Transforming Everyday Life into Extraordinary Ideas
The webinar on the update of the CLSA will begin shortly

For first-time Blackboard Collaborate users:

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• Near the top left of the Blackboard window, go to Tools >> Audio and run the Audio Setup Wizard

• The only people on the session who can speak and be heard are the moderator and presenters

• If you have questions/comments, you can type them into the chat box in the bottom left of the Blackboard window. Hitting ‘return/enter’ sends the message and everyone in the ‘Room’ can see it

• You can type your questions in at any point during the session, but they won’t be answered until the end of the presentation
CLSA Webinar Series

Dr. Susan Kirkland

An update to the research community on the CLSA: Where are we now and what’s next for Canada’s premier study on aging

1 - 2 p.m. ET | Sept. 23, 2015

The Canadian Longitudinal Study on Aging has achieved numerous milestones in the past year. Recruitment and baseline data collection for more than 50,000 participants has been completed. Versions 1.0 and 2.0 of the Tracking data are currently available for use by the research community. The Canadian Institutes of Health Research has awarded $41.6 million in funding to continue the study for the next five years, and the first follow-up wave of data collection has begun. Join Dr. Susan Kirkland, CLSA co-principal investigator and professor in the Departments of Community Health & Epidemiology and Medicine at Dalhousie University in Halifax, for an update on the progress of the CLSA, including descriptive statistics of study participants at baseline, how the second wave of data collection is being rolled out, future availability of Comprehensive data and biospecimens, and how CLSA data can be used to inform a wide range of research projects.

Register online at http://bit.ly/clsawebinars

Webinars will be broadcast using BlackBoard
Further instructions will be sent by email

www.clsa-eclv.ca
THE CANADIAN LONGITUDINAL STUDY ON AGING

An update to the research community on the CLSA: Where we are now and what’s next for Canada’s premier study on aging

Presented by

Susan Kirkland, PhD
Dalhousie University, Halifax

on behalf of

Christina Wolfson, PhD, McGill University, Montreal
Parminder Raina, PhD, McMaster University, Hamilton
and the CLSA Research Team
Overview of Presentation

• Review of study design
• Renewal funding
• Recruitment milestones achieved
• Snapshot of CLSA participants at baseline
• First follow up (FU1)
  – Protocol and content changes
  – Accommodation and retention strategies
  – ELS Issues
• Data Access
• Questions
The Canadian Longitudinal Study on Aging (CLSA)

• Strategic initiative of CIHR; on Canadian research agenda since 2001

• Team of 3 principal investigators, 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 Canadians for 20 years
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 as they age.
Study Design and Methodology
50,000 women and men aged 45 - 85 at baseline

Tracking (20,000)
Randomly selected
10 provinces

Comprehensive (30,000)
Randomly selected
25-50 km of 11 sites in 7 provinces

Questionnaire
• By telephone (CATI)

Questionnaire
• In person, in home (CAPI)

Physical Assessments
Blood, Urine
• At Data Collection Site

20 year study: Full follow up every 3 years, maintaining contact in between

Data Linkage
Recruitment Sampling Frames

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

- Partnered with provincial Ministries of Health
  - Health Card Registration databases
  - Mailouts, return Consent to Contact form

- Supplemented with Random Digit Dialing
  - Pre-recruitment, agree to recontact
Participants Consent to Participate in CLSA

Participants Provide Questionnaire Data (n=50,000)

Pre-recruitment

Biological Data Processing
- Blood
- Urine

Data Collection Site Visit
Physical/Neuropsychological Data

DATA COLLECTION SITE VISIT
Physical/Neuropsychological Data

Biorepository and Bioanalysis Centre

Storage at Biorepository and Bioanalysis Centre

Biological Data Processing

Survey Interview
- Home Interview
- Telephone Interview

Data Stored at Statistical Analysis Centre and disseminated to researchers

Questionnaire data processing
Depth and Breadth of CLSA Questionnaire modules

- **DEMOGRAPHIC**
  - Education
  - Marital status
  - Ethnicity

- **HEALTH BEHAVIOURS**
  - Smoking, alcohol
  - Nutritional risk
  - Food frequency
  - Physical activity
  - Health care utilization
  - Medication use
  - Supplement use

