The Canadian Longitudinal Study on Aging
A national platform and infrastructure for researchers and trainees.

Co-Principal Investigator: Christina Wolfson, PhD, McGill University
on behalf of
Co-PIs: Parminder Raina, PhD, McMaster University and Susan Kirkland, PhD, Dalhousie University

and the CLSA Research Team across Canada

Summer Program in Aging
May 16th, 2017 - Concordia University
Learning Objectives

1. To understand the CLSA study design and become familiar with the CLSA data access process
2. To be inspired to use the CLSA research platform
Overview

• Background
• Study Design and Infrastructure
• Study Content and Data Collection
• Current Status
• Sample demographics
• Data Access
The CLSA

• Strategic initiative of CIHR Institute of Aging; on the Canadian research agenda since 2001; nearly 10 years in the planning stages

• 3 co-principal investigators (epidemiologists) supported by more than 160 co-investigators from 26 institutions

• Multidisciplinary - biology, genetics, medicine, psychology, sociology, demography, nursing, economics, epidemiology, nutrition, health services

• Largest study of its kind to date in Canada for breadth and depth: following 50,000 participants for ≥20 years
Aim and Vision

• **AIM**: To examine life/health transitions and capture trajectories to enable the identification of modifiable factors with the potential to inform interventions (prevention/treatment/impact) to improve the health of populations as they age.

• **VISION**: To create 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 as they age.
The Journey so far...

- **2001**: RFA
- **2002**: Protocol Development
- **2003**: Acceptability Studies
- **2004**: Recruitment and Baseline Data Collection
- **2005**: Bio-specimens
- **2006**: Recruitment Data Linkage
- **2007**: Team Design Objectives Content
- **2008**: Pilot work
- **2009**: CFI
- **2011**: Recruitment and Baseline Data Collection
- **2012**: Reparation, and release
- **2013**: First Follow Up Data Collection

**International peer review**
<table>
<thead>
<tr>
<th>Funding History</th>
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<tbody>
<tr>
<td><strong>2002 to 2015</strong></td>
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<tr>
<td><strong>Development:</strong> 2002-2009</td>
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<tr>
<td>▪ CIHR, FRSQ, Universities</td>
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<tr>
<td><strong>Infrastructure:</strong> 2009-2014</td>
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<tr>
<td>▪ CFI infrastructure/equipment</td>
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<tr>
<td>▪ CFI + Provinces + Universities and other partners</td>
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<tr>
<td><strong>Operations:</strong> 2009-2015</td>
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<tr>
<td>▪ CIHR 2009-2015</td>
</tr>
<tr>
<td>▪ 86% of budget</td>
</tr>
<tr>
<td><strong>Data/biospecimen analysis:</strong></td>
</tr>
<tr>
<td>▪ No Funding</td>
</tr>
<tr>
<td><strong>2015-2020</strong></td>
</tr>
<tr>
<td><strong>First Follow-up</strong></td>
</tr>
<tr>
<td><strong>Operations</strong></td>
</tr>
<tr>
<td>▪ CIHR - 86% of budget</td>
</tr>
<tr>
<td>▪ For Follow up 1 and 2/3 of Follow up 2 and maintaining the platform</td>
</tr>
<tr>
<td><strong>Analysis</strong></td>
</tr>
<tr>
<td>▪ CIHR Analysis of baseline biospecimens for selected biomarkers</td>
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*International Scientific Peer Review at every step*
Key co-investigators

**British Columbia**: Debra Sheets, Lynne Young, Holly Tuokko, Teresa Liu-Ambrose, Michael Kobor, Andrew Wister, Scott Lear

**Alberta**: David Hogan, Marc Poulin, Eric Smith, Alex Chin

**Manitoba**: Verena Menec, Phil St. John

**Ontario**: Parminder Raina, Cynthia Balion, Lauren Griffith, Andrew Costa, Harry Shannon, Christopher Patterson, Michael Veall, Vanessa Taler, Andrew Paterson, Mark Oremus, Mary Thompson, Changbao Wu

