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

Dr. Christina Wolfson, McGill University, Montreal
&
Dr. Christopher Patterson, McMaster University, Hamilton
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
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
[www.clsa-elmv.ca](http://www.clsa-elmv.ca)
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

- **2001**: RFA
- **2002-2003**: Protocol Development
- **2004**: Phase I Feasibility Studies
- **2005-2006**: Phase II Validation, Pilot
- **2007**: Recruitment pilot
- **2008-2009**: SOPs, TMs
- **2010**: Protocol pilot
- **2011**: Recruitment + Baseline Data Collection
- **2012-2013**: First Follow Up Data Collection
- **2014-2015**: Data Collection
- **2016**: International peer Review

**Key Events:**
- Recruitment
- Baseline Data Collection
- Protocol pilot
- Recruitment + Baseline Data Collection
- First Follow Up Data Collection

**Milestones:**
- **Team Design Objectives Content**
- **Acceptability Bio-specimens Recruitment Data Linkage**
- **Recruitment pilot Validate measures SOPs, TMs Protocol pilot**

**Timeline Breakdown:**
- **2001**: Recruitment + Baseline Data Collection
- **2002**: Protocol Development
- **2003**: Phase I Feasibility Studies
- **2004-2005**: Phase II Validation, Pilot
- **2006-2007**: Recruitment pilot
- **2008-2009**: SOPs, TMs
- **2010**: Protocol pilot
- **2011-2012**: Recruitment + Baseline Data Collection
- **2013-2014**: First Follow Up Data Collection
- **2015**: Data Collection
- **2016**: International peer Review
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
Infrastructure
11 Data Collection Sites

McMaster University
McGill
Dalhousie University
Memorial University
Université de Sherbrooke
uOttawa
Université de Montréal
University of Manitoba
University of Calgary
UBC
Simon Fraser University
University of Victoria
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
Infrastructure

4 Computer Assisted Telephone Interview Sites
Consent and recruitment

Questionnaire Data (n=50,000)

Data dissemination to researchers

Biological Data Processing
- Blood
- Urine

DATA COLLECTION SITE VISIT

n=30,000 Home Interview

n=20,000 Telephone Interview

Data cleaning and quality control

Biorepository and Bioanalysis Centre

Stored at

Alphanumeric data and images stored @ SAC

Pre-recruitment
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
@ the Data Collection Site

**Reception**
Registration: Bar code
Contraindications

**Measurement Room 1**
Height, weight
Blood pressure
Spirometry
Carotid ultrasound
ECG

**Measurement Room 4**
Hearing
Disease Symptoms
Neuropsych Part II

**Hallway**
Timed Up and Go
Four metre walk
Balance test

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

**Washroom**
Urine sample

**Phlebotomy Room**
50 ml blood draw

**Check out**
Selected Results
Snack
$30

**TOTAL TIME**
2.5 – 3 HRS
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*
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)
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

