





The webinar on the update of the CLSA will begin shortly

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CLSA Webinar Series



Dr. Susan Kirkland

An update to the research community on the CLSA: Where are we now and what's next for Canada's premier study on aging

1 - 2 p.m. ET | Sept. 23, 2015

The Canadian Longitudinal Study on Aging has achieved numerous milestones in the past year. Recruitment and baseline data collection for more than 50,000 participants has been completed. Versions 1.0 and 2.0 of the Tracking data are currently available for use by the research community. The Canadian Institutes of Health Research has awarded \$41.6 million in funding to continue the study for the next five years, and the first follow-up wave of data collection has begun. Join Dr. Susan Kirkland, CLSA co-principal investigator and professor in the Departments of Community Health & Epidemiology and Medicine at Dalhousie University in Halifax, for an update on the progress of the CLSA, including descriptive statistics of study participants at baseline, how the second wave of data collection is being rolled out, future availability of Comprehensive data and biospecimens, and how CLSA data can be used to inform a wide range of research projects.

Register online at http://bit.ly/clsawebinars

Webinars will be broadcast using BlackBoard Further instructions will be sent by email













THE CANADIAN LONGITUDINAL STUDY ON AGING

An update to the research community on the CLSA: Where we are now and what's next for Canada's premier study on aging

Presented by

Susan Kirkland, PhD
Dalhousie University, Halifax

on behalf of

Christina Wolfson, PhD, McGill University, Montreal Parminder Raina, PhD, McMaster University, Hamilton and the CLSA Research Team

Overview of Presentation

- Review of study design
- Renewal funding
- Recruitment milestones achieved
- Snapshot of CLSA participants at baseline
- First follow up (FU1)
 - Protocol and content changes
 - Accommodation and retention strategies
 - ELS Issues
- Data Access
- Questions



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 coinvestigators 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

The CLSA Vision

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.







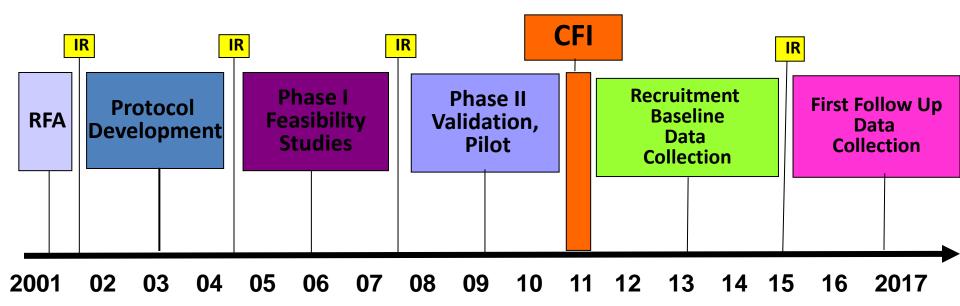
Timeline and Milestones

Team
Design
Objectives
Content

Acceptability
Bio-specimens
Recruitment
Data Linkage

Pilot recruitment Validate measures SOPs, TMs Pilot protocol

Data Collection Data Cleaning Data Release





Study Design and Methodology



Design Overview

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

Tracking (20,000)
Randomly selected
10 provinces

Comprehensive (30,000)
Randomly selected
25-50 km of 11 sites in 7 provinces

Questionnaire
• By telephone (CATI)

QuestionnaireIn person, in home (CAPI)

Physical Assessments
Blood, Urine
At Data Collection Site

20 year study: Full follow up every 3 years, maintaining contact in between

Data Linkage



National Scope



Recruitment Sampling Frames

- Partnered with Statistics Canada
 - CCHS 4.2 Healthy Aging Survey
 - 2006 Census as an area frame to select households
 - Agreed to share contact information
- Partnered with provincial Ministries of Health
 - Health Card Registration databases
 - Mailouts, return Consent to Contact form
- Supplemented with Random Digit Dialing
 - Pre-recruitment, agree to recontact