**Quebec**: Christina Wolfson, Ron Postuma, Brent Richards, Mark Lathrop, Hélène Payette, Benoît Cossette

**Nova Scotia**: Susan Kirkland

**Newfoundland**: Gerry Mugford

**The Netherlands**: Edwin van den Heuvel
International Scientific Advisory Board

- Carole Brayne (Chair)
  - Director, Cambridge Institute of Public Health, Cambridge, UK
- David Weir
  - Director, Health and Retirement Study (HRS), Survey Research Center, University of Michigan, US
- John Gallacher
  - Director, MRC Dementia Platforms UK, Oxford University, UK
Governance and Advice

**CLSA**
- Scientific Management Team
- Operations Committee
- International Scientific Advisory Board
- Advisory Council
- Knowledge Translation & Communications Committee

**CIHR**
- Oversight of Initiatives and Platforms
- Ethical, Legal, Social Issues Advisory Committee
- Training and Research Capacity Committee
- Data and Biospecimen Access Committee
Study Design and Infrastructure
Overview

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

Target: 20,000 Randomly selected within provinces

Target: 30,000 Randomly selected within 25-50 km of 11 sites

Telephone Questionnaire (CATI)

In person/in home Questionnaire (CAPI)

Physical assessments, blood, urine
• @ Data Collection Site

Full follow up every 3 years.....20 years
Maintaining Contact strategies between waves of data collection

Data Linkage
Defining the cohort

- Men and women living in any of 10 provinces in Canada aged 45-85 at recruitment
  - Capturing baby boomers (born between 1946-1964) plus members of the “silent” generation (i.e. those born before 1945)
Recruiting the Cohort

1. Partnership with Statistics Canada
   • Canadian Community Health Survey 4.2 Healthy Aging (2008-09) CCHS 4.2
     • CCHS participant agreement to share contact information with the CLSA – *a first for Statistics Canada*

2. Partnership with provincial Ministries of Health (MOH)
   • Health Card Registration databases
   • Mailouts, return Consent-to-Contact form, CLSA follow up

3. Random Digit Dialing
   • Leger Marketing and CLSA CATI
Cohort Exclusion Criteria at Baseline

Driven by CCHS 4.2 exclusion criteria 1. to 5.

1. Residents of the 3 territories
   • Northwest Territories, Nunavut, Yukon
2. Living in an institution
3. Living on a First Nation Reserve
4. Full time members of the armed forces
5. Temporary visa holders

CLSA Added Criteria

• Cognitively impaired (at baseline)
• Unable to communicate in French or English

1 to 5 exclude <4% of the target population
Terminology

• Tracking Cohort
  • Target - 20,000 participants from all 10 provinces, followed through Computer Assisted Telephone Interviews (60 minutes at baseline)
  • **21,241 recruited** *

• Comprehensive Cohort
  • Target - 30,000 participants living within 25 km (or 50 km) of a CLSA Data Collection Site (DCS)
  • Followed through in-home interviews (60 minute) and physical assessments (2-3 hours) at a DCS
  • **30,097 recruited** *

*What does recruited mean?*
Recruiting and Data Collection

Infrastructure
4 Computer Assisted Telephone Interview Sites
Four Enabling (Support) 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
Biorepository and Bioanalysis Centre (BBC)

- Central location for storage and analysis of the biological samples
  - 31 nitrogen freezers (-190°C)
  - Storage for 5 million aliquots
  - Dry storage, humidity controlled, room temperature

- Research laboratory dedicated to detailed sample analysis
  - High-throughput robotic platform for biomarker analysis
11 Data Collection Sites (DCS)

3,000 per full site

1. Simon Fraser U + UBC (split sites)
2. U Victoria
3. U Calgary
4. U Manitoba
5. U Ottawa
6. McMaster U
7. McGill U
8. U de Sherbrooke
9. Dalhousie U
10. Memorial U
Study Content and Data Collection
Questionnaire modules
All 51,338 participants

- Education
- Marital status
- Sexual orientation
- Language
- Ethnicity
- Smoking, alcohol
- Nutritional risk
- Physical activity
- Health care utilization
- Medication use
- Supplement use

- General health
- Chronic conditions
- Disease symptoms
- Sleep
- Oral health
- Injuries, falls
- Mobility
- Pain, discomfort
- Functional status
- ADL, IADL
- Cognition
- Mental Health
- Depression
- PTSD
- Life Satisfaction

