The Canadian Longitudinal Study on Aging: A Platform for Studying Transitions and Trajectories of Aging and Health

Christina Wolfson, PhD, McGill University, Montreal
on behalf of
Parminder Raina, PhD, McMaster University, Hamilton
Susan Kirkland, PhD, Dalhousie University, Halifax
and the CLSA Research Team

Canadian Longitudinal Study on Aging (CLSA)

- A CIHR strategic initiative
- 50,000 Participants from across Canada
- Aged 45-85 at recruitment
- 20 year follow up with major data collection every 3 years
- More than 160 researchers in 26 institutions

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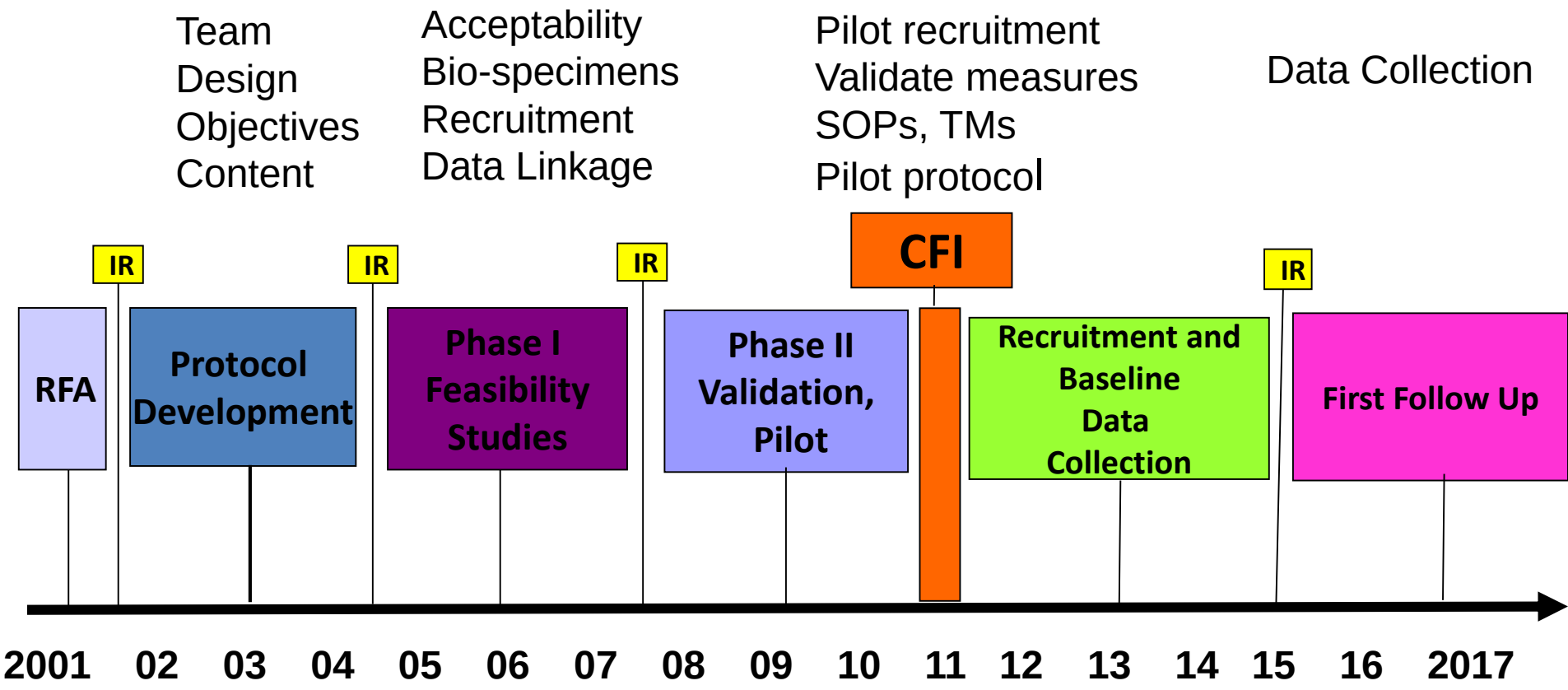
The CLSA Research Platform
Vision and Scientific Aim

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.

