmonization of measures across studies
  - Consideration of the addition of new measures in the CLSA
  - CLSA-CCNA Liaison Committee ongoing
- Brain CLSA
  - Proposal to CIHR to develop a core brain imaging sub-study

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CLSA Collaborations

- Public Health Agency of Canada
  - Injuries
  - Neurological Conditions Initiative
- Veterans Affairs
  - Veterans Health Initiative
- Health Canada
  - Air pollution
- Statistics Canada
  - CCHS and methodological input
- Ontario Ministry of Health and Long-Term Care

Thank you – Merci!

Transforming Everyday Life into Extraordinary Ideas

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