The Canadian Longitudinal Study on Aging (CLSA)

Opportunities, Needs, Challenges: Accessing Governmental Databases for Health Research

CLSA, CPT, P3G Meeting
Quebec City, Nov 11-13 2010

Overview of the CLSA

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

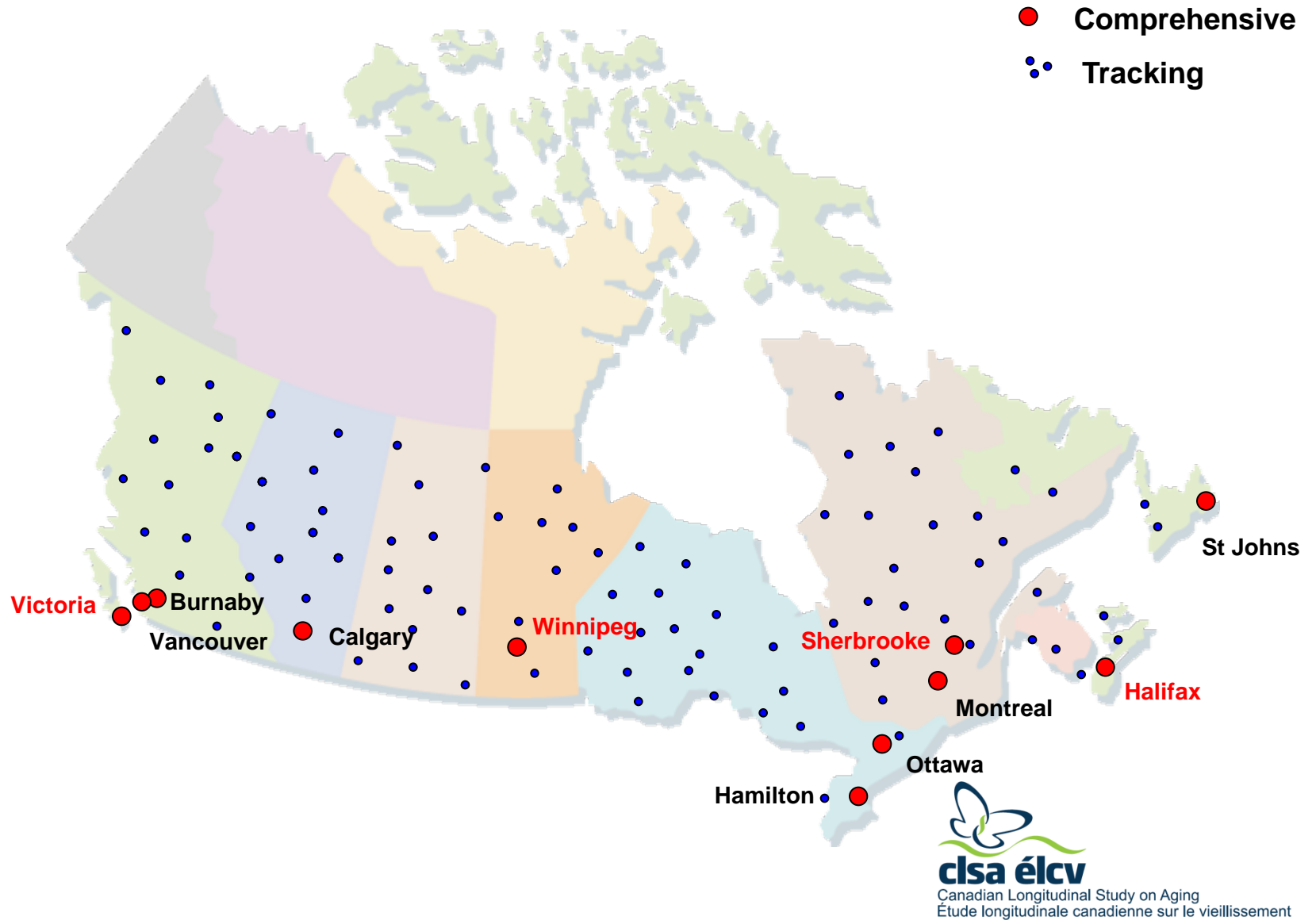| Tracking Cohort 20,000 Randomly selected within Province/Territories	Comprehensive Cohort 30,000 Randomly selected within 25 km of an academic centre in 11 sites
Questionnaire • By telephone (CATI)	**Questionnaire** •In person, in home (CAPI)
	Clinical/physical tests Neuropsych tests Blood, urine

