The Canadian Longitudinal Study on Aging

A national platform and infrastructure for researchers and trainees.

Co-Principal Investigator: Christina Wolfson, PhD, McGill University

on behalf of

Co-PIs: Parminder Raina, PhD, McMaster University and Susan Kirkland, PhD, Dalhousie University

and the CLSA Research Team across Canada

Summer Program in Aging

May 16th, 2017 -Concordia University

Learning Objectives

1. To understand the CLSA study design and become familiar with the CLSA data access process
2. To be inspired to use the CLSA research platform

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Overview

- **Background**
- **Study Design and Infrastructure**
- **Study Content and Data Collection**
- **Current Status**
- **Sample demographics**
- **Data Access**

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The CLSA

- Strategic initiative of CIHR Institute of Aging; on the Canadian research agenda since 2001; nearly 10 years in the planning stages
- 3 co-principal investigators (epidemiologists) supported by 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 participants for ≥20 years

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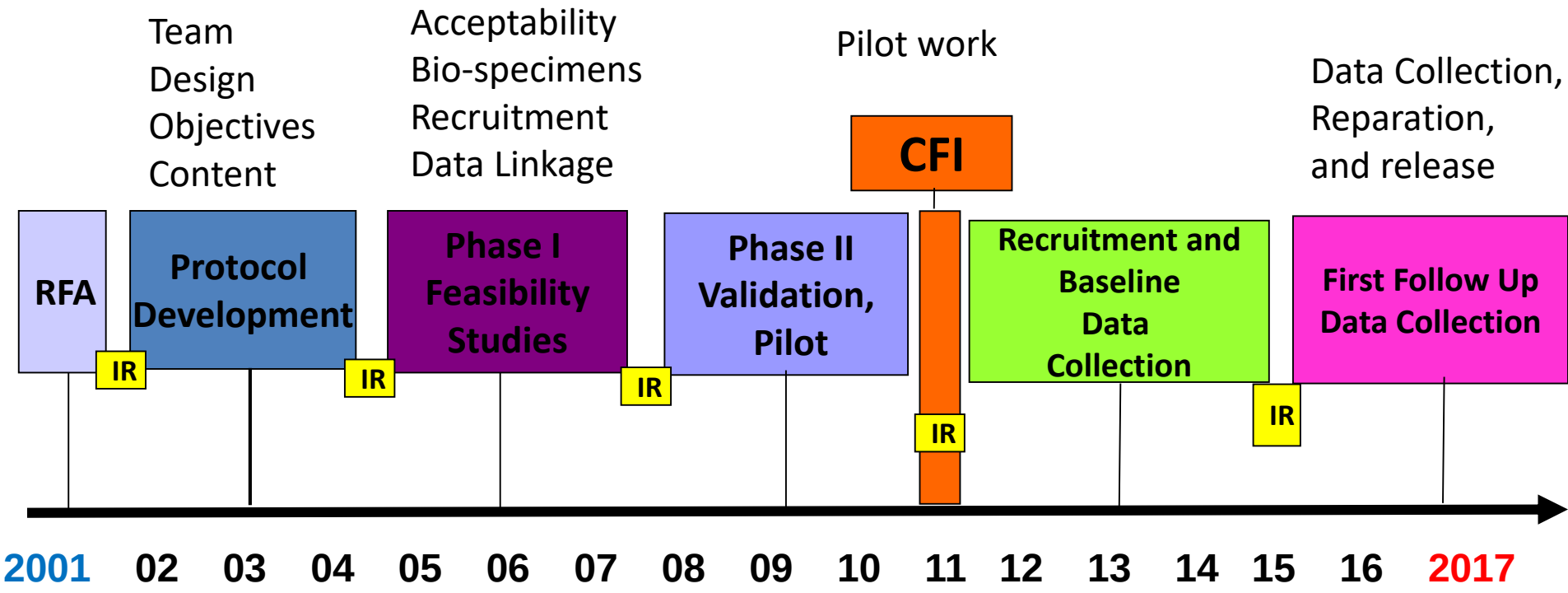
Aim and Vision

- AIM: To examine life/health transitions and capture trajectories to enable the identification of modifiable factors with the potential to inform interventions (prevention/treatment/impact) to improve the health of populations as they age

- VISION: To create a research platform infrastructure to enable state-of-the-art, interdisciplinary population-based research and evidenced-based decision-making that will lead to better health and quality of life for Canadians as they age.

The Journey so far…



IR **International peer review**

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Funding History

2002 to 2015

Development: 2002-2009

- CIHR, FRSQ, Universities

Infrastructure: 2009-2014

- CFI infrastructure/equipment
  - CFI + Provinces + Universities and other partners

Operations: 2009-2015

- CIHR 2009-2015
  - 86% of budget

Data/biospecimen analysis:

- No Funding

2015-2020

First Follow-up

Operations

- CIHR - 86% of budget
  - For Follow up 1 and 2/3 of Follow up 2 and maintaining the platform
- Analysis
  - CIHR Analysis of baseline biospecimens for selected biomarkers

***International Scientific Peer Review at every step**

Key co-investigators

British Columbia: Debra Sheets, Lynne Young, Holly Tuokko,Teresa Liu-Ambrose, Michael Kobor, Andrew Wister, Scott Lear