Standardized Paperless Process

Pre-recruitment

Participants
Consent to
Participate in
CLSA





-Blood

- Urine



DATA COLLECTION SITE VISIT Physical/Neuropsychological Data



n=20,000 Telephone n=30,000 Interview

Home Interview





Stored at
Biorepository and
Bioanalysis
Centre



Data Stored at
Statistical
Analysis Centre
and disseminated
to researchers

Questionnaire data processing



Depth and Breadth of CLSA Questionnaire modules

- DEMOGRAPHIC
- Education
- Marital status
- Ethnicity
- HEALTH BEHAVIOURS
- Smoking, alcohol
- Nutritional risk
- Food frequency
- Physical activity
- Health care utilization
- Medication use
- Supplement use
- HEALTH STATUS
- General health
- Women's health
- Chronic conditions, symptoms
- Oral health

- PHYSICAL
- Injuries, falls
- Mobility
- Pain, discomfort
- Functional status
- ADL, IADL
- PSYCHOLOGICAL
- Cognition—Executive function, memory, psychomotor speed
- Depression
- Mood
- 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

Depth and Breadth of CLSA Physical Assessment Modules

- Height, weight, BMI
- Blood pressure
- Spirometry FEV
- Carotid ultrasound CIMT
- ECG heart rate, rhythm
- DEXA BMD, body composition, aortic calcification
- Hearing
- Visual acuity
- Grip strength

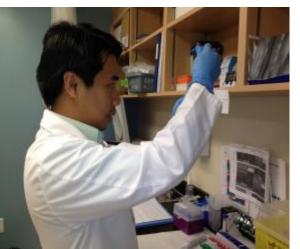
- Fundus photograph blood flow
- Tonometer ocular pressure
- Neuropsych battery memory, executive function, reaction time
- Timed up and go
- Balance
- 4 metre walk
- Chair rise
- Blood
- Urine

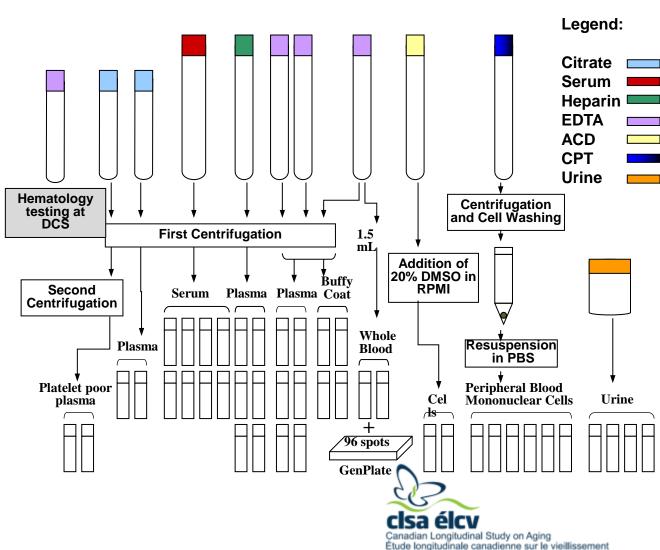




Bio specimen processing 42 aliquots per participant

- Basic hematological tests completed on site
- Remainder processed, frozen within 2 hrs



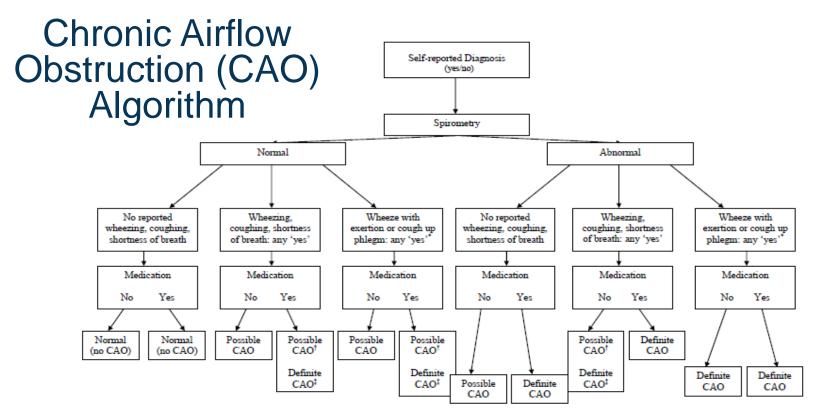


Biorepository and Bioanalysis Centre (BBC)