- **HEALTH STATUS**
  - General health
  - Women’s health
  - Chronic conditions, symptoms
  - Oral health

- **PHYSICAL**
  - Injuries, falls
  - Mobility
  - Pain, discomfort
  - Functional status
  - ADL, IADL

- **PSYCHOLOGICAL**
  - Cognition—Executive function, memory, psychomotor speed
  - Depression
  - Mood
  - Psychological distress
  - Veteran identifier
  - Satisfaction with life
  - PTSD

- **SOCIAL**
  - Social networks
  - Social support
  - Social participation
  - Online communication
  - Social inequality
  - Care receiving
  - Care giving
  - Retirement status
  - Labour force participation
  - Retirement planning
  - Transportation
  - Mobility, Migration
  - Built environments
  - Home ownership
Depth and Breadth of CLSA Physical Assessment Modules

- Height, weight, BMI
- Blood pressure
- Spirometry - FEV
- Carotid ultrasound – CIMT
- ECG – heart rate, rhythm
- DEXA – BMD, body composition, aortic calcification
- Hearing
- Visual acuity
- Grip strength

- Fundus photograph – blood flow
- Tonometer – ocular pressure
- Neuropsych battery – memory, executive function, reaction time
- Timed up and go
- Balance
- 4 metre walk
- Chair rise
- Blood
- Urine
Bio specimen processing
42 aliquots per participant

- Basic hematological tests completed on site
- Remainder processed, frozen within 2 hrs
Biorepository and Bioanalysis Centre (BBC)

- 31 nitrogen freezers (-180°C)
  - Space for 5 million aliquots
- Personal Archive
  - Dry storage, humidity controlled, room temperature
- Laboratory Information System (LabWare)
  - Sample tracking system, QC
- High-throughput robotic platform for biomarker analysis
Disease outcomes via algorithms

Chronic Airflow Obstruction (CAO) Algorithm

Self-reported Diagnosis (yes/no)

Spirometry

Normal

- No reported wheezing, coughing, shortness of breath
  - Medication: No
    - Normal (no CAO)
  - Medication: Yes
    - Normal (no CAO)

- Wheezing, coughing, shortness of breath: any ‘yes’
  - Medication: No
    - Possible CAO
  - Medication: Yes
    - Definite CAO

Abnormal

- No reported wheezing, coughing, shortness of breath
  - Medication: No
    - Possible CAO
  - Medication: Yes
    - Definite CAO

- Wheeze with exertion or cough up phlegm: any ‘yes’
  - Medication: No
    - Possible CAO
  - Medication: Yes
    - Definite CAO

- Wheeze with exertion or cough up phlegm: any ‘yes’
  - Medication: No
    - Possible CAO
  - Medication: Yes
    - Definite CAO

\(^{1}\)CAO = chronic airflow obstruction. \(^{2}\)If participant coughs without phlegm, then outcome will be possible CAO. \(^{3}\)Outcome when self-reported diagnosis = no. \(^{4}\)Outcome when self-reported diagnosis = yes.
Key Milestones
50,000 women and men aged 45 - 85 at baseline

n=20,000
Randomly selected within provinces

Questionnaire
• By telephone (CATI)

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

Questionnaire
• In person, in home (CAPI)

MCQ Interim contact, follow up every 3 years

Clinical/physical tests
• Blood, urine (consent)
• At Data Collection Site

Data Linkage (consent)

Milestones to Date

21,241 – COMPLETE!

30,111 – COMPLETE!

40,862 – TARGETED FINISH DATE DEC 2015!
Our Mission

Transforming everyday life into extraordinary ideas.