Scientific Aim: To study aging as a dynamic process, examining the inter-relationships among intrinsic and extrinsic factors from mid-life to end-of-life

Timeline and Milestones



IR **International peer review**

Research Team

(Co-PIs, Site PIs, Working Group leaders)

U Victoria: Debra Sheets, Lynne Young, Holly Tuokko
UBC: Max Cynader, Michael Kobor, Theresa Liu-Ambrose
SFU: Andrew Wister, Scott Lear
U Calgary: David Hogan, Marc Poulin
U Manitoba: Verena Menec, Phil St. John
McMaster U: Cynthia Balion, Christopher Patterson, Parminder Raina, Lauren Griffith, Harry Shannon
U Ottawa: Larry Chambers, Vanessa Taler
McGill U: Christina Wolfson, Ron Postuma
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
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Major support for the Study and the Platform*

Development: 2002-2009

- CIHR, FRSQ, Universities

Platform: 2009-2014

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

Operations: 2009-2015

- CIHR 2009-2015
  - 86% of required funds

Analysis of data/biospecimens

- No Funding

First Follow-up: 2015-20

- CIHR 2015-2020
  - (86%)
  - Maintaining the platform
  - Analysis of selected baseline biomarkers

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

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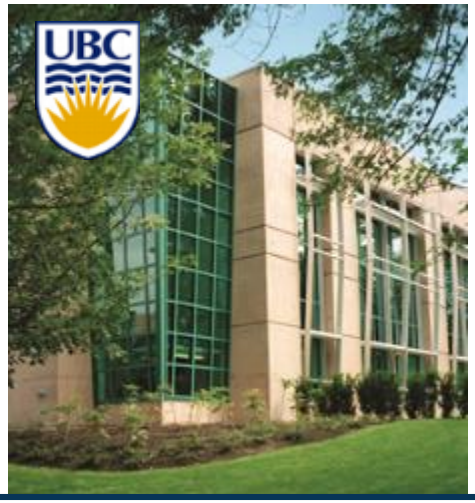
Infrastructure

4 "Enabling" Units

National Coordinating Centre (NCC)
Director: Parminder Raina

McMaster University

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

INNOVATION.CA
CANADA FOUNDATION FOR INNOVATION | FONDATION CANADIENNE POUR L'INNOVATION

CLSA Infrastructure

11 Data Collection Sites

SFU SIMON FRASER UNIVERSITY ENGAGING THE WORLD

UBC a place of mind THE UNIVERSITY OF BRITISH COLUMBIA

University of Victoria

UNIVERSITY OF CALGARY

UNIVERSITY OF MANITOBA

uOttawa

Soins continus Bruyère Continuing Care | Institut de recherche Bruyère Research Institute
Affilié à l'Université d'Ottawa
Affiliated with the University of Ottawa

McMaster University

McGill

Institut de recherche Centre universitaire de santé McGill | Research Institute McGill University Health Centre