- 31 nitrogen freezers (-180°C)
 - Space for 5 million aliquots
- Personal Archive
 - Dry storage, humidity controlled, room temperature
- Laboratory Information System (LabWare)
 - Sample tracking system, QC
- High-throughput robotic platform for biomarker analysis

Disease outcomes via algorithms



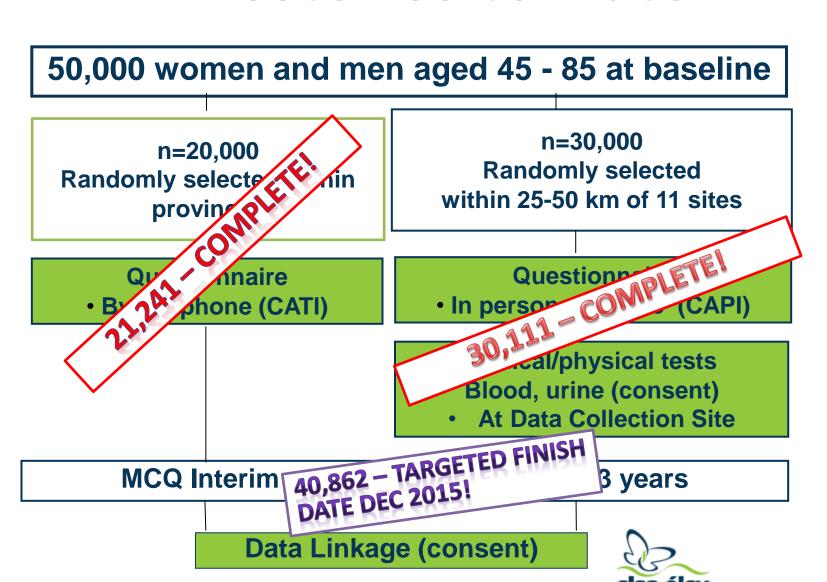
eFigure 1c: Chronic Airflow Obstruction Algorithm. CAO = chronic airflow obstruction. If participant coughs without phlegm, then outcome will be possible CAO. Outcome when self-reported diagnosis = no. Outcome when self-reported diagnosis = yes.



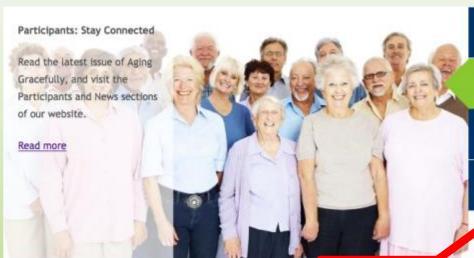
Key Milestones



Milestones to Date



Canadian Longitudinal Study on Aging Étude longitudinale canadienne sur le vieillissement



Researchers: Data Access

Participants: Stay Connected

Learn more about the CLSA

Watch our videos

Our Mission

Transforming everyday life into extraordinary ideas

The Canadian Longitudinal Study on Aging (CLSA) is a lazer, national, long-term study that will follow approximately 50,000 men and women beautiful the ages of 45 and 85 for at least 20 years. The study will collect information on the changing biological, medical, psychological, social, lifestyle and economic aspects of people lives. These factors will be studied in order to understand how, individually and in combination, they have an impact in both maintaining health and in the development of disease and disability as people age. The CLSA will be one of the most comprehensive studies of its kind undertaken to date, not only in Canada but around the world.