<table>
<thead>
<tr>
<th>Member</th>
<th>Role</th>
<th>Expertise</th>
</tr>
</thead>
<tbody>
<tr>
<td>Christopher Patterson</td>
<td>CWG lead</td>
<td>Geriatric Medicine</td>
</tr>
<tr>
<td>Matthias Friedrich</td>
<td>Heart diseases</td>
<td>Cardiology, imaging</td>
</tr>
<tr>
<td>David Hogan</td>
<td>Cognition, function Lead as of July 2015</td>
<td>Geriatric Medicine, cognition, frailty</td>
</tr>
<tr>
<td>Yaping Jin</td>
<td>Vision</td>
<td>Ophthalmology</td>
</tr>
<tr>
<td>Susan Kirkland</td>
<td>Women’s health</td>
<td>Women’s health, epidemiology</td>
</tr>
<tr>
<td>Jacek Kopec</td>
<td>Arthritis</td>
<td>Rheumatology</td>
</tr>
<tr>
<td>Bill Leslie</td>
<td>Osteoporosis</td>
<td>Osteoporosis</td>
</tr>
<tr>
<td>Maureen MacDonald</td>
<td></td>
<td>Vascular physiology &amp; metabolism</td>
</tr>
<tr>
<td>Michael Macentee</td>
<td>Oral health</td>
<td>Oral health, dentistry</td>
</tr>
<tr>
<td>Gerry Mugford</td>
<td></td>
<td>Clinical epidemiology, psychology</td>
</tr>
<tr>
<td>Harriet MacMillan</td>
<td>Child maltreatment, elder abuse</td>
<td>Pediatrics, psychiatry</td>
</tr>
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<tr>
<td>Gary Naglie</td>
<td>Function, ADL, diseases</td>
<td>Geriatric medicine</td>
</tr>
<tr>
<td>Alexandra Papaioannou</td>
<td>Osteoporosis</td>
<td>Osteoporosis, geriatric medicine, frailty</td>
</tr>
<tr>
<td>Kathy Pichora-Fuller</td>
<td>Hearing and cognition</td>
<td>Audiology, cognition</td>
</tr>
<tr>
<td>Jenny Ploeg</td>
<td>Elder abuse</td>
<td>Nursing, community health</td>
</tr>
<tr>
<td>Ron Postuma</td>
<td>CVA, sleep</td>
<td>Neurology, movement disorders, sleep</td>
</tr>
<tr>
<td>Malcolm Sears</td>
<td>Airflow limitation</td>
<td>Respirology, asthma</td>
</tr>
<tr>
<td>Debra Sheets</td>
<td></td>
<td>Nursing, gerontology</td>
</tr>
<tr>
<td>Eric Smith</td>
<td>Cognition, neurological</td>
<td>Neurology, cognition</td>
</tr>
<tr>
<td></td>
<td>conditions, epilepsy, CVA</td>
<td></td>
</tr>
<tr>
<td>Koon Teo</td>
<td>Heart diseases</td>
<td>Cardiology</td>
</tr>
<tr>
<td>Graham Trope</td>
<td>Vision</td>
<td>Ophthalmology</td>
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</tbody>
</table>
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
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
Depth and Breadth of CLSA

LIFESTYLE & SOCIO DEMOGRAPHIC

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

<table>
<thead>
<tr>
<th>Data Collection Site (DCS)</th>
<th>Title: Communication of Incidental Findings to the DCS Participant</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Version Date: 2014-NOV-11</td>
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<tr>
<td></td>
<td>Effective Date: 2014</td>
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<tr>
<td></td>
<td>Document Number: SOP_DCS_0071</td>
</tr>
<tr>
<td></td>
<td>Number of Pages: 3</td>
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</tbody>
</table>

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.
Dealing with 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.
Data and 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

<table>
<thead>
<tr>
<th>Title of Selected Applications</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumer product related senior falls and injury risk assessment</td>
<td>Ontario</td>
</tr>
<tr>
<td>CLSA Neurological Conditions Initiative (NCI)</td>
<td>Quebec</td>
</tr>
<tr>
<td>The association between hearing loss and social function in older Canadians</td>
<td>British Columbia</td>
</tr>
<tr>
<td>The Veterans' Health Initiative within the CLSA (VHI)</td>
<td>Quebec</td>
</tr>
<tr>
<td>Labour force participation: Retirement Transitions, Expectations &amp; Planning</td>
<td>Ontario/Student</td>
</tr>
<tr>
<td>Describing dementia in Nova Scotia</td>
<td>Nova Scotia</td>
</tr>
<tr>
<td>Who is at risk of social isolation and loneliness?</td>
<td>Manitoba</td>
</tr>
<tr>
<td>Companion animals and the aging population: Exploring relationships, contexts, and opportunities to contribute to health equity</td>
<td>Alberta/Student</td>
</tr>
<tr>
<td>Factorial invariance of the Centre of Epidemiologic Studies Depression Scale</td>
<td>Saskatchewan</td>
</tr>
<tr>
<td>The development of normative data and comparison standards for the cognition measures employed in the CLSA</td>
<td>British Columbia</td>
</tr>
<tr>
<td>Long term exposure to ambient air pollution and effects on cardiovascular, respiratory and neurocognitive health</td>
<td>Ontario</td>
</tr>
<tr>
<td><strong>additional applications under review (April 20th meeting)</strong></td>
<td></td>
</tr>
</tbody>
</table>
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
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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