UNIVERSITÉ DE SHERBROOKE

DALHOUSIE UNIVERSITY
Inspiring Minds

MEMORIAL UNIVERSITY

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CLSA Infrastructure

Telephone Interview Centres*

*University of Victoria CATI until 2015

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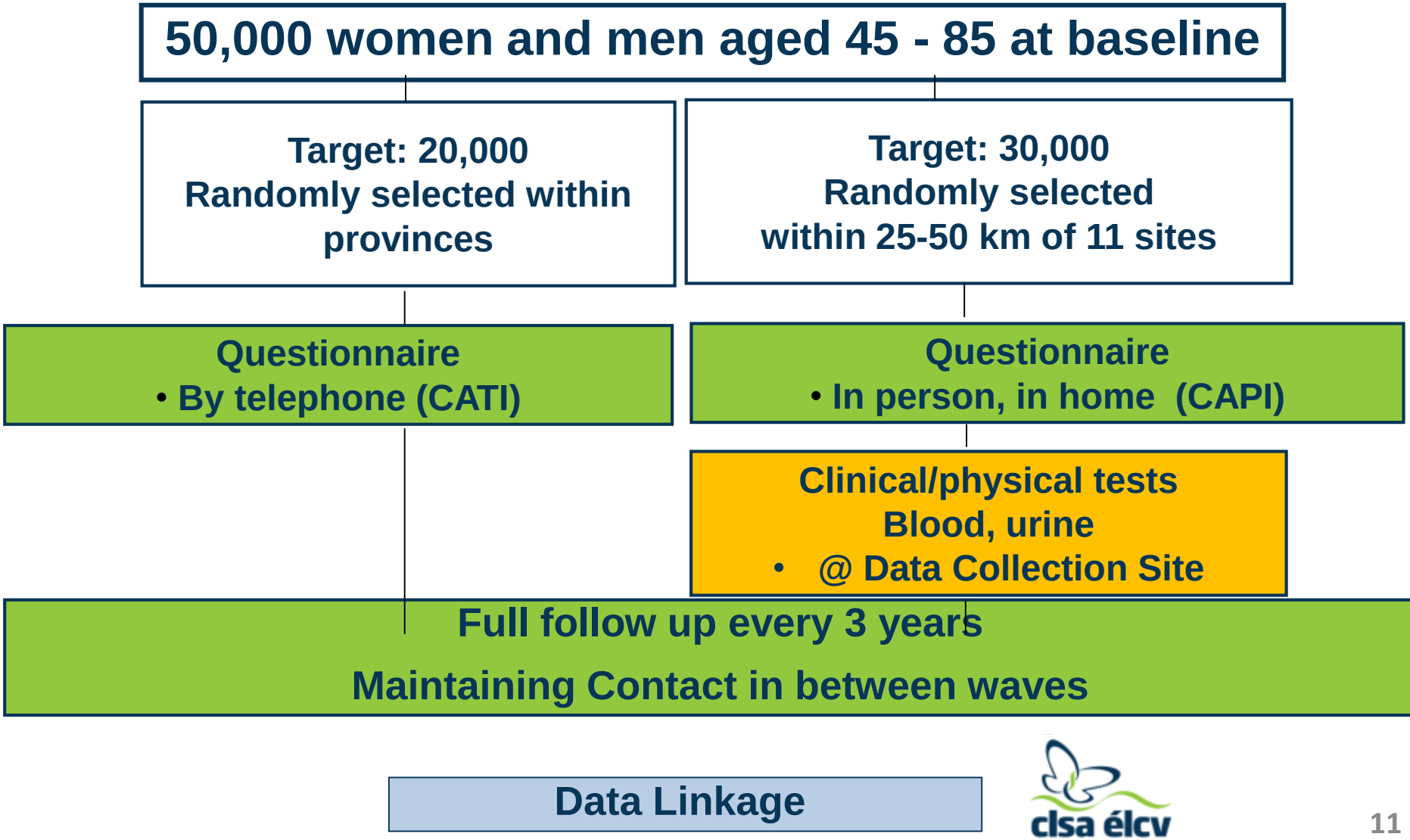
Methods

