The Canadian Longitudinal Study on Aging
A platform for interdisciplinary research
Christina Wolfson,
on behalf of the CLSA team

McGill Social Statistics and Population Dynamics Seminar
February 12th, 2014
Overview

• A little bit of background
• Study Architecture
• What is being collected
• Recruitment
• How data are being collected
• Recruitment and data collection status
• Governance
• Data and Biospecimen access
• Partners/special projects
Background

- Strategic initiative of the CIHR
- **Institute of Aging**
- Operations funded
  - 86% through a directed grant from CIHR
  - 14% through PI initiated collaborations
- Infrastructure funded by CFI
Vision

A research platform – infrastructure to enable state-of-the-art, interdisciplinary population-based research in aging
Aims

Examining aging as a dynamic process.

Investigating inter-relationships among intrinsic and extrinsic factors from mid-life to end-of-life.

Capturing transitions, trajectories and profiles of aging.

Providing infrastructure and build capacity for sustained high quality research on aging in Canada.
CLSA Working Groups
Developing, reviewing, suggesting content

- Clinical Working Group
  - Dr. Chris Patterson (McMaster)
- Lifestyle Working Group
  - Dr. Hélène Payette (Sherbrooke)
- Psychology Working Group
  - Dr. Holly Tuokko (Victoria)
- Biology Working Group
  - Dr. Cynthia Balion (McMaster)
- Health Services Working Group
  - Dr. Verena Menec (Manitoba)
- Methodology Working Group
  - Dr. Harry Shannon (McMaster)
CLSA Research Team

Debra Sheets, Lynne Young, Holly Tuokko (Victoria), Max Cynader, Michael Hayden, Michael Kobor, Theresa Liu-Ambrose (UBC), Andrew Wister, Scott Lear (SFU), David Hogan, Marc Poulin (Calgary), Verena Menec, Phil St. John (Manitoba), Cynthia Balion, Christopher Patterson, Parminder Raina, Lauren Griffith, Mark Oremus, Harry Shannon (McMaster), Larry Chambers, Vanessa Taler (Ottawa), Christina Wolfson, Ron Postuma (McGill), Hélène Payette (Sherbrooke), Susan Kirkland (Dalhousie), Gerry Mugford, Patrick Parfrey (Memorial), Mary Thompson and Changbao Wu (Waterloo)

Scientific Working Groups and Co-Investigators

See our website: www.clsa-elcv.ca
CLSA Timeline and Milestones

Team Design Objectives Content
Acceptability Specimen Collection Recruitment Data Linkage
Pilot recruitment Validate measures SOPs, Pilot protocol


Protocol Development
Phase I Feasibility Studies
Phase II Validation, Pilot
Launch

RFA IR IR IR CFI
Selected Research Domains

- Trajectories of health from middle age to older old age
- Determinants of well-being and quality of life
- Social participation, social relationships and caregiving
- Socioeconomic and health inequalities
- Retirement and post-retirement labour market activity
- Cognitive functioning, mental health and neurological conditions
- Health of aging veterans
- Disability and the compression of morbidity
50,000 women and men aged 45 - 85 at baseline

n=20,000 Randomly selected within 10 provinces

Questionnaire
• By telephone (CATI)

Maintaining contact, follow up every 3 years by phone

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

Questionnaire
• In person, in home (CAPI)

Physical Assessments
Blood, urine
• At Data Collection Site

Linkage with Administrative Databases
Home Interviews & Data Collection Site Visits

Computer Assisted Telephone Interviews

National

Cities:
- Winnipeg
- Vancouver
- Victoria
- Surrey
- Calgary
- Hamilton
- Ottawa
- Montreal
- Sherbrooke
- Halifax
- St. John’s
PHYSICAL & COGNITIVE MEASUREMENTS

- Height & weight
- Waist and hip measurements
- Body composition
- Arterial pressure
- Heart rate
- ECG
- Grip strength
- Timed up-and-go
- Chair rise, 4-m walk
- Standing balance
- Vision
- Hearing
- Spirometry
- Bone density
- Aortic calcification
- Carotid intima-media thickness
- Cognitive assessment
PSYCHOSOCIAL MEASURES

- Social participation
- Social networks and support
- Caregiving and care receiving
- Mood, psychological distress
- Satisfaction with life
- Wealth
- Personality traits
- Work-to-retirement transitions
- Retirement planning
- Social inequalities
- Mobility-lifespace
- Built environments
- “Successful aging”
HEALTH INFORMATION

- Chronic disease and symptoms
  - Screening for PD/Epilepsy
- Post traumatic stress disorder
- Medication and supplement use
- Women’s health
- Health services utilization
- Oral health
- General health
- Injuries
- Pain/discomfort
- Functional status
- Activities of daily living (ADL)
- Administrative data linkage health services and drugs
- Other administrative databases

Photo: Health Canada
LIFESTYLE & SOCIODEMOGRAPHIC

- Smoking
- Alcohol consumption
- Physical activity
- Nutrition
- Place of birth
- Ethnicity/race/gender
- Marital status
- Education
- Income
- Transportation
- Home ownership
Recruitment & Data Collection

Telephone Interviews

- Recruitment* of 20,000 participants for telephone interviews:
  - Statistics Canada Canadian Community Health Survey HS on Healthy Aging (2008-2009)
    - CLSA added a younger age category, developed the content for CCHS
  - Provincial Health Registration Databases (MOH)
  - Random Digit Dialing

