Advancing the science of population health and aging through interdisciplinary research:
The Canadian Longitudinal Study on Aging

International Training Programme on Ageing
Trinity Institute, Dublin, Ireland
September 17-19, 2013
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
CLSA Timeline and Milestones

Team Design Objectives Content

Acceptability Specimen Collection Recruitment Data Linkage

Pilot recruitment Validate measures SOPs, TMs Pilot protocol

Protocol Development

Phase I Feasibility Studies

Phase II Validation, Pilot

Launch

CLSA Grand Opening and Launch 2012
Overall Aims of the CLSA

- To examine aging as a dynamic process
- To investigate the inter-relationship among intrinsic and extrinsic factors from mid life to older age
- To capture the transitions, trajectories and profiles of aging
- To provide infrastructure and build capacity for sustained high quality research on aging in Canada
Study Overview

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

Tracking Cohort
20,000
Randomly selected within Provinces

Comprehensive Cohort
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 (optional)
• At Data Collection Site

Interim contact, Follow up every 3 years

Data Linkage (optional)
Representative Sample Frame for Recruitment

• Tracking I (~6,000)
  • Partnered with Statistics Canada
  • CCHS 4.2 Healthy Aging Survey
  • 2006 Census as an area frame to select households

• Tracking II (~14,000); Comprehensive (30,000)
  • Partnering with provincial Data Stewards
  • Health Card Registration databases
  • Supplemented with RDD
Participants consent to participate in CLSA

Potential participants receive Study Information Package

Biological Data
- Blood
- Urine

Data Collection Site Visit
Physical/Psychological Data
- Neuropsychological Battery
- Performance Testing
- Anthropometric Measures
- Bone Density, Body Composition
- Aortic Calcification
- ECG, BP
- Carotid Intimal-Medial Thickness
- Pulmonary Function
- Vision and Hearing

Biological Data stored at Biorepository and Bioanalysis Centre (BBC)

Participants provide questionnaire data (n=50,000)

Comprehensive Cohort n=30,000
- Home Interview
- Telephone Interview

Tracking Cohort n=20,000
- Questionnaire data processed

Stored at (NCC/SAC)
CLSA Data Flow and Storage

- Data Collection
  Tracking, Comprehensive
  CATI, DCS

- Data Storage, Cleaning
  NCC, BBC

- Alphanumeric Data
  Storage, Analysis, Access
  SAC

- No local data storage
- Data stored on central server
- Data Access and Utilization Committee
Mastodon - manages interactions with participants and securely stores identifying information

Sabretooth & Limesurvey – CATI software manages participant data collection, Interview scheduling and tracks the status of the interviews through to completion

Beartooth & Onyx – CAPI software used by the Data Collection Sites to coordinate the collection of questionnaire responses, physical measurements and biospecimens from participants

Opal – Central Data Repository – or databank – stores and manages all non-identifying data collected using Sabretooth, Beartooth and Onyx
CLSA Infrastructure

- National Coordinating Centre (McMaster)
- Biorepository and Bioanalysis Centre (McMaster)
- Statistical Analysis Centre (McGill)
- Genetics and Epigenetics Centre (UBC)
- 4 Computer-Assisted Telephone Interview Sites
  - Victoria, Winnipeg, Sherbrooke and Halifax
- 11 Data Collection Sites
  - Victoria, Vancouver, Surrey, Calgary, Winnipeg, Hamilton/Toronto, Ottawa, Montreal, Sherbrooke, Halifax and St John’s
Tracking Questionnaire Modules

- Demographics
- Height, Weight
- Smoking
- Alcohol
- Nutritional risk
- General health
- Women’s health
- Vision, Hearing
- Chronic conditions
- Oral health
- Injuries
- Pain, discomfort
- Health care utilization
- Preventive services
- Medication use
- Supplement use
- Functional status
- ADL, IADL
- Cognition (Rey, MAT, AN)
- Physical activities
- Depression
- Vet ID
Tracking Questionnaire Modules

- Satisfaction with life
- PTSD
- Social networks
- Social support
- Social participation
- Online communication
- Social inequality
- Care receiving
- Care giving
- Retirement status
- Labour force participation
- Retirement planning
- Changes to improve health
- Work ability
- Transportation
- Mobility, Migration
- Built environments
- Income, Wealth
- Home ownership
Comprehensive Cohort