The Canadian Longitudinal Study on Aging (CLSA) is a large, national, long-term study that will follow approximately 50,000 men and women between the ages of 45 and 85 for at least 20 years. The study will collect information on the changing biological, medical, psychological, social, lifestyle and economic aspects of people's lives. These factors will be studied in order to understand how, individually and in combination, they have an impact in both maintaining health and in the development of disease and disability as people age. The CLSA will be one of the most comprehensive studies of its kind undertaken to date, not only in Canada but around the world.

Dr. Parminder Raina (McMaster University, Hamilton) is the lead principal investigator of the CLSA. Dr. Christina Wolfson (McGill University, Montreal) and Dr. Susan Kirkland (Dalhousie University, Halifax) are co-principal investigators of the CLSA. Drs. Raina, Wolfson and Kirkland, along with a team of more than 160 investigators and collaborators from several Canadian universities, have participated in the development of this innovative, interdisciplinary study.

51,352 Participants recruited 50,000 goal

News

Sign up for our newsletter

CLSA webinar series will resume on Sept. 23

Webinars covering a broad range of topics related to the study of aging have been scheduled for this fall, with the first one on Sept. 23 providing an update to the research community on the Canadian Longitudinal Study on Aging.

CLSA launches second wave of data collection

The next major round of data collection for
Datasets

A Canadian Longitudinal Study on Aging (CLSA) variable list describes variables collected from participants at each data collection. The variable search tool is designed to enable users to locate items of interest within available data collected from CLSA participants.

Currently, data emanating from 1,025 eligible participants who completed the baseline 60-minute in-home interviews are available. Datasets from future data collection will be added as they become available. Data collected at the site visits, telephone interviews and data collections are available now.

Data collected at site visits, telephone interviews and data collections are available now.

Variable Search
- Variables currently available in the first wave of the data release, with filtering and search options.
- Version 2.0 now available – includes cognition data!

Variables not yet available
- Code text variables not yet released.

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).
Renewal Funding

• Phase 2 Renewal Directed Grant awarded
  – 5 years 2015 – 2020
  – $41.6 M for 86% of operating costs
  – Data collection for first follow up, 2/3 second follow up
  – Analysis of baseline biological samples: key biomarkers, genetic, epigenetic analyses

• CFI infrastructure amendment finalized
  – Added SFU CATI site
  – DCS@home equipment
  – Replacement equipment
  – NCC renovations
A Snapshot of CLSA Participants
## CLSA Participant Recruitment From Sampling Frames

<table>
<thead>
<tr>
<th>Sampling Frame</th>
<th>Tracking</th>
<th>Comprehensive</th>
<th>Total</th>
</tr>
</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>4,135</td>
<td>7,945</td>
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<tr>
<td>Random Digit Dialing</td>
<td>13,508</td>
<td>25,913</td>
<td>39,421</td>
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<tr>
<td>NuAge Study</td>
<td>0</td>
<td>66</td>
<td>66</td>
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</table>

**Total:** 51,355
## Socio-demographic Characteristics Tracking and Comprehensive

<table>
<thead>
<tr>
<th></th>
<th>Tracking N=21,171</th>
<th>Comprehensive N=30,094</th>
<th>Total N=51,265</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<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>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>10796 (51.0)</td>
<td>15310 (50.9)</td>
<td>26106 (50.9)</td>
</tr>
<tr>
<td>Male</td>
<td>10375 (49.0)</td>
<td>14784 (49.1)</td>
<td>25159 (49.1)</td>
</tr>
<tr>
<td><strong>Language</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<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>
<tr>
<td>Born in Canada</td>
<td>18455 (87.2)</td>
<td>24644 (81.9)</td>
<td>43099 (84.1)</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, Lab</td>
<td>1251 (5.9)</td>
<td>2219 (7.4)</td>
<td>3470 (6.8)</td>
</tr>
</tbody>
</table>
# Chronic Conditions Tracking and Comprehensive