Alberta: David Hogan, Marc Poulin, Eric Smith, Alex Chin

Manitoba: Verena Menec, Phil St. John

Ontario: Parminder Raina, Cynthia Balion, Lauren Griffith, Andrew Costa, Harry Shannon, Christopher Patterson, Michael Veall, Vanessa Taler, Andrew Paterson, Mark Oremus, Mary Thompson, Changbao Wu

Quebec: Christina Wolfson, Ron Postuma, Brent Richards, Mark Lathrop, Hélène Payette, Benoît Cossette

Nova Scotia: Susan Kirkland

Newfoundland: Gerry Mugford

The Netherlands: Edwin van den Heuvel

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International Scientific Advisory Board

- Carole Brayne (Chair)
  - Director, Cambridge Institute of Public Health, Cambridge, UK
- David Weir
  - Director, Health and Retirement Study (HRS), Survey Research Center, University of Michigan, US
- John Gallacher
  - Director, MRC Dementia Platforms UK, Oxford University, UK

Governance and Advice

CIHR

- Oversight of Initiatives and Platforms
- Ethical, Legal, Social Issues Advisory Committee

CLSA

- Scientific Management Team
- Operations Committee
- International Scientific Advisory Board
- Advisory Council
- Knowledge Translation & Communications Committee
- Training and Research Capacity Committee
- Data and Biospecimen Access Committee

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Study Design and Infrastructure

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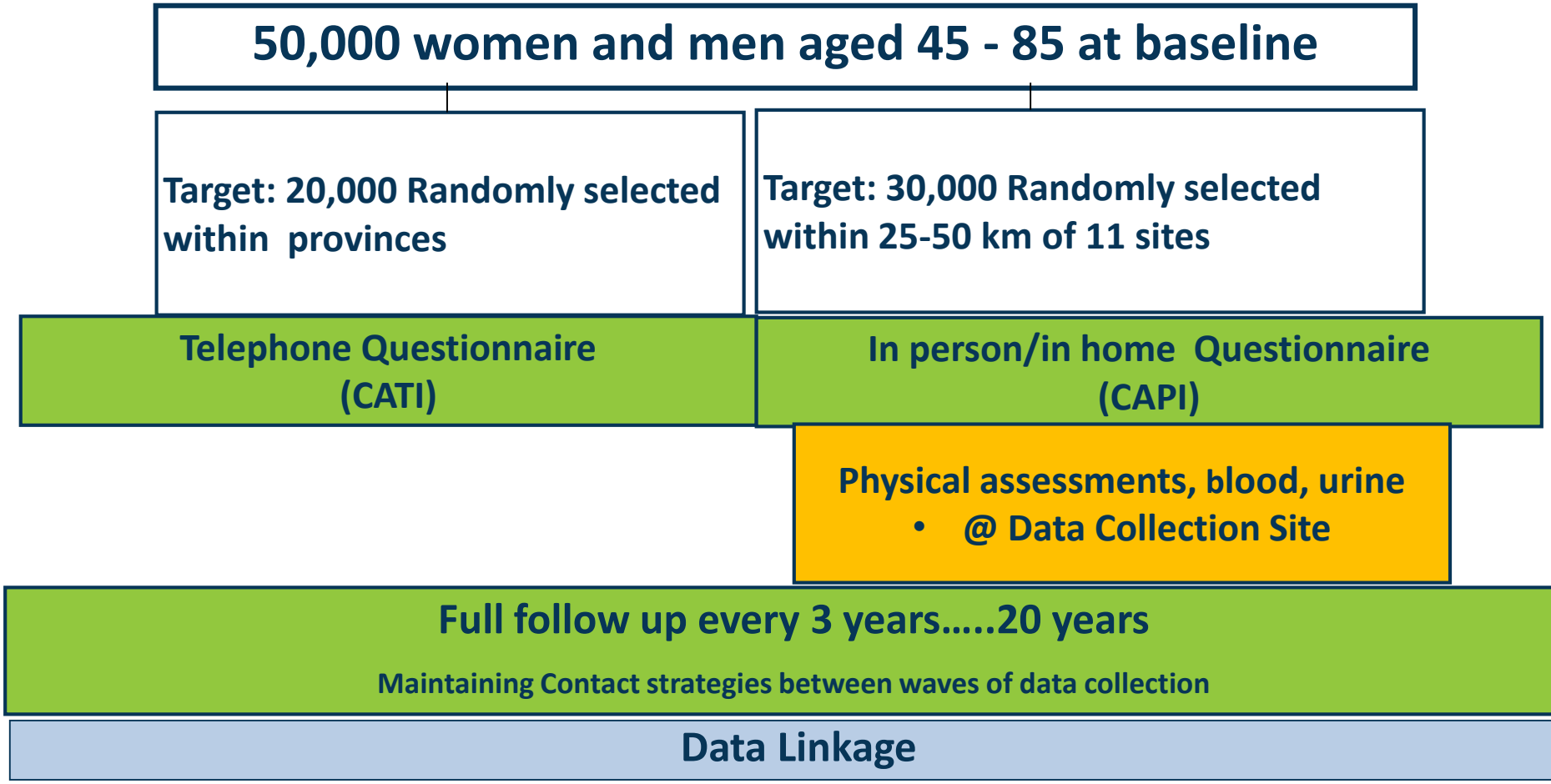
Overview