• In Home Visit (50 minutes)
  • Informed consent, Questionnaire, Medications

• Data Collection Site Visit (3 hours)
  • 5 participants per day
  • 25 participants per week
  • 40 weeks per year
  • 1000 participants per year per site

• Telephone follow up at 18 months (35 mins)
At the Data Collection Site

Reception
- Sign in
- Bar code scan
- Contraindications Q

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

Measurement Room 2
- DEXA
- BMD, body composition, aortic calcification

Measurement Room 3
- Visual acuity
- Fundus photograph
- Ocular pressure
- Grip strength
- Neuropsych I
- Chronic Diseases Q

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

Measurement Room 4
- Hearing
- Neuropsych II

Washroom
- Urine Sample

Phlebotomy Lab
- 50 ml Blood Draw

Check out
- Review of results
- Snack
- Honorarium

TOTAL TIME
2.5 – 3 HRS
Neuropsychological Battery

- Executive Function
  - Mental Alternation Test
  - Prospective Memory Test
  - Weschler Individual Achievement Test II
  - Controlled Oral Word Association Test
  - Stroop Neuropsychological Screening Test
  - 60 Second Animal Naming Test

- Memory
  - Rey Auditory Verbal Learning Test

- Psychomotor Speed
  - Simple and choice reaction times
  - Symbol Digit Modalities Test
Bio specimen processing
42 aliquots per participant

- Basic hematological tests completed on site
- Remainder processed, frozen within 2 hrs
Biospecimen Storage Systems

Matrix Tubes
- 500-μL V bottom screw top tubes
- 96 well open-bottomed boxes for fast scanning
- Potential for ‘pick and place’ robotic retrieval
- Frozen at -80

Microwell Plates
- 3 section GenPlates (Genvault)
- 96 well format
- Dried overnight, sealed with adhesive foil cover

Shipping
- Precharged vapour shippers (-160°C)
- Weekly to BBC via overnight courier
Biorepository and Bioanalysis Centre (BBC)

- 31 nitrogen tanks (5 million aliquots)
- Personal Archive, dry storage, humidity controlled, at room temperature
- LIMS (LabWare)
- CryoMORE, (Air Liquide) safety monitoring system
Linking CLSA Data with Administrative Databases

• 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
# Provincial Administrative Health Databases

<table>
<thead>
<tr>
<th>Database</th>
<th>Description, Example of Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Registry</td>
<td>HCN, DOB, Sex, PC, Eligibility start and end dates</td>
</tr>
<tr>
<td>Physician Billing</td>
<td>Physician Visits: Procedure category/code, diagnostic codes</td>
</tr>
<tr>
<td>Pharmacare</td>
<td>Prescriptions paid for on drug plan: DIN, days supply, quantity dispensed, cost</td>
</tr>
<tr>
<td>Hospital Discharge</td>
<td>Diagnostic codes, procedures, case mix, length of stay</td>
</tr>
<tr>
<td>Vital Statistics</td>
<td>Underlying cause of death, contributing causes, date and location of death</td>
</tr>
<tr>
<td>Mental Health Outpatient</td>
<td>Principal diagnosis, event type, clinician disciplines</td>
</tr>
<tr>
<td>Long Term Care</td>
<td>Services paid for by continuing care in institutions, daycare programs, and homecare</td>
</tr>
</tbody>
</table>
Recruitment: Comprehensive Cohort

Recruitment Forecast
Consent to Contact (Pre-Recruited)
Completed Data collection (Actual Recruitment)
CLSA by the numbers

- 50,000 participants
- 20 years to complete the study
- Up to 140,000 telephone interviews
- Up to 210,000 home interviews
- Up to 210,000 visits to data collection sites
- Up to 8,820,000 biospecimen aliquots
- Up to 300,000 follow-up calls
- Up to 129 million questions asked during telephone interviews
- Up to 219 million data points collected during CLSA home interviews and visits to data collection sites
- Up to 348 million data points will form the CLSA research platform
What is required to create a centralized platform like CLSA?