<table>
<thead>
<tr>
<th>Chronic Condition</th>
<th>Tracking</th>
<th>Comprehensive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Osteoarthritis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knee</td>
<td>3406</td>
<td>4499</td>
</tr>
<tr>
<td>Hand</td>
<td>2966</td>
<td>3852</td>
</tr>
<tr>
<td>Hip</td>
<td>2075</td>
<td>2500</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>8451</td>
<td><strong>6851</strong></td>
</tr>
<tr>
<td>Asthma</td>
<td>2340</td>
<td>3983</td>
</tr>
<tr>
<td>COPD</td>
<td>1430</td>
<td>1725</td>
</tr>
<tr>
<td>Hypertension</td>
<td>8065</td>
<td>11099</td>
</tr>
<tr>
<td>Diabetes</td>
<td>3536</td>
<td>5311</td>
</tr>
<tr>
<td>Heart disease</td>
<td>2170</td>
<td>3499</td>
</tr>
<tr>
<td>Angina</td>
<td>1136</td>
<td>1323</td>
</tr>
<tr>
<td>Heart attack</td>
<td>1303</td>
<td>1461</td>
</tr>
<tr>
<td>Stroke</td>
<td>388</td>
<td>521</td>
</tr>
<tr>
<td>Cataracts</td>
<td>5236</td>
<td>8607</td>
</tr>
<tr>
<td>Mood disorder</td>
<td>3100</td>
<td>5140</td>
</tr>
<tr>
<td>Cancers</td>
<td>3250</td>
<td>4680</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>1998</td>
<td>2688</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>19,844</td>
<td><strong>38,041</strong></td>
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</tbody>
</table>
## Chronic Conditions by Age and Sex

Tracking and Comprehensive

<table>
<thead>
<tr>
<th>Chronic Condition</th>
<th>45 – 64 Men</th>
<th>45 – 64 Women</th>
<th>65+ Men</th>
<th>65+ Women</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Osteoarthritis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knee</td>
<td>953 (12.1)</td>
<td>1467 (17.5)</td>
<td>2209 (13.0)</td>
<td>3276 (18.8)</td>
</tr>
<tr>
<td>Hand</td>
<td>612 (7.7)</td>
<td>1393 (16.6)</td>
<td>1549 (9.1)</td>
<td>3264 (18.7)</td>
</tr>
<tr>
<td>Hip</td>
<td>437 (5.5)</td>
<td>877 (10.5)</td>
<td>1186 (7.0)</td>
<td>2075 (11.9)</td>
</tr>
<tr>
<td><strong>Asthma</strong></td>
<td>856 (10.8)</td>
<td>1287 (15.3)</td>
<td>1714 (10.0)</td>
<td>2466 (14.0)</td>
</tr>
<tr>
<td><strong>COPD</strong></td>
<td>418 (5.3)</td>
<td>517 (6.1)</td>
<td>1022 (6.0)</td>
<td>1198 (6.8)</td>
</tr>
<tr>
<td><strong>Hypertension</strong></td>
<td>2977 (37.5)</td>
<td>2663 (31.6)</td>
<td>6853 (40.1)</td>
<td>6671 (37.9)</td>
</tr>
<tr>
<td><strong>Diabetes</strong></td>
<td>1513 (19.1)</td>
<td>1305 (15.5)</td>
<td>3372 (19.7)</td>
<td>2657 (15.1)</td>
</tr>
<tr>
<td><strong>Heart disease</strong></td>
<td>842 (10.6)</td>
<td>480 (5.7)</td>
<td>2735 (16.0)</td>
<td>1612 (9.2)</td>
</tr>
<tr>
<td>Angina</td>
<td>336 (4.2)</td>
<td>196 (2.3)</td>
<td>1211 (7.1)</td>
<td>716 (4.1)</td>
</tr>
<tr>
<td><strong>Heart attack</strong></td>
<td>501 (6.3)</td>
<td>175 (2.1)</td>
<td>1524 (8.9)</td>
<td>564 (3.2)</td>
</tr>
<tr>
<td><strong>Stroke</strong></td>
<td>111 (1.4)</td>
<td>107 (1.3)</td>
<td>430 (1.3)</td>
<td>261 (1.5)</td>
</tr>
<tr>
<td><strong>Cataracts</strong></td>
<td>968 (12.3)</td>
<td>1364 (16.3)</td>
<td>511 (30.1)</td>
<td>640 (36.8)</td>
</tr>
<tr>
<td><strong>Mood disorder</strong></td>
<td>1130 (14.2)</td>
<td>2002 (23.7)</td>
<td>1888 (11.0)</td>
<td>3220 (18.3)</td>
</tr>
<tr>
<td><strong>Cancers</strong></td>
<td>880 (11.1)</td>
<td>1238 (14.7)</td>
<td>2936 (17.1)</td>
<td>2876 (16.3)</td>
</tr>
<tr>
<td><strong>Osteoporosis</strong></td>
<td>164 (2.1)</td>
<td>1077 (12.8)</td>
<td>522 (3.2)</td>
<td>2923 (16.7)</td>
</tr>
</tbody>
</table>
# Self Rated Health Tracking and Comprehensive