Design Overview



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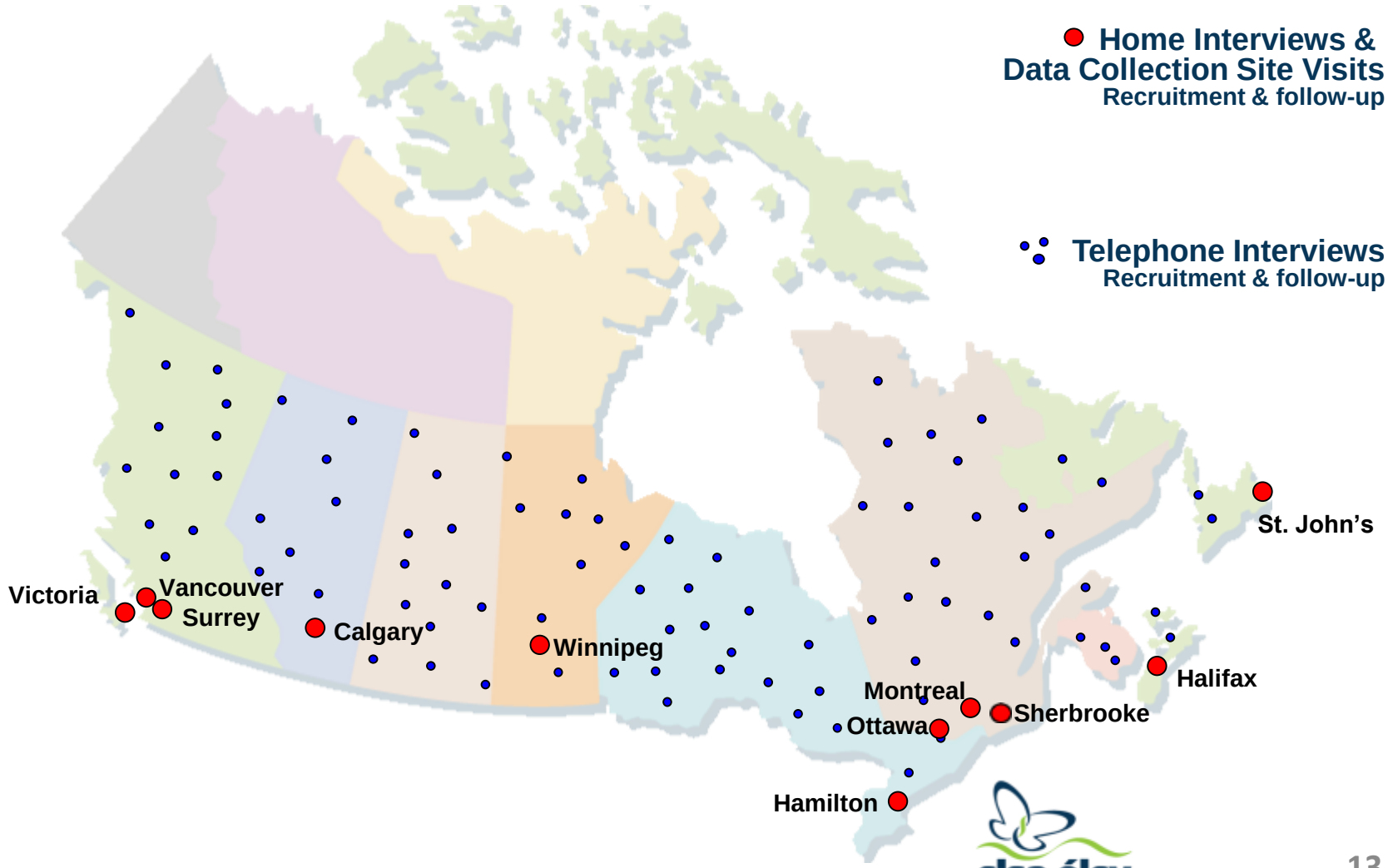
Terminology

- Tracking Cohort
  - Target of 20,000 participants from all 10 provinces, followed through Computer Assisted Telephone Interviews (60 minutes)
- Comprehensive Cohort
  - Target of 30,000 participants living within 25 km (or 50 km as required) of a CLSA Data Collection Site
  - Followed through inhome interviews (60 minute) and physical assessments
- Maintaining Contact Interview
  - All 50,000 computer assisted interview (30 minutes)
  - 18 months after baseline

National Scope



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Recruitment: Multiple Sampling Frames

1. Partnership with Statistics Canada
   - CCHS 4.2 Healthy Aging Survey Content Development
     - 2006 Census as an area frame to select households
   - Agreement to share contact information
2. Partnership with provincial Ministries of Health (MOH)
   - Health Card Registration databases
   - Mailouts, return Consent-to-Contact form
3. Random Digit Dialing
   - Pre-recruitment