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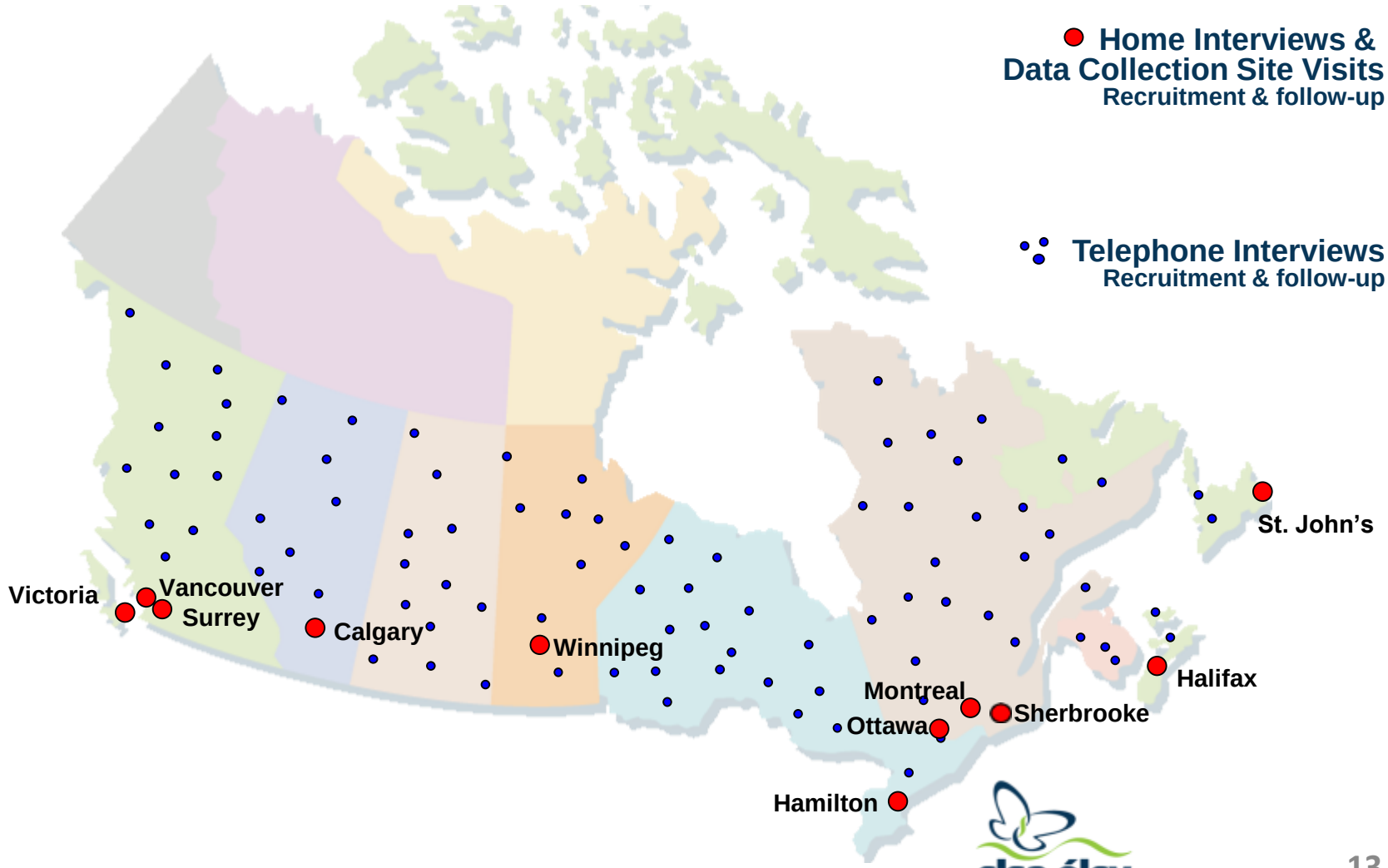
National in Scope



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Defining the cohort

- Men and women living in any of 10 provinces in Canada aged 45-85 at recruitment
  - Capturing baby boomers (born between 1946-1964) plus members of the “silent” generation (i.e. those born before 1945)

Recruiting the Cohort

1. Partnership with Statistics Canada
   - Canadian Community Health Survey 4.2 Healthy Aging (2008-09) CCHS 4.2
     - CCHS participant agreement to share contact information with the CLSA – *a first for Statistics Canada*
2. Partnership with provincial Ministries of Health (MOH)
   - Health Card Registration databases
   - Mailouts, return Consent-to-Contact form, CLSA follow up
3. Random Digit Dialing
   - Leger Marketing and CLSA CATI

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Cohort Exclusion Criteria at Baseline

Driven by CCHS 4.2 exclusion criteria 1. to 5.