<table>
<thead>
<tr>
<th></th>
<th>Tracking</th>
<th>Comprehensive</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self Rated General Health</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>3969 (18.8)</td>
<td>5991 (19.9)</td>
<td>9960 (19.5)</td>
</tr>
<tr>
<td>Very Good</td>
<td>8103 (38.3)</td>
<td>12423 (41.3)</td>
<td>20526 (40.1)</td>
</tr>
<tr>
<td>Good</td>
<td>6237 (29.5)</td>
<td>8872 (29.5)</td>
<td>15109 (29.5)</td>
</tr>
<tr>
<td>Fair</td>
<td>2218 (10.5)</td>
<td>2318 (7.7)</td>
<td>4536 (8.9)</td>
</tr>
<tr>
<td>Poor</td>
<td>623 (3.0)</td>
<td>467 (1.6)</td>
<td>1090 (2.1)</td>
</tr>
<tr>
<td><strong>Satisfaction with Life</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>2068 (9.8)</td>
<td>2971 (9.9)</td>
<td>5039 (9.8)</td>
</tr>
<tr>
<td>Neutral</td>
<td>849 (4.0)</td>
<td>1338 (4.5)</td>
<td>2187 (4.3)</td>
</tr>
<tr>
<td>Satisfied</td>
<td>18229 (86.2)</td>
<td>25752 (85.7)</td>
<td>43981 (85.9)</td>
</tr>
</tbody>
</table>

* Limited age and sex differences
First Follow Up (FU1)
2015 - 2018
First Follow Up (2015-2018)

- 1st follow up Comprehensive (July 2015 - June 2018)
  - Re-contacting 30,111 participants for their follow up in-home interviews and DCS visits

- 1st follow up Tracking (Oct 2015 - June 2018)
  - Re-contacting 21,242 participants for their follow up telephone interviews

  - All participants re-contacted at 18 months via phone
Preparing for Follow Up 1

NCC:
- Finalize questionnaires
- Re-programming software suite
- Optimizing IT infrastructure
- New software development
- Website
- Communications
- Programming content changes
- SOP updates

DCS/CATI:
- Pilot work
- Managing operations
- Quality Control
- Reviewing SOPs
- Staffing/Training

BBC:
- Sample storage
- Sample retrieval
- Updating LIMS processes
- Changes to protocols
- Quality Control
- Supporting DCS sites CPT tubes

SAC:
- Data cleaning
- Coding
- Variable naming
- Disease algorithms
- DataPreview Portal

WG:
- Update study content
FU1: Modifications to the protocol

- Questionnaire revisions
  - Delete some questions
  - Revise some questions to reflect time window
  - Add new content
- Decedent Questionnaire
- Proxy Questionnaire
- Accommodation strategies
- DCS@home
- Timing of when MCQ content administered
FU1: New content

• From working groups, partners
  • Elder abuse (PHAC)
  • Childhood maltreatment (PHAC)
  • Gender identity
  • Unmet health care needs
  • Preventive health behaviours
  • Workability
  • Loneliness
  • Subjective cognitive decline
  • Decedent Questionnaire
FU1: New Content

