A Platform for Research: The Canadian Longitudinal Study on Aging

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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
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 address aging from cell to society
- 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
Representative Sample Frame for Recruitment

• Statistics Canada: CCHS 4.2 Healthy Aging Survey

• Health Ministries: Health Insurance Card registration databases

• Random Digit Dialing
Standardized, Centralized Process

Potential participants receive Study Information Package

Participants consent to participate in CLSA

Participants provide questionnaire data (n=50,000)

- 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

COMPREHENSIVE COHORT n=30,000
- Home Interview

Biological Data stored at Biorepository and Bioanalysis Centre (BBC)

COMPREHENSIVE COHORT n=30,000
- Telephone interview

TRACKING COHORT n=20,000
- Questionnaire data processed

Stored at (NCC/SAC)
Depth and Breadth of CLSA

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

- **HEALTH BEHAVIOURS**
  - Smoking, alcohol
  - Nutritional risk
  - Health care utilization
  - Medication use
  - Supplement use

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

- **PHYSICAL**
  - Injuries, falls
  - Physical activity
  - Pain, discomfort

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

- **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
At the Data Collection Site

- Reception
  - Sign in
  - Bar code scan
  - Contraindications

- 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
  - Occular pressure
  - Grip strength
  - Neuropsych I
  - Chronic Diseases

- Measurement Room 4
  - Hearing
  - Neuropsych II

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

- Washroom
  - Urine Sample

- Phlebotomy Lab
  - 50 ml Blood Draw

- Check out
  - Review of results
  - Snack
  - Honorarium

TOTAL TIME
2.5 – 3 HRS
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 tanks (5 million aliquots)
- Personal Archive, dry storage, humidity controlled, at room temperature
- LIMS (LabWare)
- CryoMORE, (Air Liquide) safety monitoring system
Milestones

• Past half way mark for recruitment, baseline data collection
• Coordinated REB process
• Automated quality assurance, quality control
• Data cleaning process established
• Development of data dissemination protocol
• Collaborations with other large national initiatives
• ELSI: Protocols for identifying cognitive decline, proxy decision makers, proxy information providers, withdrawal
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

- 20,000 Telephone Interviews: anticipate 1\textsuperscript{st} release of data Spring 2014
- 30,000 Data Collection Site Visits: anticipate 1\textsuperscript{st} 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
- Coordinated linkage with administrative health data bases
- Data sharing, including biological samples
- Data harmonization
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
CLSA Sites Leads
Data Collection Sites

- Debra Sheets, Lynn Young, Victoria
- Andrew Wister and Max Cynader, Vancouver
- David Hogan, Calgary
- Verena Menec, Winnipeg
- Parminder Raina, Hamilton
- Vaness Taler, Ottawa
- Christina Wolfson, Montreal
- Hélène Payette, Sherbrooke
- Susan Kirkland, Halifax
- Gerry Mugford, St. John’s
Transforming Everyday Life into Extraordinary Ideas
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www.clsa-elcv.ca