<u>Dr. Parminder Raina</u> (McMaster University, Hamilton) is the lead principal investigator of the CLSA. <u>Dr. Christina Wolfson</u> (McGill University, Montreal) and <u>Dr. Susan Kirkland</u> (Dalhousie University, Halifax) are co-principal investigators of the CLSA. Drs. Raina, Wolfson and Kirkland, along with a team of more than 160 investigators and collaborators from several Canadian universities, have participated in the development of this innovative, interdisciplinary study.

51,352 Participants recruited

50,000 **goal**

News

Sign up for our newsletter

Sep

CLSA webinar series w

Webinars covering a broad range of topics related to the study of aging have been scheduled for this fall, with the first one on Sept. 23 providing an update to the research community on the Canadian Longitudinal Study on Aging.

Aug 13th

CLSA launches second wave of data collection

The next major round of data collection for

Tracking Data Release Version 2.0

Home

Datasets

A Canadian Longitudinal Study on Aging (Cl variables collected from participants at ea variable search tool is designed to eng within available data collected from

d describes ction. The ate items of interest

Currently, data emanating from completed the baseline 60

g participants who erviews are available

Datasets from future d available.

will be added as they become

Data collected site visit wil

e in-home interviews and data collections 16. Stay tuned!



>> Variable Search

Variables currently available in the first wave of the data rease, with filtering and search options.

Version 2.0 now available – includes cognition data!



en text variables not yet released.



> San pling weights

Description of sampling weights used in the CLSA.



Questionnaire

Baseline 60-minute Telephone Interview questionnaire (Tracking).



Study design of the Canadian Longitudinal Study on Aging (Tracking participants).



Renewal Funding

- Phase 2 Renewal Directed Grant awarded
 - 5 years 2015 2020
 - \$41.6 M for 86% of operating costs
 - Data collection for first follow up, 2/3 second follow up
 - Analysis of baseline biological samples: key biomarkers, genetic, epigenetic analyses
- CFI infrastructure amendment finalized
 - Added SFU CATI site
 - DCS@home equipment
 - Replacement equipment
 - NCC renovations







A Snapshot of CLSA Participants













CLSA Participant Recruitment From Sampling Frames

Sampling Frame	Tracking	Comprehensive	Total
CCHS 4.2 Healthy Aging	3,923	0	3,923
Provincial Ministry of Health Mailouts	3,810	4,135	7,945
Random Digit Dialing	13,508	25,913	39,421
NuAge Study	0	66	66
			51,355

Socio-demographic Characteristics Tracking and Comprehensive

	Tracking	Comprehensive	Total
	N=21,171	N=30,094	N=51,265
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			
Female	10796 (51.0)	15310 (50.9)	26106 (50.9)
Male	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)

CLSA Participants by Province Tracking and Comprehensive

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, Lab	1251 (5.9)	2219 (7.4)	3470 (6.8)

Chronic Conditions Tracking and Comprehensive

Chronic Condition	Trac	king	Comprehensive	
Osteoarthritis				
Knee	3406	(16.1)	4499 (15.2)	
Hand	2966	(14.1)	3852 (13.0)	
Hip	2075	(9.8)	2500 (8.4)	
Asthma	2340	(11.1)	3983 (13.3)	
COPD	1430	(6.8)	1725 (5.8)	
Hypertension	8065	(38.2)	11099 (37.1)	
Diabetes	3536	(16.7)	5311 (17.7)	
Heart disease	2170	(10.3)	3499 (11.7)	
Angina	1136	(5.4)	1323 (4.4)	
Heart attack	1303	(6.2)	1461 (4.9)	
Stroke	388	(1.8)	521 (1.7)	
Cataracts	5236	(24.8)	8607 (29.2)	
Mood disorder	3100	(14.7)	5140 (17.1)	
Cancers	3250	(15.4)	4680 (15.6)	
Osteoporosis	1998	(9.5)	2688 (9.0)	

Chronic Conditions by Age and Sex Tracking and Comprohensive

517

2663

1305

480

196

175

107

1364

2002

1238

1077

(6.1)

(31.6)

(15.5)

(5.7)

(2.3)

(2.1)

(1.3)

(16.3)

(23.7)

(14.7)

(12.8)