- Despite additional content, very little change in overall time to administer
- Deletion of questions that do not change/require repetition
- Questionnaire content removed from Maintaining Contact at 18 months
- Tracking: conduct in two interviews close together
- Comprehensive: content spread over in home, DCS visit
FU1: Ongoing consent

- Consent for continued participation is confirmed verbally at first contact (phone)
- Signed consent for significant changes to the protocol (in person or mailed)
  - HCN retrospective linkage
  - Decedent Questionnaire
  - Institutionalization
FU1: Retention and Accommodation Strategies

- Accommodation strategies developed to maintain long term participant retention in the face of changing circumstances
  - Migration out of area
  - Sensory losses: hearing, sight, speech
  - Mobility, travel challenges
  - Institutionalization
  - Cognitive decline
- Allows for flexible participation
- Baseline exclusion criteria no longer apply
Participant Retention Issues and Procedures

- **Out of area (Comp only)**
  - Guidelines
  - Options
    - Regular IH & DCS visit (for 25 to 50 Km distance)
    - IH & DCS at DCS same day
    - IH (by phone) & DCS
    - Follow Outside of Canada procedure

- **Outside of Canada (Comp & Tra)**
  - USA
    - Telephone interview
  - Other countries
    - Web based (future)
    - Need programming and SOP to do Comp

- **Participant Accommodation Guidance**
  - Institutionalized
  - Contact Institution
    - Comp-Modified IH & DCS@home
    - Tra - proceed as normal
  - Loss of vision/Blind
  - Hard of hearing
  - Speech Incoherent
    - Strategies to minimize issue and proceed with DCS or Tra
  - Cognitive Loss Prefer Proxy
    - Follow Proxy process
  - Deaf
    - Follow Proxy process
  - Mobility/Travel Issues
    - DCS@home Guidelines
    - No travel options found

- **HelpingTech SOP**

- **DCS@home SOP**
Comprehensive: DCS at Home

Full visit at the DCS

If not

Accommodation:
DCS by Phone (if participant is willing to come for a full DCS visit at next follow up).

If not

Accommodation:
DCS AT Home
DCS at Home

Stadiometer
7 lbs
3 kg

Tanita
30 lbs
14 kg

Other
35 lbs
16 kg
CLSA ELS Issues at FU1

- Use of proxies
- Identifying potential cognitive decline
- Withdrawal process
Use of Proxies

- As participants reach age 70, given Proxy Information Package and Consent to identify a proxy decision maker/information provider.
- Consent includes an advance directive to indicate their preferences for future participation in the event that they are unable to make decisions, provide information on their own.
- Participant asked to inform proxy of their role.
- Documents developed with advice from ELSI.
- Proxy information is verified with participant at FU1.
- Proxy decision maker and information provider are contacted, proxy consent is initiated when the decision is made to utilize them.
- Proxy Questionnaire.
Participant Consent re Proxy

Should I become unable in the future to take part in the CLSA on my own:

Tracking and Comprehensive:

• I would like my proxy information provider to continue to answer the research questions asked by an interviewer on my behalf (Y/N)

Comprehensive:

• I would like to continue to do the physical tests as long as it is feasible (Y/N)

• If I have agreed to give blood and urine:
  • I would like to continue to give blood and urine (Y/N)

• If I have agreed to give my health card number:
  • I would like to continue to have my information collected by the CLSA linked with information about me in health care records (Y/N)
FU1: Identifying Cognitive Decline

- Validated Six Item Screener to be done at FU1 for all participants 70 and older
  - Delayed recall of three words (penny, table, apple)
  - What year is it?
  - What month is it?
  - What day of the week is it?
- For those who recall $\leq 3/6$, initiate conversation about comfort in continuing to answer on own, use of proxy
- Initiate proxy process as required
- In addition, option always available to initiate proxy discussion at the request of participant or discretion of interviewer
- Methodological work re neurocognitive battery
Process of Withdrawal

