A Platform for Research: The Canadian Longitudinal Study on Aging

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CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

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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

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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

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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
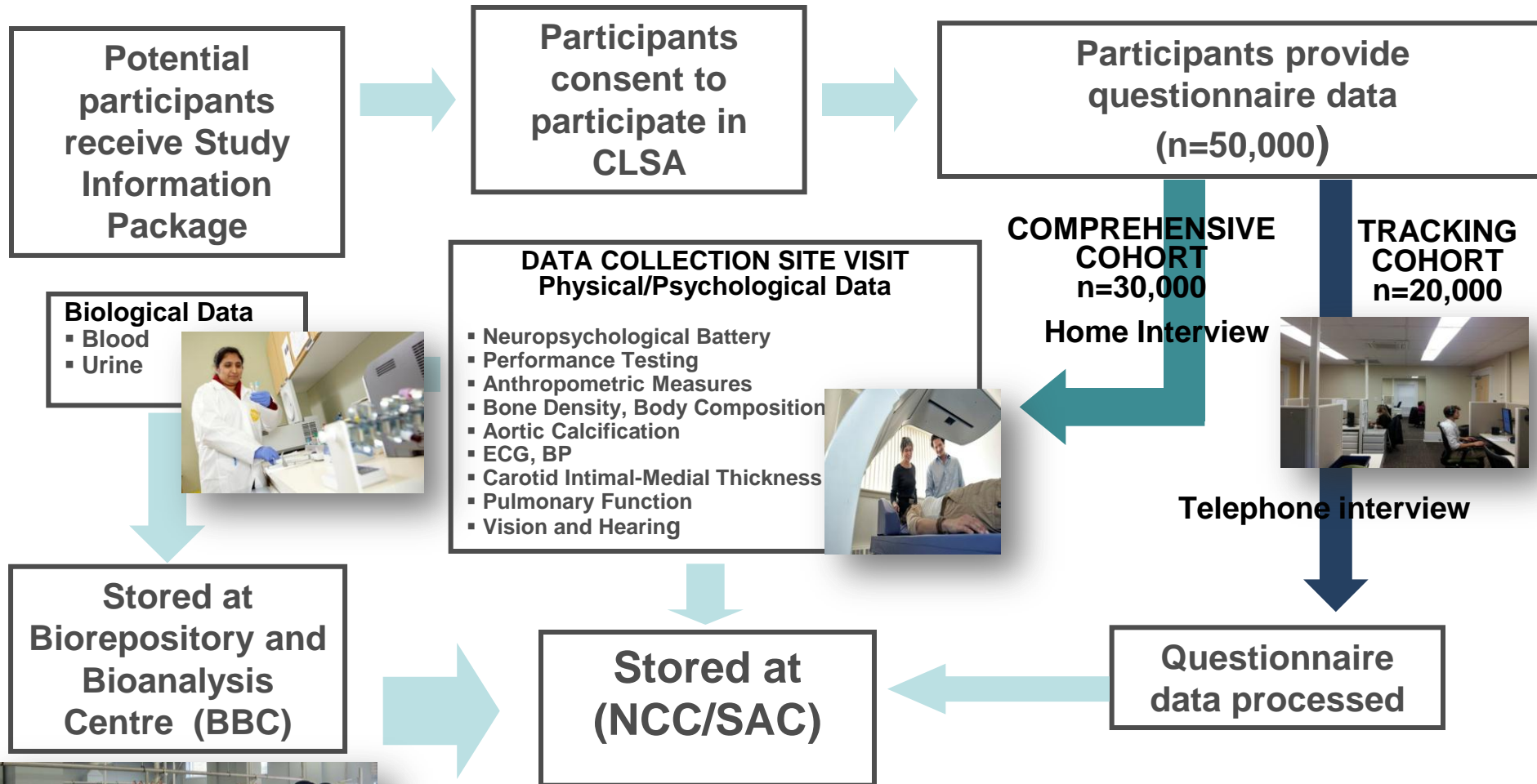
Data Linkage

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Representative Sample Frame for Recruitment

- Statistics Canada: CCHS 4.2 Healthy Aging Survey

- Health Ministries: Health Insurance Card registration databases

- Random Digit Dialing

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Standardized, Centralized Process

Potential participants receive Study Information Package → **Participants consent to participate in CLSA** → **Participants provide questionnaire data (n=50,000)**

COMPREHENSIVE COHORT n=30,000
Home Interview

TRACKING COHORT n=20,000

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

Telephone interview

Stored at Biorepository and Bioanalysis Centre (BBC) → **Stored at (NCC/SAC)** ← **Questionnaire data processed**