1022

6853

3372

1211

1524

430

(6.0)

(40.1)

(19.7)

(7.1)

(8.9)

(1.3)

511 (30.1)

1888 (11.0)

2936 (17.1)

522 (3.2)

2735 (16.0)

(18.8)(18.7)

(11.9)

(14.0)

(6.8)

(37.9)

(15.1)

(9.2)

(4.1)

(3.2)

(1.5)

(36.8)

(18.3)

(16.3)

2923 (16.7)

1198

6671

2657

1612

716

564

261

640

3220

2876

Tracking and Comprehensive					
Chronic Condition	45 – 64 Men	45 – 64 Women	65+ Men	65+ Women	
Osteoarthritis Knee	953 (12.1)	1467 (175)	2209 (13.0)	3276 (18.8)	

Chronic Condition	45 – 64 Men	45 – 64 Women	65+ Men
	141611	VVOITICIT	141611
Osteoarthritis			
Knee	953 (12.1)	1467 (17.5)	2209 (13.0)
Hand	612 (7.7)	1393 (16.6)	1549 (9.1)

418

2977

1513

842

336

501

111

968

1130

880

164

(5.3)

(37.5)

(19.1)

(10.6)

(4.2)

(6.3)

(1.4)

(12.3)

(14.2)

(11.1)

(2.1)

COPD

Hypertension

Heart disease

Heart attack

Diabetes

Angina

Stroke

Cataracts

Cancers

Mood disorder

Osteoporosis

Tracking and Comprehensive					
Chronic Condition	45 – 64 Men	45 – 64 Women	65+ Men	W	
Osteoarthritis					
Knee	953 (12.1)	1467 (17.5)	2209 (13.0)	3276	
Hand	612 (7.7)	1393 (16.6)	1549 (9.1)	3264	
Hip	437 (5.5)	877 (10.5)	1186 (7.0)	2075	
Asthma	856 (10.8)	1287 (15.3)	1714 (10.0)	2466	

Self Rated Health Tracking and Comprehensive

	Tracking	Comprehensive	Total
Self Rated General Health			
Excellent	3969 (18.8)	5991 (19.9)	9960 (19.5)
Very Good	8103 (38.3)	12423 (41.3)	20526 (40.1)
Good	6237 (29.5)	8872 (29.5)	15109 (29.5)
Fair	2218 (10.5)	2318 (7.7)	4536 (8.9)
Poor	623 (3.0)	467 (1.6)	1090 (2.1)
Satisfaction with Life			
Dissatisfied	2068 (9.8)	2971 (9.9)	5039 (9.8)
Neutral	849 (4.0)	1338 (4.5)	2187 (4.3)
Satisfied	18229 (86.2)	25752 (85.7)	43981 (85.9)



^{*} Limited age and sex differences



First Follow Up (FU1)

2015 - 2018



First Follow Up (2015-2018)

- 1st follow up Comprehensive (July 2015 June 2018)
 - Re-contacting 30,111 participants for their follow up in-home interviews and DCS visits
- 1st follow up Tracking (Oct 2015 June 2018)
 - Re-contacting 21,242 participants for their follow up telephone interviews
- MCQ (2015 2018)
 - All participants re-contacted at 18 months via phone



Preparing for Follow Up 1

NCC:



- Finalize questionnaires
- Re-programming software suite
- Optimizing IT infrastructure
- New software development
- Website
- Communications
- Programming content changes
- SOP updates

DCS/CATI:

- Pilot work
- Managing operations
- Quality Control
- Reviewing SOPs
- Staffing/Training

BBC:



- Sample storage
- Sample retrieval
- Updating LIMS processes
- Changes to protocols
- Quality Control
- Supporting DCS sites CPT tubes

SAC:

- Data cleaning
- Coding
- Variable naming
- Disease algorithms
- DataPreview Portal

WGs:

Update study content

FU1: Modifications to the protocol

- Questionnaire revisions
 - Delete some questions
 - Revise some questions to reflect time window
 - Add new content
- Decedent Questionnaire
- Proxy Questionnaire
- Accommodation strategies
- DCS@home
- Timing of when MCQ content administered