• Multiple complex considerations related to options for future use of data, samples and data linkage
• For Tracking: Questionnaire, linkage using HIN
• For Comprehensive: In home interview and DCS visit, blood and urine, linkage using HIN
• Withdrawal can occur at multiple points (e.g. call to help line, during interview) and via multiple mechanisms (e.g. phone, mail, email)
• De-link option permanently destroys the link between the participant’s identifying information and their data
• Scripts developed regarding options in consultation with ELSI, REBs
Data Access
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 are unique resources that must be used optimally to support research to benefit all Canadians.
Data Release Timelines

• Tracking
  • Questionnaire data, cognition - available now
  • Occupation, medications – next release
  • MCQ – early 2016

• Comprehensive
  • Questionnaire data – first release
  • MCQ data – second release
  • Simple clinical data – third release
  • Complex clinical data – fourth release
  • Biosamples, biosample data – fifth release
Biomarker and epigenetic analyses

• Complete Blood Count (analysis at DCS) – 2nd Comprehensive data release – Tentative release date early 2017

• Proposed panel of biomarkers: albumin, ALT, creatinine, CRP, ferritin, hemoglobin A1C, lipids (cholesterol, HDL, Triglycerides, LDL), thyroid stimulating hormone, free T4, 25-hydroxyvitamin D
  ➢ N~30,000  (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)

• Tentative release date 2018
Data Access Steps: Tracking

Application process via CLSA DataPreview portal

- Administrative Review
- Data and Sample Access Committee Review
- Recommendation to Scientific Management Team
- Notification of applicant
  - Steps 1 to 4 take 3-4 weeks
- CLSA Access Agreement preparation and signatures
  - Institutional review/signature timing is unpredictable
- Raw data provided to approved investigator
  - Takes 5 working days following completion of step 5

access@clsa-elcv.ca
Data Access Costing

Tracking
- Cost Recovery
- $1,000 for baseline Tracking dataset
- No cost for data for graduate student theses

Comprehensive
- Much more complex – guidelines under development
- Questionnaire data more extensive
- Clinical data
- Biosamples – biomarkers, genetics
- For grant submissions, early consultation

Quarterly submission deadlines to DSAC
Potential for Ancillary Studies

• YES, but…
• Anything added to participant data collection has to be incorporated as core component of the CLSA
• Can only add elements at the beginning of each follow up wave
• Vetted through working groups
• Must be a priority for CLSA, logistically feasible, bring funding
• No exclusive right to data
• Ancillary policy to be posted on website 2016
DataPreview Portal
https://datapreview.clsa-elcv.ca/

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.
The Research Team

**U Victoria**: Debra Sheets, Lynne Young, Holly Tuokko  
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**SFU**: Andrew Wister, Scott Lear  
**U Calgary**: David Hogan, Marc Poulin  
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**Memorial U**: Gerry Mugford, Patrick Parfrey  
**U Waterloo**: Mary Thompson, Changbao Wu, Mark Oremus

+ Scientific Working Groups and Co-Investigators

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Operations Committee and Scientific Leads
CLSA Team
Transforming Everyday Life
into Extraordinary Ideas

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Thermo Fisher Scientific

Thermo Fisher Scientific

Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

VWR

NICE
Dr. Brent Richards

The Genetics of Osteoporosis: An aging-related disease

12 - 1 p.m. ET | Oct. 19, 2015

Most aging-related diseases are partially heritable, and osteoporosis is particularly so, with genetic factors explaining approximately 80% of variation in bone mineral density, and 50% of fracture risk. Dr. Brent Richards, an endocrinologist and genetic epidemiologist at the Jewish General Hospital of McGill University, will discuss recent advances in whole-genome sequencing programs, and genome-wide genotyping approaches to understand genetic determinants of osteoporosis. The utility of such approaches and potential ways to use emerging genome-wide genotyping within the CLSA to address clinically relevant questions such as identifying the genetic determinants of common aging-related diseases, will also be explained. The CLSA has recently received funds to genome-wide genotype 10,000 study participants, which will enable researchers using CLSA data to lead global genetic efforts.

Register online at http://bit.ly/clsawebinars

Webinars will be broadcast using BlackBoard
Further instructions will be sent by email