1. Residents of the 3 territories
   - Northwest Territories, Nunavut, Yukon
2. Living in an institution
3. Living on a First Nation Reserve
4. Full time members of the armed forces
5. Temporary visa holders

CLSA Added Criteria

- Cognitively impaired (at baseline)
- Unable to communicate in French or English

1 to 5 exclude <4% of the target population

Terminology

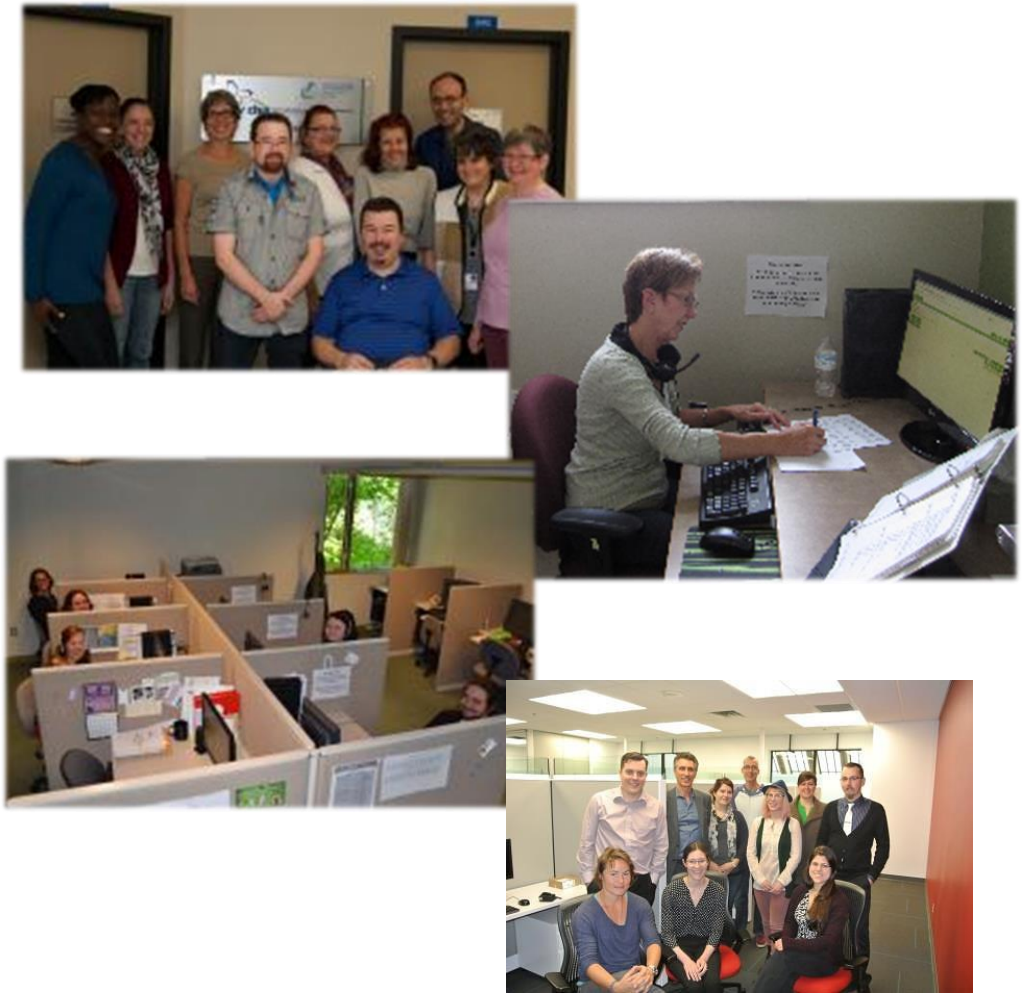
- Tracking Cohort
  - Target - 20,000 participants from all 10 provinces, followed through Computer Assisted Telephone Interviews (60 minutes at baseline)
  - **21,241 recruited***
- Comprehensive Cohort
  - Target - 30,000 participants living within 25 km (or 50 km) of a CLSA Data Collection Site (DCS)
  - Followed through in-home interviews (60 minute) and physical assessments (2-3 hours) at a DCS
  - **30,097 recruited***

What does recruited mean?

Recruiting and Data Collection

Infrastructure

4 Computer Assisted Telephone Interview Sites



UNIVERSITÉ DE SHERBROOKE

DALHOUSIE UNIVERSITY
Inspiring Minds

UNIVERSITY OF MANITOBA

SFU SIMON FRASER UNIVERSITY
ENGAGING THE WORLD

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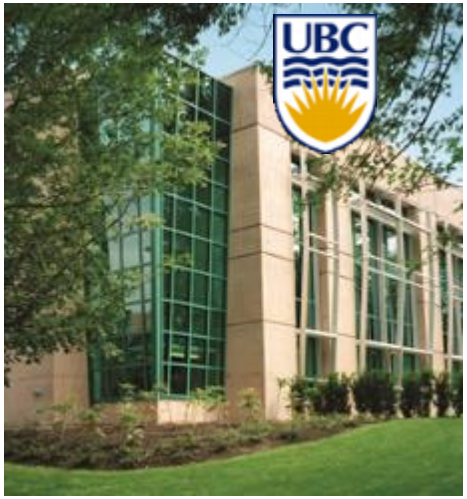
Four Enabling (Support) Units

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

Biorepository and Bioanalysis Centre (BBC)

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- Central location for storage and analysis of the biological samples
  - 31 nitrogen freezers (-190°C)
  - Storage for 5 million aliquots
  - Dry storage, humidity controlled, room temperature
- Research laboratory dedicated to detailed sample analysis
  - High-throughput robotic platform for biomarker analysis