FU1: New content

- From working groups, partners
 - Elder abuse (PHAC)
 - Childhood maltreatment (PHAC)
 - Gender identity
 - Unmet health care needs
 - Preventive health behaviours
 - Workability
 - Loneliness
 - Subjective cognitive decline
 - Decedent Questionnaire



FU1: New Content

- Despite additional content, very little change in overall time to administer
- Deletion of questions that do not change/require repetition
- Questionnaire content removed from Maintaining Contact at 18 months
- Tracking: conduct in two interviews close together
- Comprehensive: content spread over in home, DCS visit

FU1: Ongoing consent

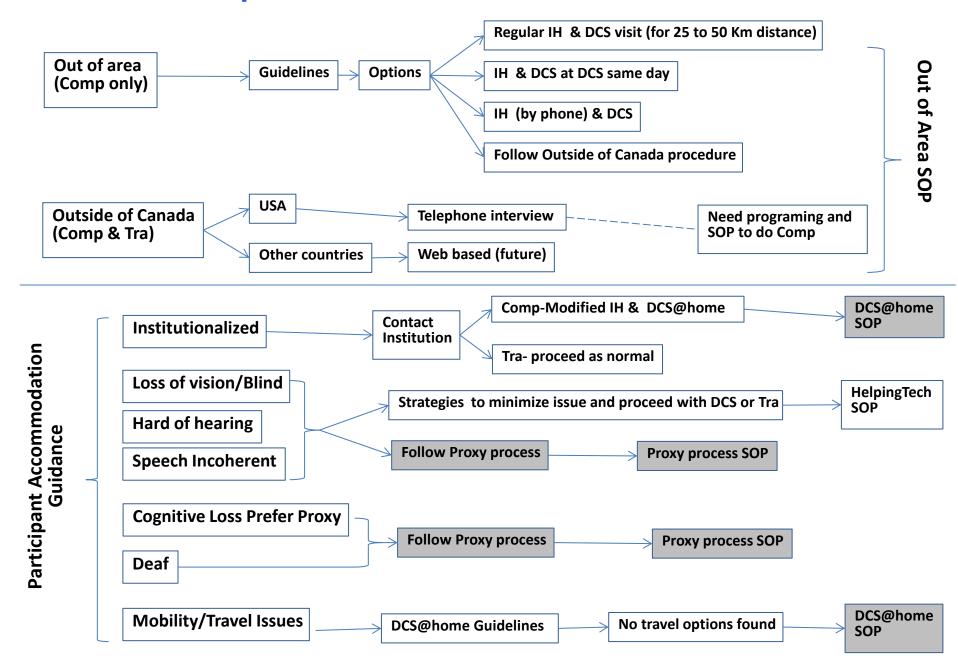
- Consent for continued participation is confirmed verbally at first contact (phone)
- Signed consent for significant changes to the protocol (in person or mailed)
 - HCN retrospective linkage
 - Decedent Questionnaire
 - Institutionalization



FU1: Retention and Accommodation Strategies

- Accommodation strategies developed to maintain long term participant retention in the face of changing circumstances
 - Migration out of area
 - Sensory losses: hearing, sight, speech
 - Mobility, travel challenges
 - Institutionalization
 - Cognitive decline
- Allows for flexible participation
- Baseline exclusion criteria no longer apply

Participant Retention Issues and Procedures



Comprehensive: DCS at Home

Full visit at the DCS



Accommodation:

DCS by Phone (if participant is willing to come for a full DCS visit at next follow up).