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Depth and Breadth of CLSA
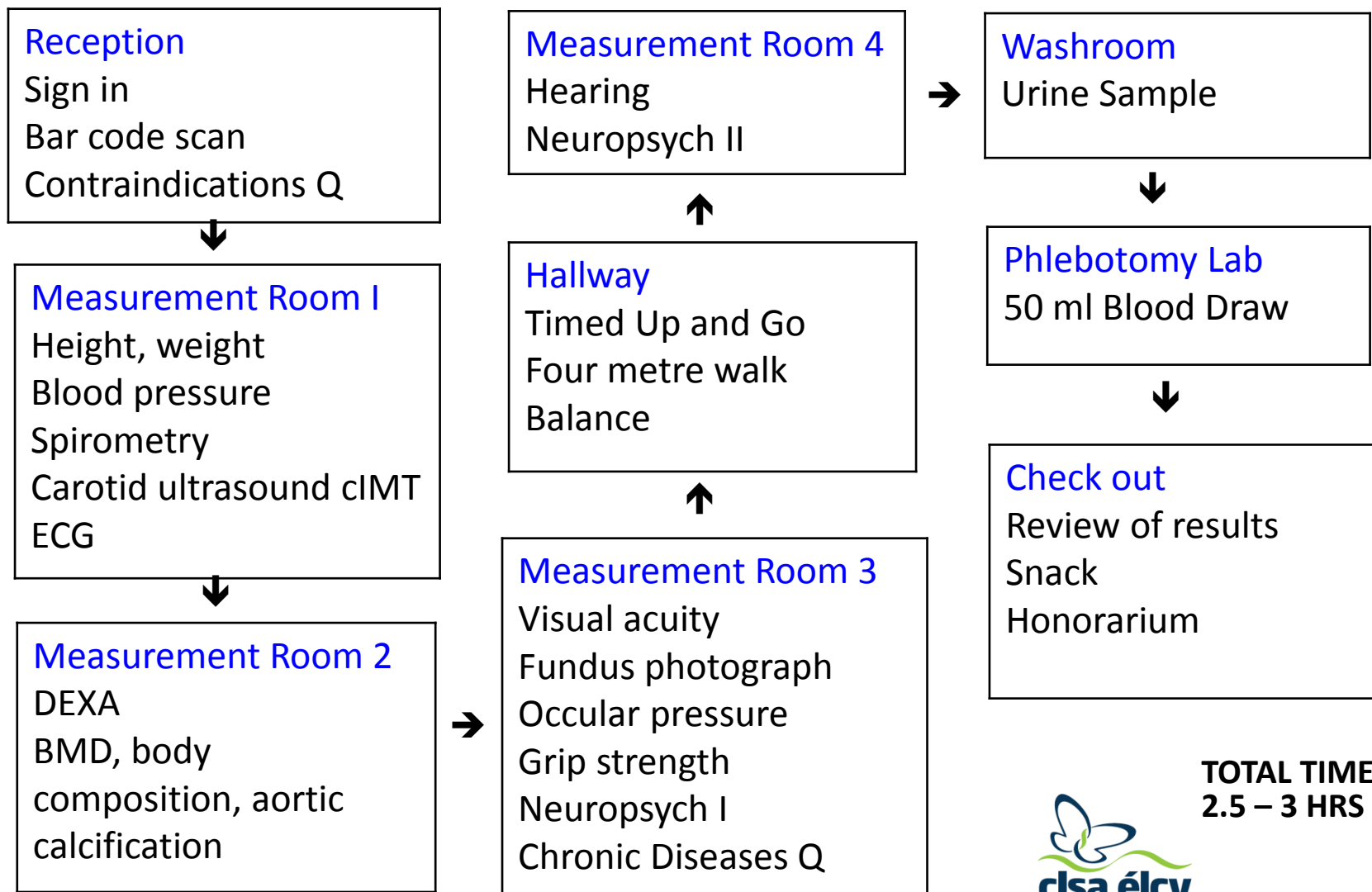
- DEMOGRAPHIC
- Education
- Marital status
- Ethnicity
- HEALTH BEHAVIOURS
- Smoking, alcohol
- Nutritional risk
- Health care utilization
- Medication use
- Supplement use
- HEALTH STATUS
- General health
- Women's health
- Chronic conditions, symptoms
- Oral health

- PHYSICAL
- Injuries, falls
- Physical activity
- Pain, discomfort
- Functional status
- ADL, IADL
- PSYCHOLOGICAL
- Cognition—Executive function, memory, psychomotor speed
- Depression
- 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
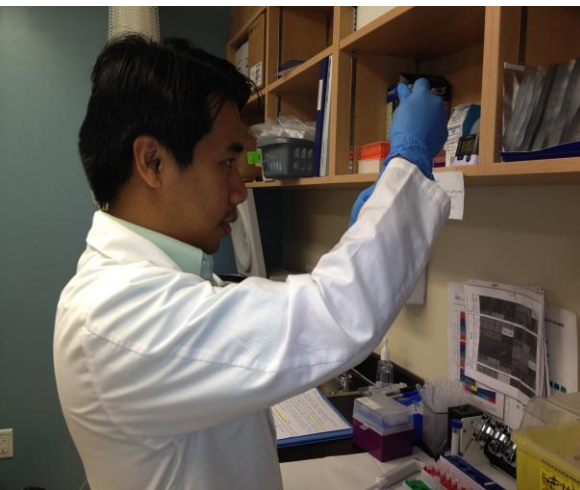- Mobility, Migration
- Built environments
- Home ownership

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At the Data Collection Site

Reception
Sign in
Bar code scan
Contraindications Q

⬇

Measurement Room I
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 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**

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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

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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

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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 1st release of data Spring 2014

- 30,000 Data Collection Site Visits: 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

- Coordinated linkage with administrative health data bases

- Data sharing, including biological samples

- Data harmonization

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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

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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**

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Transforming Everyday Life
into Extraordinary Ideas

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