• Good governance
• Coordinated ongoing ethics approval process
• Transparent Data and Sample Access Policies
• Transparent Data Ownership and IP Policies
• Integrated and secure IT infrastructure
• Ethical, Legal, and Social Issues
CLSA Governance Structure

CIHR Advisory Committee on Ethical, Legal and Social Issues

Scientific Advisory Board

CLSA Advisory Council

Scientific Management Team

Data and Sample Access Committee

Intellectual Property and Commercialization Committee

Operations Committee

Training and Research Capacity Committee

Knowledge Translation and Communications Committee
Coordinated REB Process

- First known coordinated approach for a national observational study in Canada
- 11 sites, 11 REBs, one standardized set of study documentation for informed consent
- Online documentation process developed by the Public Health Agency of Canada (PHAC)
- Submit to McMaster (lead) REB
  - Provisional approval, comments posted on PHAC portal for other sites to review
  - Sites post local reviews; one set of comments sent to CLSA team for response
- Annual amendments, coordinated ethics renewals
Informed Consent

• I have read the Information Package for the Canadian Longitudinal Study on Aging (CLSA) and I understand it.
• I have had a chance to ask questions about the study, and all my questions have been answered.
• I understand that as long as I choose to take part in the CLSA information about me will be collected for 20 years.
• I understand that information about me will be stored for 25 years after the end of the study.
• I understand that if I choose to give blood and urine samples they will also be stored for 25 years after the end of the study.
• I understand that if I choose to give my Health Card Number, it will be used to link information about me in my public healthcare records held by the Provincial Government.
• I understand that my information and samples will be used for research purposes only and this research may also have commercial uses that benefit society.
• I understand that I can withdraw my consent at any time. If I choose to withdraw consent, I will be offered a number of options for how the information already collected about me will be used.

• Required: I agree to participate in the Canadian Longitudinal Study on Aging.
  • I understand this involves having a home visit and undergoing physical tests at a Data Collection Site every 3 years. I also understand that I will be contacted at the mid-point of 3 years for a telephone interview.

• Optional: I agree to provide blood and urine samples.
  • I understand this involves blood and urine collection when I visit the Data Collection Site every 3 years.

• Optional: I give permission to the Provincial Government to provide the CLSA team with information about me held in provincial health databases.
  • I understand that this will allow researchers to link my provincial health information to information collected from me by the CLSA.
  • I also understand that, should I withdraw my consent, data about me that has already been linked will remain part of the CLSA database.
Ethical, Legal, Social Issues

- Cognitive decline, use of proxies
  - Participant proxy consent, advance directive at age 70

- Withdrawal process
  - Options for use of data, samples, HCN linkage

- Incidental findings

- Return of results
  - Routine return of individual test results
    - Population reference values available, clinical relevance, feasibility
  - Requests for additional individual test results, access to personal information
  - Return of group research results
Data and Sample Access

- Data and samples available to the research community
- Guiding principles
  - Rights and privacy of participants must be protected
  - Confidentiality and security of data must be safeguarded
  - Data and samples made available in timely manner
  - Data and samples can only be used for research purposes
  - No exclusive access
  - Cost neutral
Data and Sample Access: Process

- Tracking Cohort: anticipate 1st release of data Spring 2014
- Comprehensive Cohort: anticipate 1st release of data after baseline complete ~Spring 2016
- Application process via CLSA website portal
- Review: Administrative, Data and Sample Access Committee recommendation
- Approval, data/sample sharing agreements
- Return of derived variables to CLSA dataset
- Ancillary Studies (Studies that require additional data collection on all or subset of participants) in Wave 2
Upcoming areas of interest and development for the CLSA

- Planning and development underway for Wave 2
- Core biomarker analysis
- Structural and functional brain imaging
- Epigenetics
- Veteran’s health
- Environmental exposures
- Assistive technologies, accelerometry
- Data linkage
- Data harmonization
CLSA Sites Leads and Data Collection Sites

- Margaret Penning, Victoria
- Andrew Wister and Max Cynader, Vancouver
- David Hogan, Calgary
- Verena Menec, Winnipeg
- Parminder Raina, Hamilton
- Larry Chambers, Ottawa
- Christina Wolfson, Montreal
- Hélène Payette, Sherbrooke
- Susan Kirkland, Halifax
- Gerry Mugford, St. John’s
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www.clsa-elcv.ca