Accommodation: DCS AT Home



DCS at Home

Stadiometer 7 lbs 3 kg

> Tanita 30 lbs 14 kg



Other 35 lbs 16 kg

CLSA ELS Issues at FU1

- Use of proxies
- Identifying potential cognitive decline
- Withdrawal process



Use of Proxies

- As participants reach age 70, given Proxy Information Package and Consent to identify a proxy decision maker/information provider
- Consent includes an advance directive to indicate their preferences for future participation in the event that they are unable to make decisions, provide information on their own
- Participant asked to inform proxy of their role
- Documents developed with advice from ELSI
- Proxy information is verified with participant at FU1
- Proxy decision maker and information provider are contacted, proxy consent is initiated when the decision is made to utilize them
- Proxy Questionnaire



Participant Consent re Proxy

Should I become unable in the future to take part in the CLSA on my own:

Tracking and Comprehensive:

 I would like my proxy information provider to continue to answer the research questions asked by an interviewer on my behalf (Y/N)

Comprehensive:

- I would like to continue to do the physical tests as long as it is feasible (Y/N)
- If I have agreed to give blood and urine:
- I would like to continue to give blood and urine (Y/N)
- If I have agreed to give my health card number:
- I would like to continue to have my information collected by the CLSA linked with information about me in health care records (Y/N)

FU1: Identifying Cognitive Decline

- Validated Six Item Screener to be done at FU1 for all participants 70 and older
 - Delayed recall of three words (penny, table, apple)
 - What year is it?
 - What month is it?
 - What day of the week is it?
- For those who recall <=3/6, initiate conversation about comfort in continuing to answer on own, use of proxy
- Initiate proxy process as required
- In addition, option always available to initiate proxy discussion at the request of participant or discretion of interviewer
- Methodological work re neurocognitive battery

Process of Withdrawal

- Multiple complex considerations related to options for future use of data, samples and data linkage
- For Tracking: Questionnaire, linkage using HIN
- For Comprehensive: In home interview and DCS visit, blood and urine, linkage using HIN
- Withdrawal can occur at multiple points (e.g. call to help line, during interview) and via multiple mechanisms (e.g. phone, mail, email)
- De-link option permanently destroys the link between the participant's identifying information and their data
- Scripts developed regarding options in consultation with ELSI, REBs

Etude longitudinale canadienne sur le vieillissement

Data Access



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 unique resources that must be used optimally to support research to benefit all Canadians.



Data Release Timelines

Tracking

- Questionnaire data, cognition available now
- Occupation, medications next release
- MCQ early 2016

Comprehensive

- Questionnaire data first release
- MCQ data second release
- Simple clinical data third release
- Complex clinical data fourth release
- Biosamples, biosample data fifth release

Biomarker and epigenetic analyses

- Complete Blood Count (analysis at DCS) 2nd Comprehensive data release – Tentative release date early 2017
- Proposed panel of biomarkers: albumin, ALT, creatinine, CRP, ferritin, hemoglobin A1C, lipids (cholesterol, HDL, Triglycerides, LDL), thyroid stimulating hormone, free T4, 25-hydroxyvitamin D
 - N~30,000 (Calgary Laboratory Services)
- Proposed genotyping: Affymetrix UKBiorepository array assay 820,967 SNPs
 - n=10,000 (McGill Genome Centre)
- Proposed epigenetic analysis: targeted age-associated CpG methylation using pyrosequencing and Sequenom EpiTyper

de longitudinale canadienne sur le vieillissement

- n=5,000 (UBC Genetics and Epigenetics Centre)
- Tentative release date 2018

Data Access Steps: Tracking

Application process via CLSA DataPreview portal

- Administrative Review
- Data and Sample Access Committee Review
- Recommendation to Scientific Management Team
- Notification of applicant
 - Steps 1 to 4 take 3-4 weeks
- CLSA Access Agreement preparation and signatures
 - Institutional review/signature timing is unpredictable
- Raw data provided to approved investigator
 - Takes 5 working days following completion of step 5

access@clsa-elcv.ca



Data Access Costing

Tracking

- Cost Recovery
- \$1,000 for baseline Tracking dataset
- No cost for data for graduate student theses

Comprehensive

- Much more complex guidelines under development
- Questionnaire data more extensive
- Clinical data
- Biosamples biomarkers, genetics
- For grant submissions, early consultation