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11 Data Collection Sites (DCS)

3,000 per full site

1. Simon Fraser U + UBC (split sites)
2. U Victoria
3. U Calgary
4. U Manitoba
5. U Ottawa
6. McMaster U
7. McGill U
8. U de Sherbrooke
9. Dalhousie U
10. Memorial U

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Study Content and Data Collection

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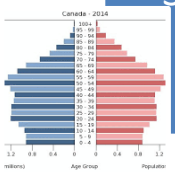
Questionnaire modules
All 51,338 participants

Demographic

- Education
- Marital status
- Sexual orientation
- Language
- Ethnicity
- Smoking, alcohol
- Nutritional risk
- Physical activity
- Health care utilization
- Medication use
- Supplement use



Health

- General health
- Chronic conditions
- Disease symptoms
- Sleep
- Oral health
- Injuries, falls
- Mobility
- Pain, discomfort
- Functional status
- ADL, IADL
- Cognition
- Mental Health
- Depression
- PTSD
- Life Satisfaction

Social

- Social
  - networks
  - support
  - Participation
  - inequality
- Online communication
- Care receiving
- Care giving
- Labour force participation
- Retirement planning
- Retirement status
- Transportation
- Mobility, Migration
- Built environments
- Home ownership

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Additional Objective Assessments (30,097 of 51,338)

Basic Measures

- Height
- Weight
- Hip Circumference
- Hearing
- Vision

Function

- Timed-up-and-go
- Standing balance
- 4 metre walk
- Chair rise
- Hand grip strength
- Neuropsychological testing

Physical Measures

- Blood pressure
- Spirometry
- Carotid ultrasound
- ECG
- DEXA
- Blood sample
- Urine Sample
- Tonometry
- Fundus photography

At The Data Collection Site

Reception
Registration: Bar code
Contraindications check

Measurement Room I
Height, weight
Blood pressure
Spirometry
Carotid ultrasound
ECG

Measurement Room 2
DEXA

Measurement Room 3
Visual acuity
Fundus photograph
Ocular pressure
Grip strength
Neuropsych Part I

Hallway
Timed Up and Go
Four metre walk
Balance test

Measurement Room 4
Hearing
Disease Symptoms Q
Neuropsych Part II

Washroom
Urine sample

Phlebotomy Room
50 ml blood draw

Check out
Selected Results
Snack
$30

TOTAL TIME
2.5 – 3 HRS

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First Follow Up
2015-2018

First Follow-Up: New Content Added

- *Child maltreatment
- **Elder abuse
- Epilepsy screening
- Decedent interview
- Unmet health-care needs
- Preventive health behaviours (screening, vaccination, etc)
- Enhanced hearing, oral health and transportation modules
- Gender identity questions
- Subjective cognitive decline
- Loneliness

*Childhood Experiences of Violence Questionnaire. Walsh et al 2012
**National Initiative for the Care of the Elderly (NICE)

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Follow up considerations

- Keeping participants engaged
- Tracing participants who have moved
- Attention to changes in life circumstances that may affect ability to participate
  - Cognitive, sensory, mobility impairment
- Ensuring that changes in content permit the ongoing examination of transitions and trajectories

First Follow Up (2015-2018) – Status

- 1st follow up Tracking
  - Re-contacting 21,241 participants for follow up telephone interviews
    - ~ 9,600 completed
- 1st follow up Comprehensive
  - Re-contacting 30,097+ participants for follow up in-home interviews and DCS visits
    - As of last week ~18,200

- Losses to date:
  - Deaths 1047
  - Withdrawn - 1947

Passive Data Collection Work in progress

- Linkage is an important CLSA strategy
  - Great potential for collecting information that is difficult to get from participants due to time, accuracy limitations; and/or may even be unknown to participants
  - Potential to obtain historical data prior to CLSA entry
- Types of databases
  - Individual level administrative provincial health databases
  - Vital statistics/disease registries
  - Population level databases of community characteristics, climate, pollution

Baseline Demographics

CLSA Participant Recruitment From 3 Sampling Frames

Sampling Frame	Tracking	Comprehensive	Total
CCHS 4.2 Healthy Aging	3,923	0	3,923
Provincial Ministry of Health Mailouts	3,810	4,129	7,939
Random Digit Dialing	13,508	25,968	39,476
Total	21,241	30,097	51,338

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CLSA Participants by Province unweighted

Province	Tracking	Comprehensive	Total
British Columbia	2613 (12.3)	6254 (20.8)	8867 (17.3)
Alberta	2103 (9.9)	2958 (9.8)	5061 (9.9)
Saskatchewan	1382 (2.7)	0	1382 (2.7)
Manitoba	1477 (7.0)	3114 (10.4)	4591 (9.0)
Ontario	4705 (22.2)	6417 (21.3)	11122 (21.7)
Quebec	**3601 (17.0)**	**6057 (20.1)**	**9658 (18.8)**
New Brunswick	1355 (2.6)	0	1355 (2.6)
Nova Scotia	1546 (7.3)	3075 (10.2)	4621 (9.0)
Prince Edward Island	1138 (2.2)	0	1138 (2.2)
Newfoundland	1251 (5.9)	2219 (7.4)	3470 (6.8)

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Socio-demographic Characteristics unweighted

