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

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Ottawa, June 15th, 2015
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
The CLSA Vision

A research platform – infrastructure to enable state-of-the-art, interdisciplinary population-based research and evidenced-based decision-making that will lead to better health and quality of life for Canadians.
Innovation - Cell to Society

- Mid life to old age
- Quantitative traits
  - Physical
  - Social
  - Psychological
- Gene-environment interactions
- Disease, disability, psychosocial consequences
- Adaptation
Timeline and Milestones

Team Design
Objectives
Content
Acceptability
Bio-specimens
Recruitment
Data Linkage
Pilot recruitment
Validate measures
SOPs, TMs
Pilot protocol
Data Collection

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

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

IR
IR
IR
CFI
IR
Design Overview

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

- n=20,000
  Randomly selected within provinces

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

- Questionnaire
  - By telephone (CATI)

- Questionnaire
  - In person, in home (CAPI)

- Clinical/physical tests
  Blood, urine
  - At Data Collection Site

- Full follow up every 3 years
  Maintaining Contact in between waves

Data Linkage
Participant Recruitment

- Vancouver
- Victoria
- Surrey
- Calgary
- Winnipeg
- Hamilton
- Ottawa
- Montreal
- Sherbrooke
- Halifax
- St. John’s

Comprehensive

Tracking
Recruitment Sampling Frames

Sampling weights are available

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

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

3. Random Digit Dialing
   - Pre-recruitment
Exclusion Criteria At Baseline

Adapted from CCHS exclusion criteria

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

- Pre-recruitment

Participants Consent to Participate in CLSA

Participants Provide Questionnaire Data (n=50,000)

DATA COLLECTION SITE VISIT
Physical/Neuropsychological Data

Biological Data Processing
- Blood
- Urine

Stored at Biorepository and Bioanalysis Centre

Data Stored at Statistical Analysis Centre and disseminated to researchers

n=20,000 Telephone Interview

n=30,000 Home Interview

Questionnaire data processing
Content: Tracking Modules

60 minute Computer Assisted Telephone Interviews

- Sociodemographics
- Home ownership
- Veteran identifier
  - PTSD screen
- Lifestyle
- Health
  - General, women’s, vision, hearing, chronic conditions
- Functional Status
- Cognition
- Depression
- Satisfaction with life
- Social networks/support/participation
- Care-giving/receiving
- Injuries
- Labour Force/Retirement
- Income

Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement
The Tracking CATI plus

- Short diet questionnaire
- Sleep
- Medications
- More extensive cognition module and disease symptoms questionnaire
CLSA Data Collection
At the Data Collection Site

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

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

Biological Data Collected
- Blood
- Urine
Content: Maintaining Contact

30 minutes CATI

- Built Environment
- Transportation, migration, mobility
- Falls
- Pain
- Oral Health
- Health Care Utilization
- Dietary Supplement Use
- Nutritional Risk
- Physical Activity
- Social Inequality
- Online social networking
- Wealth
- Parkinsonism (T)
- Medication (T)
- Psychological Distress (C)
- Personality Traits (C)
Status

As of June 12th, 2015
Recruitment & Data Collection Update

Telephone Interviews

- Recruitment of 20,000* participants, 60 minute telephone interviews every 3 years:
- Recruitment and baseline data collection are complete!
- Data available for release to researchers‡
  - MC interviews initiated 2013 (16,487 completed, ~4% lost)
- First full follow-up begins end of summer 2015

*21,241 result of over sampling low SES
‡ cognition data and some open text in second release
Recruitment & Data Collection Update

Home Interviews and Data Collection Site Visits

- Recruitment of 30,000 for Home Interviews and Data Collection Site Visits:
  - Baseline data collection 2012 to 2015:
    - In Home Interviews: 30,240
    - DCS visits: 29,650
    - Data release target: Spring 2016
    - MC 14,534 to date (~4% lost)
  - First full follow-up begins summer 2015
Matters of Place - Transportation and the Built Environment

Built Environment

- Home ownership†
  - Current dwelling
  - Own or rent

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

- Satisfaction with current home

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

† From Baseline Questionnaire
Matters of Place - Transportation and the Built Environment