Quarterly submission deadlines to DSA

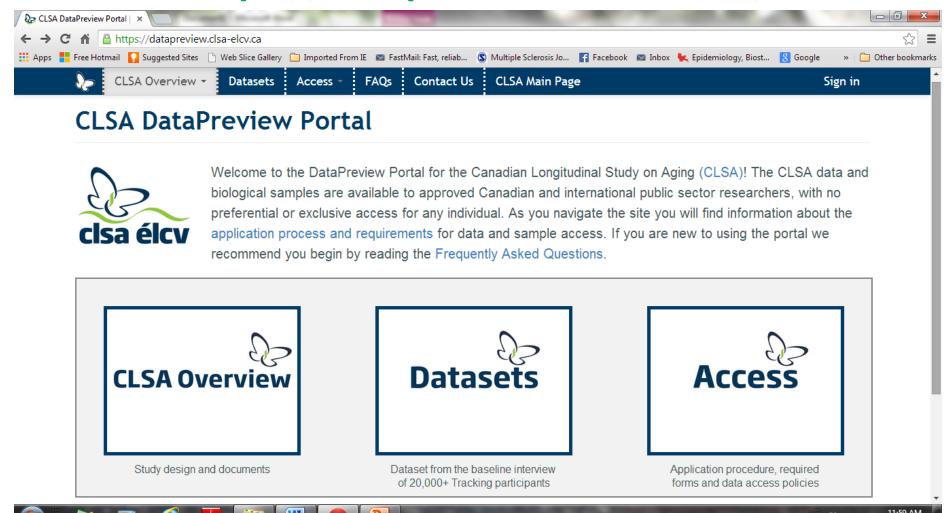
Canadian Longitudinal Study on Aging Étude longitudinale canadienne sur le vieillissement

Potential for Ancillary Studies

- YES, but...
- Anything added to participant data collection has to be incorporated as core component of the CLSA
- Can only add elements at the beginning of each follow up wave
- Vetted through working groups
- Must be a priority for CLSA, logistically feasible, bring funding
- No exclusive right to data
- Ancillary policy to be posted on website 2016

DataPreview Portal

https://datapreview.clsa-elcv.ca/





The Research Team

U Victoria: Debra Sheets, Lynne Young, Holly Tuokko

UBC: Max Cynader, Michael Kobor, Theresa Liu-Ambrose

SFU: Andrew Wister, Scott Lear

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Lauren Griffith, Harry Shannon

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U Sherbrooke: Hélène Payette, Benoit Cossette

Dalhousie U: Susan Kirkland

Memorial U: Gerry Mugford, Patrick Parfrey

U Waterloo: Mary Thompson, Changbao Wu, Mark Oremus

+ Scientific Working Groups and Co-Investigators www.clsa-elcv.ca



CLSA Research Team

Operations Committee and Scientific Leads







Transforming Everyday Life into Extraordinary Ideas



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CLSA Funders and Partners



















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CLSA funded by the Government of Canada through CIHR and CFI, and provincial governments and universities

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CLSA Webinar Series



Dr. Brent Richards

The Genetics of Osteoporosis: An aging-related disease

12 - 1 p.m. ET | Oct. 19, 2015

Most aging-related diseases are partially heritable, and osteoporosis is particularly so, with genetic factors explaining approximately 80% of variation in bone mineral density, and 50% of fracture risk. Dr. Brent Richards, an endocrinologist and genetic epidemiologist at the Jewish General Hospital of McGill University, will dsicuss recent advances in whole-genome sequencing programs, and genome-wide genotyping approaches to understand genetic determinants of osteoporosis. The utility of such approaches and potential ways to use emerging genome-wide genotyping within the CLSA to address clinically relevant questions such as identifying the genetic determinants of common aging-related diseases, will also be explained. The CLSA has recently received funds to genome-wide genotype 10,000 study participants, which will enable researchers using CLSA data to lead global genetic efforts.

Register online at http://bit.ly/clsawebinars

Webinars will be broadcast using BlackBoard Further instructions will be sent by email