	Tracking	Comprehensive	Total N=51,338
Age			
45-54	5826 (27.5)	7596 (25.2)	13422 (26.2)
55-64	6563 (31.0)	9863 (32.8)	16426 (32.0)
65-74	4634 (21.9)	7363 (24.5)	11997 (23.4)
75-85	4148 (19.6)	5272 (17.5)	9420 (18.4)
Sex			
Male	10796 (51.0)	15310 (50.9)	26106 (50.9)
Female	10375 (49.0)	14784 (49.1)	25159 (49.1)
Language			
English	17423 (82.3)	24291 (80.7)	41714 (81.4)
French	3748 (17.7)	5803 (19.3)	9551 (18.6)
Born in Canada	18455 (87.2)	24644 (81.9)	43099 (84.1)

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Data Access
Baseline Data ONLY

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Data and Bio specimen Access

- The CLSA was designed as a research study but is funded as a research platform
- Data and biospecimens available to the research community
- Who:
  - Researchers based in academic settings and research institutes in Canada and *elsewhere can apply
  - Graduate students and postdoctoral fellows based at Canadian institutions or trainees studying elsewhere funded by a Canadian agency
- *As yet, biospecimens cannot be released to researchers outside Canada

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What do you get?

- Alphanumeric data on all 51,338 participants
  - Raw data
- De-identified open text for selected variables
- Technical documentation
- Sampling weights

Data Access Steps

Application process via access@clsa-elcv.ca

1. Submit application (pre-set deadlines) **Next deadline is June 12, 2017**
2. Administrative and Statistical Review
3. Review by Data and Biospecimen Access Committee
4. Notification of applicant
5. CLSA Access Agreement preparation and signatures, ethics approval
   - Security, confidentiality and scientific requirements
6. Raw data provided to approved applicant

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How much does it cost?

- Costing
  - *Partial* Cost Recovery Model
- Alphanumeric data
  - $3,000 for a straightforward alphanumeric dataset
  - Graduate student - No cost for dataset to be used solely for thesis research
  - Postdoctoral fellow – No cost for one dataset to be used solely for the postdoctoral project
- Bio specimen costing
  - In development

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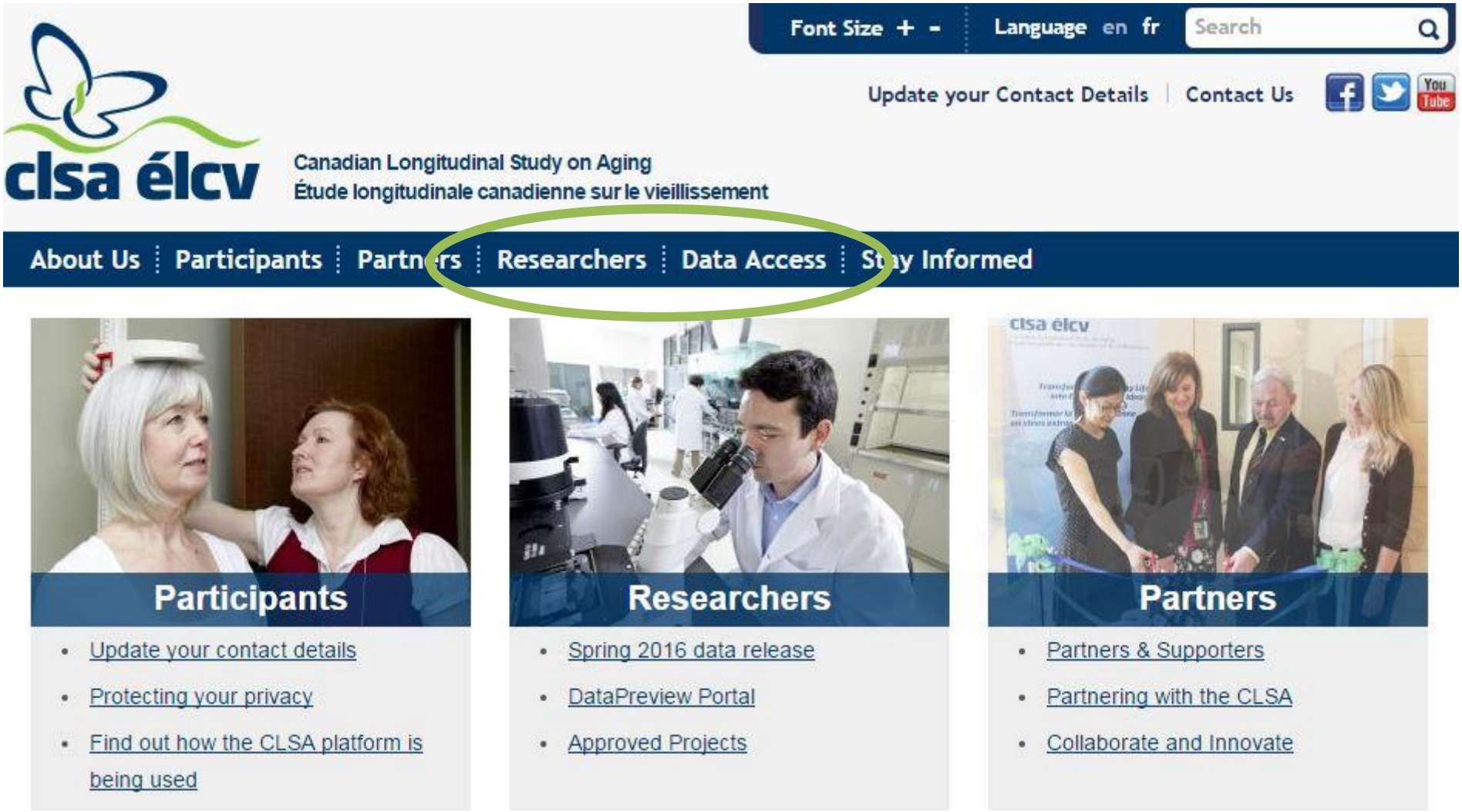