Built Environment

11 questions regarding individuals’ perceptions of their neighbourhood

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

Adapted from Health and Retirement Study/English Longitudinal Study of Ageing
Matters of Place - Transportation and the Built Environment

Transportation

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

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

Self-reported diagnosis by a health professional of:

- Memory problems
- Dementia or Alzheimer’s disease

Neurocognitive battery

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

Comprehensive only

- Prospective memory test (event-based and time-based)
- Stroop Neuropsychological Screening Test
- Controlled Oral Word Association (F, A, S)
- Choice reaction time
Algorithm created by Dr. Holly Tuokko and the Psychological Health Working Group for Comprehensive participants

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

**STEP 1**

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

**SCALEd** = (RAW | Age, Edu, Gender)

How many SD below the mean?

If < 2 SD = Impaired
If 1 ≤ SD ≤ 2 = MCI
Else = Normal
Dementia Algorithm

**STEP 2**

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

A set of parallel clinician’s judgements can also be used to examine correspondence.
**Dementia Algorithm**

<table>
<thead>
<tr>
<th>Normal</th>
<th>All domain scores = 0</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Multiple Domain CI – not dementia</strong></td>
<td>At least 2 of 3 domain scores = 1 or 2, but does not meet dementia criteria below</td>
</tr>
<tr>
<td><strong>Amnesic CI</strong></td>
<td>Memory domain score = 1 or 2, all else = 0</td>
</tr>
<tr>
<td><strong>Single Domain Non-Memory</strong></td>
<td>Memory domain score = 0, one other domain score = 1 or 2</td>
</tr>
<tr>
<td><strong>Dementia</strong></td>
<td>Memory domain score = 2 &amp; one other domain = 2</td>
</tr>
</tbody>
</table>

The higher the number of impaired domains, the more confident the diagnosis

**STEP 3**

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

- Socio-Demographic Characteristics
- Psychological Characteristics
- Physical Health and Physical Functioning
- Social Environment
- Injuries (including workplace injuries)
Access

Alphanumeric data from 21,241 CLSA participants who completed 60 minute CATIs
Data and Biospecimen Access

- Data and biospecimens will be available to the research community
- Fundamental tenets:
  - The *rights*, *privacy* and *consent* of participants must be protected and respected at all times
  - The *confidentiality* and *security* of data and biospecimens must be safeguarded at all times
  - CLSA data and biospecimens are unique resources that must be used optimally to support research to benefit all Canadians.
Data Access Continued

- Costing
- Cost Recovery
  a. $1,000 for a straightforward dataset
  b. No cost for data for graduate student theses
- DSAC Meetings 2015
  - February, April, June, September, December
- Application deadlines
  - March 23rd, May 15th, August 14th, November 16th
DataPreview Portal

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

CLSA DataPreview Portal

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.

CLSA Overview
Study design and documents

Datasets
Dataset from the baseline interview of 20,000+ Tracking participants

Access
Application procedure, required forms and data access policies
Transforming Everyday Life into Extraordinary Ideas

griffith@mcmaster.ca
www.clsa-elcv.ca
Questions? Comments?
Matters of Place - Transportation and the Built Environment

Built Environment

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

I am satisfied with my current housing
Agree, neither agree or disagree, disagree
Matters of Place - Transportation and the Built Environment

Built Environment

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

Strongly agree, agree or disagree
Biological Samples

BIOCHEMICAL & HEMATOLOGICAL ANALYSIS (50 ml Blood; Urine)

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

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

Genetic and Epigenetic Markers
Data Access Steps

Tracking Data Only

Application process via CLSA DataPreview portal

1. Administrative Review
2. Data and Sample Access Committee Review
3. Recommendation to Scientific Management Team
4. Notification of applicant
   - Steps 1 to 4 take 3-4 weeks
5. CLSA Access Agreement preparation and signatures
   - Institutional review/signature timing is unpredictable
6. Raw data provided to approved investigator
   - Step 6 takes 5 working days following completion of step 5

acces@clsa-elcv.ca
DataPreview Portal

Datasets

A Canadian Longitudinal Study on Aging (CLSA) dataset holds and describes variables collected from participants at each wave of data collection. The variable search tool enables researchers to locate items of interest within all available data collected from CLSA participants.