- Social
  - networks
  - support
  - Participation
  - inequality
  - Online communication
  - Care receiving
  - Care giving
  - Labour force participation
  - Retirement planning
  - Retirement status
  - Transportation
  - Mobility, Migration
  - Built environments
  - Home ownership
Additional Objective Assessments (30,097 of 51,338)

### Basic Measures
- Height
- Weight
- Hip Circumference
- Hearing
- Vision

### Function
- Timed-up-and-go
- Standing balance
- 4 metre walk
- Chair rise
- Hand grip strength
- Neuropsychological testing

### Physical Measures
- Blood pressure
- Spirometry
- Carotid ultrasound
- ECG
- DEXA
- Blood sample
- Urine Sample
- Tonometry
- Fundus photography
### At The Data Collection Site

<table>
<thead>
<tr>
<th>Reception</th>
<th>Measurement Room 3</th>
<th>Measurement Room 4</th>
<th>Washroom</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registration: Bar code</td>
<td></td>
<td>Hearing</td>
<td>Urine sample</td>
</tr>
<tr>
<td>Contraindications check</td>
<td></td>
<td>Disease Symptoms Q</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Neuropsych Part II</td>
<td></td>
</tr>
</tbody>
</table>

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

#### Measurement Room 2
- DEXA

#### Measurement Room 4
- Hearing
- Disease Symptoms Q
- Neuropsych Part II

#### Hallway
- Timed Up and Go
- Four metre walk
- Balance test

#### Check out
- Selected Results
- Snack
- $30

#### Phlebotomy Room
- 50 ml blood draw

#### Washroom
- Urine sample

**TOTAL TIME**
- 2.5 – 3 HRS

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**Reception**
- Registration: Bar code
- Contraindications check

**Measurement Room 1**
- 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

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

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

**Check out**
- Selected Results
- Snack
- $30

**Phlebotomy Room**
- 50 ml blood draw

**Washroom**
- Urine sample

---

**TOTAL TIME**
- 2.5 – 3 HRS
First Follow Up
2015-2018
First Follow-Up: **New Content Added**

- *Child maltreatment
- **Elder abuse
- Epilepsy screening
- Decedent interview
- Unmet health-care needs
- Preventive health behaviours (screening, vaccination, etc)
- Enhanced hearing, oral health and transportation modules
- Gender identity questions
- Subjective cognitive decline
- Loneliness

*Childhood Experiences of Violence Questionnaire. Walsh et al 2012

**National Initiative for the Care of the Elderly (NICE)
Follow up considerations

• Keeping participants engaged
• Tracing participants who have moved
• Attention to changes in life circumstances that may affect ability to participate
  • Cognitive, sensory, mobility impairment
• Ensuring that changes in content permit the ongoing examination of transitions and trajectories
First Follow Up (2015-2018) – Status

• 1st follow up Tracking
  • Re-contacting 21,241 participants for follow up telephone interviews
    • ~ 9,600 completed

• 1st follow up Comprehensive
  • Re-contacting 30,097+ participants for follow up in-home interviews and DCS visits
    • As of last week ~18,200

• Losses to date:
  • Deaths 1047
  • Withdrawn - 1947
Passive Data Collection  Work in progress

• Linkage is an important CLSA strategy
  • Great potential for collecting information that is difficult to get from participants due to time, accuracy limitations; and/or may even be unknown to participants
  • Potential to obtain historical data prior to CLSA entry

• Types of databases
  • Individual level administrative provincial health databases
  • Vital statistics/disease registries
  • Population level databases of community characteristics, climate, pollution
Baseline Demographics
## CLSA Participant Recruitment From 3 Sampling Frames

<table>
<thead>
<tr>
<th>Sampling Frame</th>
<th>Tracking</th>
<th>Comprehensive</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td>CCHS 4.2 Healthy Aging</td>
<td>3,923</td>
<td>0</td>
<td>3,923</td>
</tr>
<tr>
<td>Provincial Ministry of Health Mailouts</td>
<td>3,810</td>
<td>4,129</td>
<td>7,939</td>
</tr>
<tr>
<td>Random Digit Dialing</td>
<td>13,508</td>
<td>25,968</td>
<td>39,476</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>21,241</td>
<td>30,097</td>
<td>51,338</td>
</tr>
</tbody>
</table>
## CLSA Participants by Province