Follow up every 3 years; interim contact

Data Linkage

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CLSA Participant Recruitment

Comprehensive

Tracking

Victoria
Burnaby
Vancouver
Calgary
Winnipeg
Sherbrooke
Montreal
Halifax
St Johns
Ottawa
Hamilton

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CLSA Timeline

Tracking

e from
Provincial Health
Registration
Databases
Baseline

2011

Comprehensive

| 1st phase recruitment+ baseline data collection n=10,000 | 2nd phase recruitment+ baseline data collection n=10,000 | 3rd phase recruitment+ baseline data collection n=10,000 |

| 2010 | 2011 | 2012 | 2013 | 2014 |

REB Process

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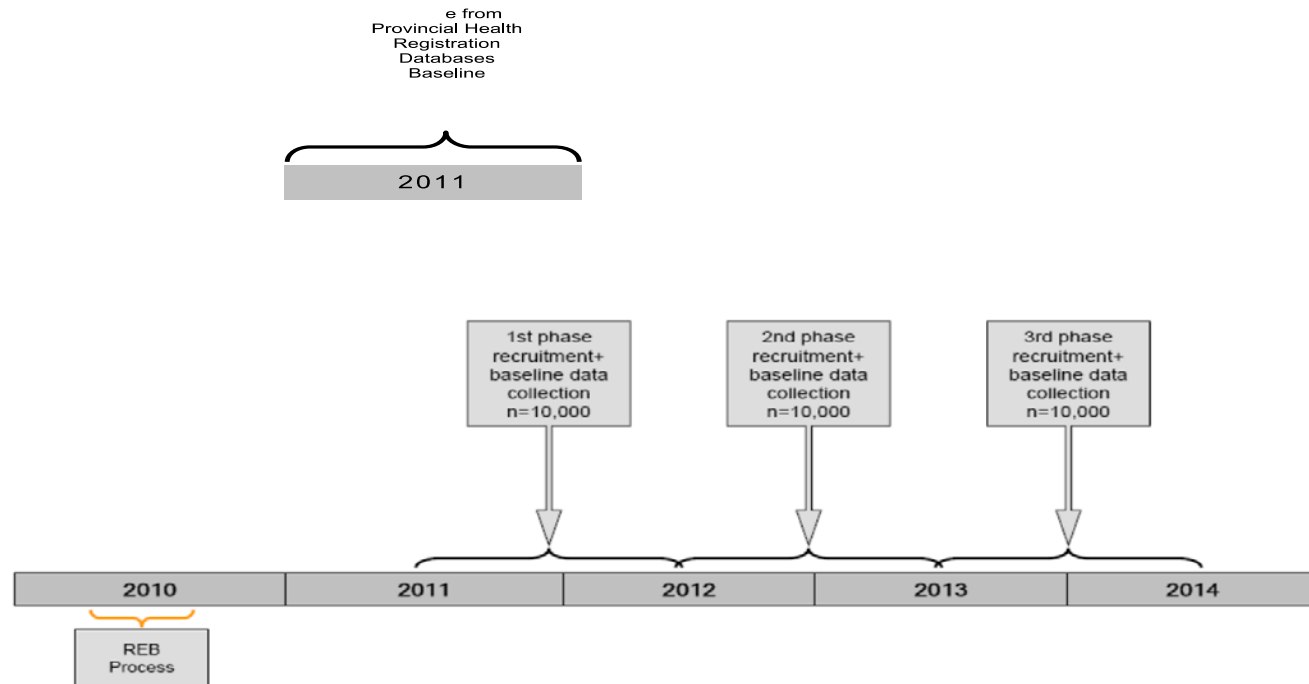
Linkage with Governmental Databases

- Exploring the potential for linkage
  - Feasibility study with Provincial Data Stewards
  - Dialogue with each provincial representative
  - Focusing on applications for sampling strategy first for remainder of Tracking, Comprehensive

Sampling 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)**
  - Partnering with provincial Data Stewards
  - Health Card Registration databases

- **Comprehensive (30,000)**
  - Partnering with provincial Data Stewards
  - Health Card Registration databases

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Recruitment Process I

- CCHS: Signed consent to release contact information, survey results to the CLSA