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Exclusion Criteria

Based on CCHS exclusion criteria

- Residents of the 3 territories
  - i.e. Northwest Territories, Nunavut, Yukon
- Living in an institution
- Living on First Nations Reserves
- Full time members of the armed forces
- Temporary visa holders
- Cognitive impairment
- Unable to communicate in French or English

Baseline Content development

Scientific Management Team and Content Working Groups

SMT

- Parminder Raina
- Christina Wolfson
- Susan Kirkland
- Lauren Griffith
- Mark Oremus
- Ine Wauben

CWGs

- Clinical – Chris Patterson
- Biology – Cynthia Balion
- Lifestyle – Hélène Payette
- Social – Andrew Wister
- Health Services – Verena Menec
- Psychology – Holly Tuokko
- Methodology –Harry Shannon

Content: Tracking Modules

60 minute Computer Assisted Telephone Interviews

- Sociodemographic
- Lifestyle
- Health
  - General, women's, vision, hearing, chronic conditions,
- Functional Status
- Cognition (recorded)
  - Rey Auditory Verbal LT
  - Mental Alternation Test
  - Animal Naming
- Depression
- PTSD screener
- Satisfaction with life
- Social networks/support
- Caregiving
- Care receiving
- Injuries
- Labour force participation
  - retirement
- Income

Content: Comprehensive

InHome Computer Assisted Personal Interviews

- Includes the content of the Tracking CATI minus the Social module (moved to the DCS)
- Plus
  - Short diet questionnaire
  - Sleep questions
  - Medication (questions plus visual assessment by interviewers)

Content: Comprehensive

@ the Data Collection Site

- Contraindications questionnaire
- Disease symptoms questionnaire
- Neuropsychological measures
- Social Support
- Social Participation
- Physical Assessments
- Blood/urine specimen

@ the Data Collection Site

Reception
Registration: Bar code
Contraindications Q

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

Measurement Room 2
DEXA

Measurement Room 3
Visual acuity
Fundus photograph
Occular 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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Content: Maintaining Contact

30 minutes CATI

- Falls
- Pain
- Oral Health
- Health Care Utilization
- Dietary Supplement Use
- Nutritional Risk
- Physical Activity
- Social Inequality
- Online social networking
- Transportation, migration, mobility
- Built Environment
- Wealth

- Parkinsonism (T)
- Medication (T)
- Snoring (C)
- Psychological Distress (C)
- Personality Traits (C)

Standardized Paperless Process

Pre-recruitment

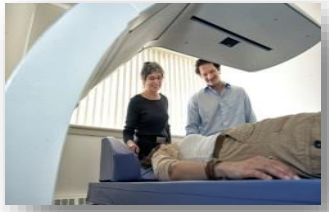
Consent and recruitment

Questionnaire Data (n=50,000)

n=30,000 Home Interview

n=20,000 Telephone Interview

DATA COLLECTION SITE VISIT



Biological Data Processing
-Blood
- Urine

Stored at Biorepository and Bioanalysis Centre

Alphanumeric data and images stored @ SAC

Data cleaning and quality control

Data dissemination to researchers

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Status

As of May 1st, 2015

Recruitment & Data Collection Update

Telephone Interviews

Tracking Cohort

- Recruitment of 21,241* participants, 60 minute telephone interviews every 3 years:
  - ✓From….Statistics Canada CCHS on Healthy Aging
  - ✓From….Provincial Ministries of Health
  - ✓From….Random Digit Dialing
- Recruitment and baseline data collection are complete!
- Data available for release to researchers‡
  - Maintaining contact interviews initiated 2013 (~15,000 completed, ~2% lost)
- First full follow-up begins summer 2015

*21,241 result of over sampling low SES

‡ cognition data and some open text in second release

Recruitment & Data Collection Update

Home Interviews and Data Collection Site Visits

Comprehensive Cohort

- Recruitment of 30,000 for Home Interviews and Data Collection Site Visits:
  - ✓ From…Provincial Health Care Registries
  - ✓ From…Random Digit Dialing
- Baseline data collection 2012 to 2015:
  - In Home Interviews: 30,531 (28,915 viable)
  - DCS visits: 27,864
  - Data release target: Spring 2016
  - Maintaining Contact 10,519 to date (~2% lost)
- First full follow-up begins summer 2015