Tools for Researchers

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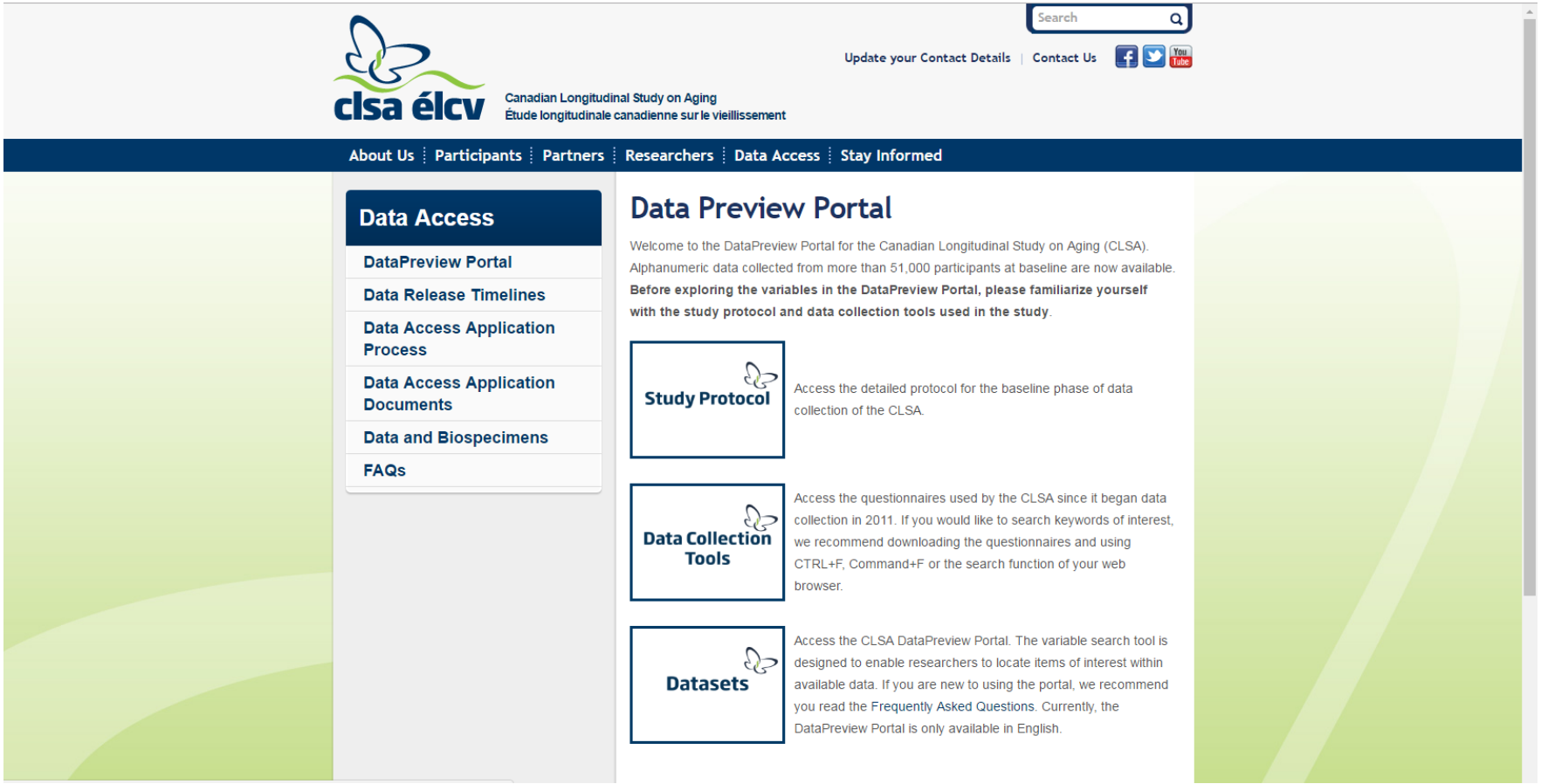
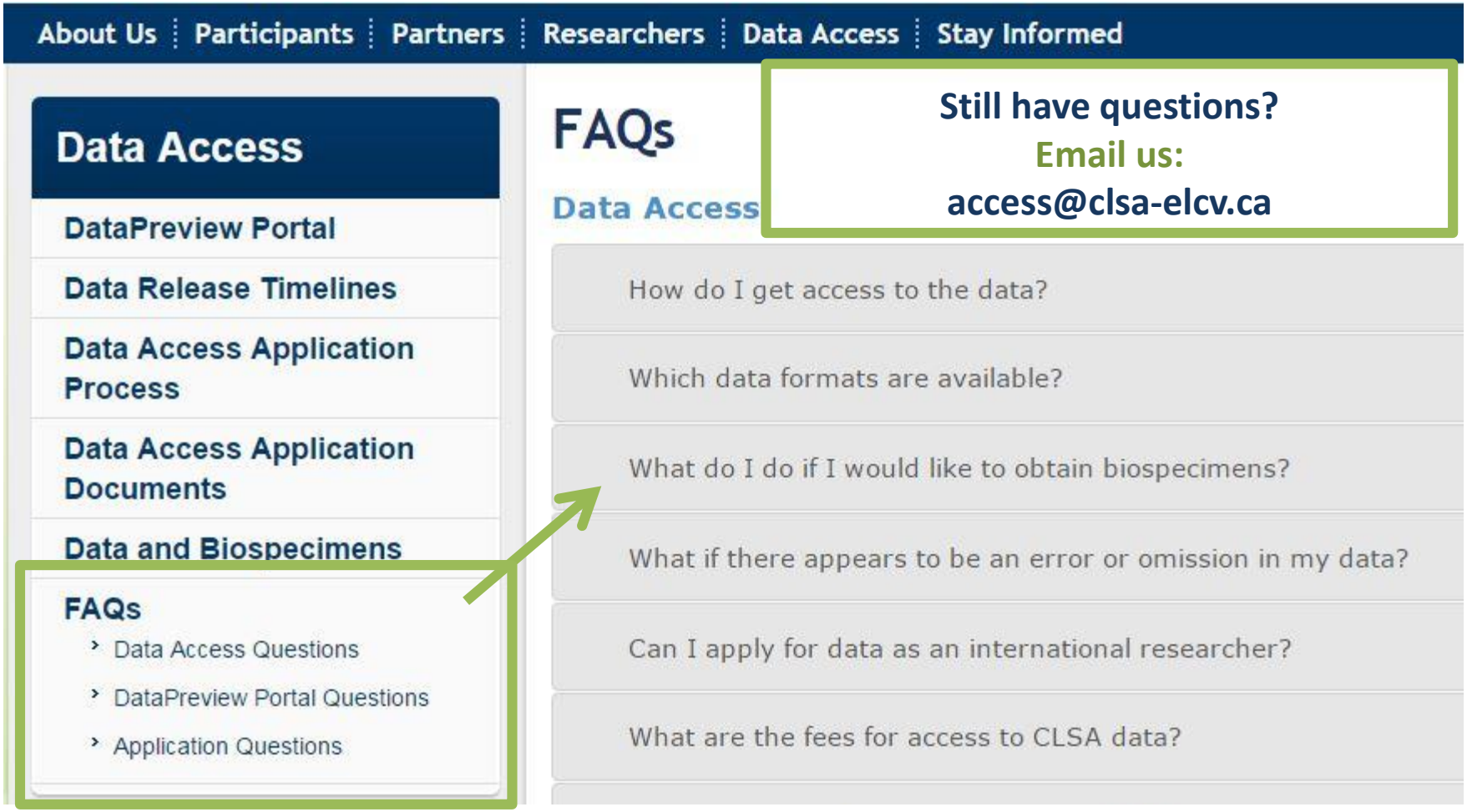
Data Preview Portal