- Potential participant mailed info package, informed consent

- Telephone contact made 1-2 weeks later

- Interview conducted or scheduled

- Informed consent signed, mailed

- 30 minute questionnaire completed via CATI

- Signed consent returned by mail

Recruitment Process II

- Health Registration databases
- Introductory letter signed by provincial government representative, CLSA PIs
- Info package, informed consent included
- Mailed by data stewards in most provinces; CLSA has no access to identifying information
- Participants invited to contact CLSA via 1-800 number, email, website, mail
- *Tracking*: Contact, consent, 60 minute questionnaire via CATI
- *Comprehensive*: Contact, home visit scheduled

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Issues, Challenges for Sampling Using Provincial Health Databases

- Can we maintain the response rate?
  - CCHS 74%; CLSA 55%; Combined 41%
  - Anticipate 20% for Provincial databases; 15% among 75-85 yr
- How do we combine the two samples?
  - Complex sample weights
- Draw single sample at baseline, or over 3 years?
  - Tradeoffs
- Allows for comparison of responders, non-responders on key demographic information
- Other options: RDD, telephone directory listings
  - Can't guarantee that each individual in the target population is in the sample frame

Linkage of CLSA Data with Governmental Databases

- Linkage is key to research strategy
  - We also have ongoing primary data collection
  - Enormous potential for collection of information that is difficult to get from participants due to time, accuracy limitations

- Types of databases
  - Individual level administrative health databases (priority)
  - Disease registries
  - Population level databases of community characteristics
  - Individual level economic characteristics

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Administrative Health Databases

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

Community Characteristics Databases

- **Social cohesion**: voter turnout, recycling rates, volunteer organizations per capita, newspaper readership, stability, charitable donations

- **Neighbourhood quality**: neighbourhood income, ratio of private homes to businesses, amenities for older people, rental costs, vacancy rates, shopping facilities, crime rates, vandalism

- **Environmental quality**: green space per capita, air and water quality, climate

- **Sources**: Statistics Canada, Environment Canada, police reports, provincial and municipal data

- Linkage via postal code

CLSA Participant Consent: Comprehensive

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Consent Form

If you do not agree with each of these statements please take the time to talk about your questions or concerns with the interviewer who speaks with you.

I have read the Information Package for the Canadian Longitudinal Study on Aging (CLSA) and I understand the information I have received about the CLSA.

I have had an opportunity to ask questions about the study, and all my questions have been answered to my satisfaction.

I understand that if I choose to participate in the CLSA, personal information about me will be used for research related to health in the aging process and it will be stored for 25 years after study completion.

I understand that the blood and urine samples I supply and the information they provide may have potential commercial uses.

I understand that while I have consented to take part in the study I can withdraw my consent at any time. If I choose to withdraw

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If you would like to take part in this study please read and sign the next page.

Please note that you can take part in the study without agreeing to Option #2 or #3. However, by agreeing to Option #2 and #3 you are offering more opportunities for learning about adult development and aging.

		Yes	No
1)	I agree to participate in the Canadian Longitudinal Study on Aging.	☐	☐
	I understand this involves completing questionnaires every 18 months and having physical measures conducted at a Data Collection Site (DCS) every 3 years.		
2)	I agree to provide blood and urine samples when I visit the DCS.	☐	☐
	This will allow researchers to find out more about bodily processes and the role of genetics in aging.		
3)	I agree to provide my provincial health card number.	☐	☐

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Access to CLSA Data, Linked Data

- Data and Sample Access Policy and Procedures for Research Purposes
  - Canadian researchers have access to the CLSA data
  - Intent is for all researchers to have access to the linked data as well
  - Return of derived variables to the master data set
  - Does not currently include researchers outside the country
  - Does include private, public organizations

CLSA Data Flow and Storage

Data Collection
CATI, DCS

- No local data storage

Data Storage, Cleaning
NCC, BBC

- Data stored on central server

Alphanumeric Data Storage, Access
SAC

- Data Access and Utilization Committee

Data Linkage?

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Compatibility with Privacy Policy

- Is there anything in the privacy policy that could create a concern for an eventual linkage with a governmental database?

  – Something that would make the data stewards "less comfortable" or that might raise questions?

Issues, Opportunities for Linkage in the CLSA

- CLSA is a national study--All CLSA data is stored centrally
  - Will the provinces allow provincial databases to be stored outside of the province?
  - How often can the linkage be done?
  - When is the data linked? Annually? On a project by project basis?
  - Can linked data be returned to the master database for future use?
  - Do we need to do a Privacy Impact Assessment?
- Lessons learned
  - Early involvement of Data Stewards

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