Currently, data emanating from the over 20,000 Tracking participants who completed the baseline 60-minute telephone interviews are available. Cognitive scoring is ongoing and these data will be available as part of the second CLSA data release in December 2014.

Datasets from future data collection events will be added when they are available.

Variables (June 2014)

Variables currently available in the first wave of the data release, with filtering and search options.

Variables (December 2014)

Variables that will be available in the second CLSA data release in December 2014.

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).
DataPreview Portal

Variables

Help: To obtain all the variables contained in a CLSA questionnaire module, type the two- or three-letter module prefix (e.g. SDC for socio-demographic variables) into the full-text search box.

<table>
<thead>
<tr>
<th>Name</th>
<th>Label</th>
<th>Dataset</th>
</tr>
</thead>
<tbody>
<tr>
<td>startdate</td>
<td>Date and time at start of interview</td>
<td>Tracking - Baseline Interview</td>
</tr>
<tr>
<td>startlanguage</td>
<td>Language at start of interview</td>
<td>Tracking - Baseline Interview</td>
</tr>
<tr>
<td>AGE_NMBR_TRM</td>
<td>Age (years)</td>
<td>Tracking - Baseline Interview</td>
</tr>
<tr>
<td>SEX_ASK_TRM</td>
<td>Sex</td>
<td>Tracking - Baseline Interview</td>
</tr>
<tr>
<td>SDC_COB_TRM</td>
<td>Country of birth</td>
<td>Tracking - Baseline Interview</td>
</tr>
<tr>
<td>SDC_COB_OTSP_TRM</td>
<td>Country of birth other, Specify</td>
<td>Tracking - Baseline Interview</td>
</tr>
<tr>
<td>SDC_YACA_YR_TRM</td>
<td>Year arrival in Canada</td>
<td>Tracking - Baseline Interview</td>
</tr>
<tr>
<td>SDC_ETHN_CA_TRM</td>
<td>Parental ethnic background Canadian</td>
<td>Tracking - Baseline Interview</td>
</tr>
<tr>
<td>SDC_ETHN_FR_TRM</td>
<td>Parental ethnic background French</td>
<td>Tracking - Baseline Interview</td>
</tr>
<tr>
<td>SDC_ETHN_PRI_TRM</td>
<td>Parental ethnic background Australian</td>
<td>Tracking - Baseline Interview</td>
</tr>
<tr>
<td>SDC_ETHN_UK_TRM</td>
<td>Parental ethnic background United Kingdom</td>
<td>Tracking - Baseline Interview</td>
</tr>
<tr>
<td>SDC_ETHN_ANZ_TRM</td>
<td>Parental ethnic background Australian</td>
<td>Tracking - Baseline Interview</td>
</tr>
</tbody>
</table>
## Approved Applications

<table>
<thead>
<tr>
<th>Applicant Title</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 (CLSA-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 (CLSA-VHI)</td>
<td>Quebec</td>
</tr>
<tr>
<td>Labour force participation: Retirement Transitions, Expectations and Planning</td>
<td>Ontario Student application</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 application</td>
</tr>
<tr>
<td>Factorial invariance of the CES-D</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>
</tbody>
</table>

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Linking CLSA Data

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

- Types of databases
  - Individual level administrative provincial health databases (priority)
  - Disease registries
  - Population level databases of community characteristics, climate, pollution
  - Individual level economic characteristics
First Follow Up (2015-2018)

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

- **1st follow up Comprehensive (July 2015)**
  - Re-contacting 30,000 participants for their follow up in-home interviews and DCS visits
First Follow Up
New Content

– Child maltreatment
– Elder Abuse
– Epilepsy
– Hearing handicap
– Arterial stiffness
– Workability
– Subjective cognitive decline
– Transportation
– Health care use
– Preventive health behaviours
Analysis of baseline biomarkers

Biomarker and epigenetic analyses repeated over time

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