Need More Information?



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Take Home Messages

- This large cohort was designed, assembled and data collection is ongoing
  - Baseline data and biospecimens have been collected
- Alphanumeric data from questionnaires, physical assessments and basic hematology results on 51,338 participants from across Canada are now available
  - These data are free for student thesis research and for postdoctoral fellow projects

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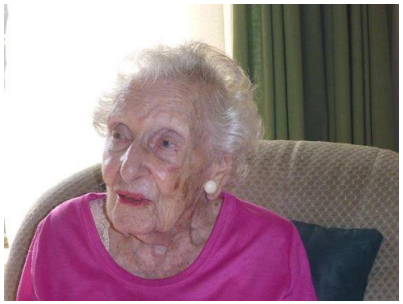
You've achieved your
learning objective.

Acknowledgements CLSA Montreal



- **Data Collection Site**
  - Josee Mayer(Manager)
  - Katya Lopez
  - Sanjivlall Balgobin
  - Jessica Noseworthy
  - Mario Polosa
  - **In home Interviewers**
  - Amy Striemer
  - Yan Romanesky
  - Elizabeth Grou

- **Statistical Analysis Centre**
  - Dr. Isabel Fortier -(Assoc Director)
  - Dr. Istvan Molnar-Szakacs (Data Access Officer)
  - Sarah Youssef (Sr. Data Curator)
  - Khaled Boulsaien (Data Curator)
  - Dr. Geva Maimon (Statistician)
  - Jennifer Uniat (Manager, on leave)
  - Bin Zhu (PT Statistician)
  - Caterina DeLeo (PT Research assistant)
  - Philippe Boileau (PT Assistant)
  - Claire Heffernan (summer student)
  - Norah Finn (biostatistics intern)
- **Translation**
  - Marie-Eve Veilleux (Coordinator)
  - Laurie Torres (Assistant)
- **Administration**
  - Karen Zabowski

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