- Baseline data collection 2010 to 2014
- Maintaining contact interviews initiated 2013
- First follow-up 2015

* sampling weights for multiple frame sampling are being created
CLSA Data Collection

Telephone Interviews

4 CATI Sites conduct telephone interviews

Participants provide questionnaire data in a 60 minute interview (n=20,000)
CLSA Infrastructure
4 Telephone Interview Centres

University of Manitoba
Dalhousie University
Université de Sherbrooke
University of Victoria
Recruitment & Data Collection

Home Interviews and Data Collection Site Visits

- *Recruitment of 30,000 for Home Interviews and Data Collection Site Visits:
  - Provincial Health Registration Databases
  - Random Digit Dialing
- Baseline data collection 2012-15
- Maintaining Contact Interviews initiated 2014
- First follow-up begins 2015

* sampling weights for multiple frame sampling are being created
CLSA Data Collection
Home Interview and Data Collection Site Visit
Electronic Data Entry

Participants provide questionnaire data in a 60 minute home interview (n=30,000)

Participants visit one of 11 data collection sites for a 2-3 hour assessment (n=30,000)
CLSA Infrastructure
11 Data Collection Sites

Simon Fraser University
Engaging the World

The University of British Columbia
A place of mind

Dalhousie University
Inspiring Minds

University of Manitoba

McMaster University

University of Calgary

McGill

Institut de recherche Centre universitaire de santé McGill

Research Institute
McGill University Health Centre

Brûlére
Continuing Care

Université de Sherbrooke

University of Victoria

CLSA ÉLVÆ
Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

uOttawa

Memorial University
Biospecimen Room
Collection, processing, analysis

- 5 – 6 participants per day
- 50 mL blood
- Urine sample
- 2 hours from blood collection to storage
  - Weekly shipping to BBC

AcT DIFF, Beckman Coulter
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

Biospecimens
- Blood
- Urine

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

42 aliquots per participant
CLSA Data Processing

Telephone interview (n=20,000)

Home interview and data collection site visit (n=30,000)

Alphanumeric data and images

Blood and urine stored in Biorepository and Bioanalysis Centre (BBC)

Data stored in National Coordinating Centre and at the Statistical Analysis Centre

Linkage with administrative data
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
4 Enabling Units

National Coordinating Centre (NCC)
Director: Parminder Raina

Biorepository and Bioanalysis Centre (BBC)
Director: Cynthia Balion

Genetics and Epigenetics Centre (GEC)
Directors: Michael Kobor and Michael Hayden

Statistical Analysis Centre (SAC)
Director: Christina Wolfson
Status
February 12th, 2014

- Completes for 60-minute CATI: 20,000
  - Completes MCQ: 2,389
- Completes InHome interviews: 17,367
- Completes DCS Visits: 14,945
CLSA Governance Structure

CIHR Advisory Committee on Ethical, Legal and Social Issues
Kieran O’Doherty & Elaine Gibson

International Scientific Advisory Board
Carole Brayne (UK)

CLSA Advisory Council
Ann Martin-Matthews

Scientific Management Team
Parminder Raina

Data and Sample Access Committee
Christina Wolfson

Intellectual Property and Commercialization Committee

Operations Committee
Andrew Wister

Training and Research Capacity Committee
Susan Kirkland & Mike Kobor

Knowledge Translation and Communications Committee
Larry Chambers
Ethics Review

• For feasibility and pilot studies we submitted separate applications to each site that was involved

• For the full study (and amendments) we are using a collaborative process
  – Canadian Network for Public Health Intelligence (CNPHI) portal
  – Ethics review boards agree(..) to participate
  – McMaster University REB is the board of record

n.b. 11 data collection sites + 4 CATI sites
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 resources that will be used optimally to support research to benefit all Canadians.
What is the data access process?

......a priority activity.....

- 20,000 telephone interviews: first release scheduled for mid-2014
- Application process via CLSA website
- Review, Data and Sample Access Committee recommendation
- Approval, data sharing agreements
  - Proof of ethics approval
- Raw data to approved applicant
  - Cost recovery
- Return of derived variables to CLSA
- Monitoring process
CLSA Partners

- Public Health Agency of Canada
  - Injuries
  - Neurological Conditions Initiative
- Veterans Affairs
  - Veterans Health Initiative
- Statistics Canada
  - CCHS and methodological input
- Ontario Ministry of Health and Long-Term Care
- Provinces
- Universities
- Large number of in-kind contributions from vendors and suppliers (CFI)
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  – Roselene Baltus
  – Katya Lopez
  – Claudia Greco
  – Sanjivall Balgobin
  – Sharon Herrera

• Inhome Interviews
  – Amy Striemer
  – Christina DelGaudio
  – Rahim Karmali

• Statistical Analysis Centre
  – Isabel Fortier (Assoc Director)
  – Jennifer Uniat (Manager)
  – The Minh Luong (Statistician)
  – Bin Zhu (Statistician)
  – Sarah Youssef (Data Curator)

• Translation
  – Marie-Eve Veilleux (Coordinator)
  – Laurie Torres

• Administration
  – Karen Zabowski
Transforming Everyday Life into Extraordinary Ideas

Connect with us
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