<table>
<thead>
<tr>
<th>Province</th>
<th>Tracking</th>
<th>Comprehensive</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>British Columbia</td>
<td>2613 (12.3)</td>
<td>6254 (20.8)</td>
<td>8867 (17.3)</td>
</tr>
<tr>
<td>Alberta</td>
<td>2103 (9.9)</td>
<td>2958 (9.8)</td>
<td>5061 (9.9)</td>
</tr>
<tr>
<td>Saskatchewan</td>
<td>1382 (2.7)</td>
<td>0</td>
<td>1382 (2.7)</td>
</tr>
<tr>
<td>Manitoba</td>
<td>1477 (7.0)</td>
<td>3114 (10.4)</td>
<td>4591 (9.0)</td>
</tr>
<tr>
<td>Ontario</td>
<td>4705 (22.2)</td>
<td>6417 (21.3)</td>
<td>11122 (21.7)</td>
</tr>
<tr>
<td>Quebec</td>
<td>3601 (17.0)</td>
<td>6057 (20.1)</td>
<td>9658 (18.8)</td>
</tr>
<tr>
<td>New Brunswick</td>
<td>1355 (2.6)</td>
<td>0</td>
<td>1355 (2.6)</td>
</tr>
<tr>
<td>Nova Scotia</td>
<td>1546 (7.3)</td>
<td>3075 (10.2)</td>
<td>4621 (9.0)</td>
</tr>
<tr>
<td>Prince Edward Island</td>
<td>1138 (2.2)</td>
<td>0</td>
<td>1138 (2.2)</td>
</tr>
<tr>
<td>Newfoundland</td>
<td>1251 (5.9)</td>
<td>2219 (7.4)</td>
<td>3470 (6.8)</td>
</tr>
</tbody>
</table>
### Socio-demographic Characteristics

<table>
<thead>
<tr>
<th>Age</th>
<th>Tracking</th>
<th>Comprehensive</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>45-54</td>
<td>5826 (27.5)</td>
<td>7596 (25.2)</td>
<td>13422 (26.2)</td>
</tr>
<tr>
<td>55-64</td>
<td>6563 (31.0)</td>
<td>9863 (32.8)</td>
<td>16426 (32.0)</td>
</tr>
<tr>
<td>65-74</td>
<td>4634 (21.9)</td>
<td>7363 (24.5)</td>
<td>11997 (23.4)</td>
</tr>
<tr>
<td>75-85</td>
<td>4148 (19.6)</td>
<td>5272 (17.5)</td>
<td>9420 (18.4)</td>
</tr>
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<thead>
<tr>
<th>Sex</th>
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<tbody>
<tr>
<td>Male</td>
<td>10796 (51.0)</td>
<td>15310 (50.9)</td>
<td>26106 (50.9)</td>
</tr>
<tr>
<td>Female</td>
<td>10375 (49.0)</td>
<td>14784 (49.1)</td>
<td>25159 (49.1)</td>
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<table>
<thead>
<tr>
<th>Language</th>
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<tbody>
<tr>
<td>English</td>
<td>17423 (82.3)</td>
<td>24291 (80.7)</td>
<td>41714 (81.4)</td>
</tr>
<tr>
<td>French</td>
<td>3748 (17.7)</td>
<td>5803 (19.3)</td>
<td>9551 (18.6)</td>
</tr>
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**Born in Canada**

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<tbody>
<tr>
<td>18455 (87.2)</td>
<td>24644 (81.9)</td>
<td>43099 (84.1)</td>
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Data Access
Baseline Data ONLY
Data and Bio specimen Access

• The CLSA was designed as a research study but is funded as a research platform
• Data and biospecimens available to the research community
  ▪ Who:
    ▪ Researchers based in academic settings and research institutes in Canada and *elsewhere can apply
    ▪ Graduate students and postdoctoral fellows based at Canadian institutions or trainees studying elsewhere funded by a Canadian agency
  ▪ *As yet, biospecimens cannot be released to researchers outside Canada
What do you get?

- Alphanumeric data on all 51,338 participants
  - Raw data
- De-identified open text for selected variables
- Technical documentation
- Sampling weights
Data Access Steps

Application process via access@clsa-elcv.ca

1. Submit application (pre-set deadlines) **Next deadline is June 12, 2017**
2. Administrative and Statistical Review
3. Review by Data and Biospecimen Access Committee
4. Notification of applicant
5. CLSA Access Agreement preparation and signatures, ethics approval
   • Security, confidentiality and scientific requirements
6. Raw data provided to approved applicant
How much does it cost?

- **Costing**
  - *Partial Cost Recovery Model*

- **Alphanumeric data**
  - $3,000 for a straightforward alphanumeric dataset
  - Graduate student - No cost for dataset to be used solely for thesis research
  - Postdoctoral fellow – No cost for one dataset to be used solely for the postdoctoral project

- **Bio specimen costing**
  - In development
Tools for Researchers

Data Collection Tools

Below are links to all of the questionnaires used by CLSA since it began data collection in 2011. Among the more than 51,000 participants in the study, data are collected from more than 21,000 people through telephone interviews only, also referred to as the tracking assessment. The remaining 30,000+ participants provide data through in-home interviews and data collection site visits, also referred to as the comprehensive assessment. All participants are also contacted 18 months after each full telephone or in-home interview to maintain contact. During the Baseline phase of data collection, this interview was known as the Maintaining Contact Questionnaire (MCQ), and included some additional data collection.

Baseline

- Telephone interview - (60 minutes, data collected from September 2011 to May 2014)
- Telephone interview - (30 minutes, data collected from September 2013 to December 2015)
- In-home, face-to-face interview - (90 minutes, data collected from May 2012 to May 2015)
- Data Collection Site visit interview - (2.5 hours, May 2012 to May 2015, including Contraindications, Neuropsychological Battery and Disease Symptoms)
Data Preview Portal

Welcome to the Data Preview Portal for the Canadian Longitudinal Study on Aging (CLSA). Alphanumeric data collected from more than 51,000 participants at baseline are now available. Before exploring the variables in the Data Preview Portal, please familiarize yourself with the study protocol and data collection tools used in the study.

**Study Protocol**
Access the detailed protocol for the baseline phase of data collection of the CLSA.

**Data Collection Tools**
Access the questionnaires used by the CLSA since it began data collection in 2011. If you would like to search keywords of interest, we recommend downloading the questionnaires and using CTRL+F, Command+F or the search function of your web browser.

**Datasets**
Access the CLSA Data Preview Portal. The variable search tool is designed to enable researchers to locate items of interest within available data. If you are new to using the portal, we recommend you read the Frequently Asked Questions. Currently, the Data Preview Portal is only available in English.
Need More Information?

Still have questions? Email us: access@clsa-elcv.ca
Take Home Messages

• This large cohort was designed, assembled and data collection is ongoing
  – Baseline data and biospecimens have been collected
• Alphanumeric data from questionnaires, physical assessments and basic hematology results on 51,338 participants from across Canada are now available
  – These data are free for student thesis research and for postdoctoral fellow projects
Acknowledgements
CLSA Montreal

• Data Collection Site
  – Josee Mayer (Manager)
  – Katya Lopez
  – Sanjivlall Balgobin
  – Jessica Noseworthy
  – Mario Polosa
  – In home Interviewers
    – Amy Striemer
    – Yan Romanesky
    – Elizabeth Grou

• Statistical Analysis Centre
  – Dr. Isabel Fortier - (Assoc Director)
  – Dr. Istvan Molnar-Szakacs (Data Access Officer)
  – Sarah Youssef (Sr. Data Curator)
  – Khaled Boulsaien (Data Curator)
  – Dr. Geva Maimon (Statistician)
  – Jennifer Uniat (Manager, on leave)
  – Bin Zhu (PT Statistician)
  – Caterina DeLeo (PT Research assistant)
  – Philippe Boileau (PT Assistant)
  – Claire Heffernan (summer student)
  – Norah Finn (biostatistics intern)

• Translation
  – Marie-Eve Veilleux (Coordinator)
  – Laurie Torres (Assistant)

• Administration
  – Karen Zabowski
CLSA Funders and Partners