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“Results”
Tracking Only

N=21,241

Acknowledgements to SAC team, Jennifer Uniat, Susan Kirkland, Andrew Wister, Verena Menec and Lauren Griffith

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CLSA Tracking Telephone Interviews

	Count	%	Weighted %
Age			
45-54	5826	27.5	38.2
55-64	6554	30.9	31.2
65-74	4525	21.8	18.8
75-85	4203	19.8	11.8
Sex			
Male	10387	49.0	48.3
Female	10821	51.0	51.7
Language			
English	17457	82.3	75.9
French	3751	17.7	24.1
Born in Canada	18486	87.2	84.5

CLSA Tracking Telephone Interviews

Province	Count	%	Weighted %
British Columbia	2619	12.4	13.8
Alberta	2110	10.0	9.3
Saskatchewan	1388	6.5	2.9
Manitoba	1472	6.9	3.3
Ontario	4722	22.3	38.3
Quebec	3603	17.0	24.7
New Brunswick	1350	6.4	2.4
Nova Scotia	1564	7.4	3.1
Prince Edward Island	1132	5.3	0.5
Newfoundland, Lab	1248	5.9	1.7

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CLSA Tracking Telephone Interviews

	Count	%	Weighted %
Arthritis	8194	38.9	35.1
Asthma	2344	11.1	11.7
COPD	1433	6.8	5.8
Hypertension	8090	38.2	33.4
Diabetes	3542	16.7	15.1
Heart disease	2189	10.3	9.0
Angina	1149	5.4	4.3
Heart attack	1299	6.2	4.9
Stroke	388	1.8	1.5
Dementia	43	0.2	0.2
Parkinson's, Parkinsonism	78	0.4	0.3
Multiple Sclerosis	141	0.7	0.6
Cancer	3262	15.4	13.2
Osteoporosis	2008	9.5	8.7

CLSA Tracking Telephone Interviews

	Count	%	Weighted %
Marital status			
Single/Never married	1694	8.0	8.4
Married/Common Law	14586	68.8	73.0
Widowed	2355	11.1	7.3
Divorced	1988	9.4	8.5
Separated	579	2.7	2.7
Education			
Less than Secondary	1978	9.3	7.0
Secondary School	2875	13.6	12.8
Some Post-Secondary	1622	7.7	7.6
Post Secondary Degree/ Dipl	14650	69.1	72.2
Annual Household Income			
Less than $20,000	1341	6.8	5.5
$20,000 - < $50,000	5841	29,4	23.9
$50,000 - < $100,000	7212	36.3	35.9
$100,000 - < $150,000	3212	16.2	19.4
$150,000+	2237	11.3	15.4

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CLSA Tracking Telephone Interviews

	Count	%	Weighted %
Self Rated General Health			
Excellent	3972	18.8	20.8
Very Good	8115	38.3	38.3
Good	6249	29.5	28.7
Fair	227	10.5	9.6
Poor	624	2.9	2.7
Self reported Weight Status			
Overweight	11188	53.0	52.1
Underweight	432	2.0	1.9
Just about right	9492	45.0	46.0
Satisfaction with Life			
Dissatisfied	2068	9.8	9.8
Neutral	850	4.0	4.5
Satisfied	18264	86.2	85.6

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Data Access

Alphanumeric data from 21,241 CLSA participants who completed 60 minute CATIs

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Data Access Steps

Tracking Data Only

Application process via CLSA **DataPreview** portal

1. Administrative Review
2. Data and Sample Access Committee Review
3. Recommendation to Scientific Management Team
4. Notification of applicant
   - Steps 1 to 4 take 3-4 weeks
5. CLSA Access Agreement preparation and signatures
   - Institutional review/signature timing is unpredictable
6. Raw data provided to approved investigator
   - Step 6 takes 5 working days following completion of step 5

acces@clsa-elcv.ca

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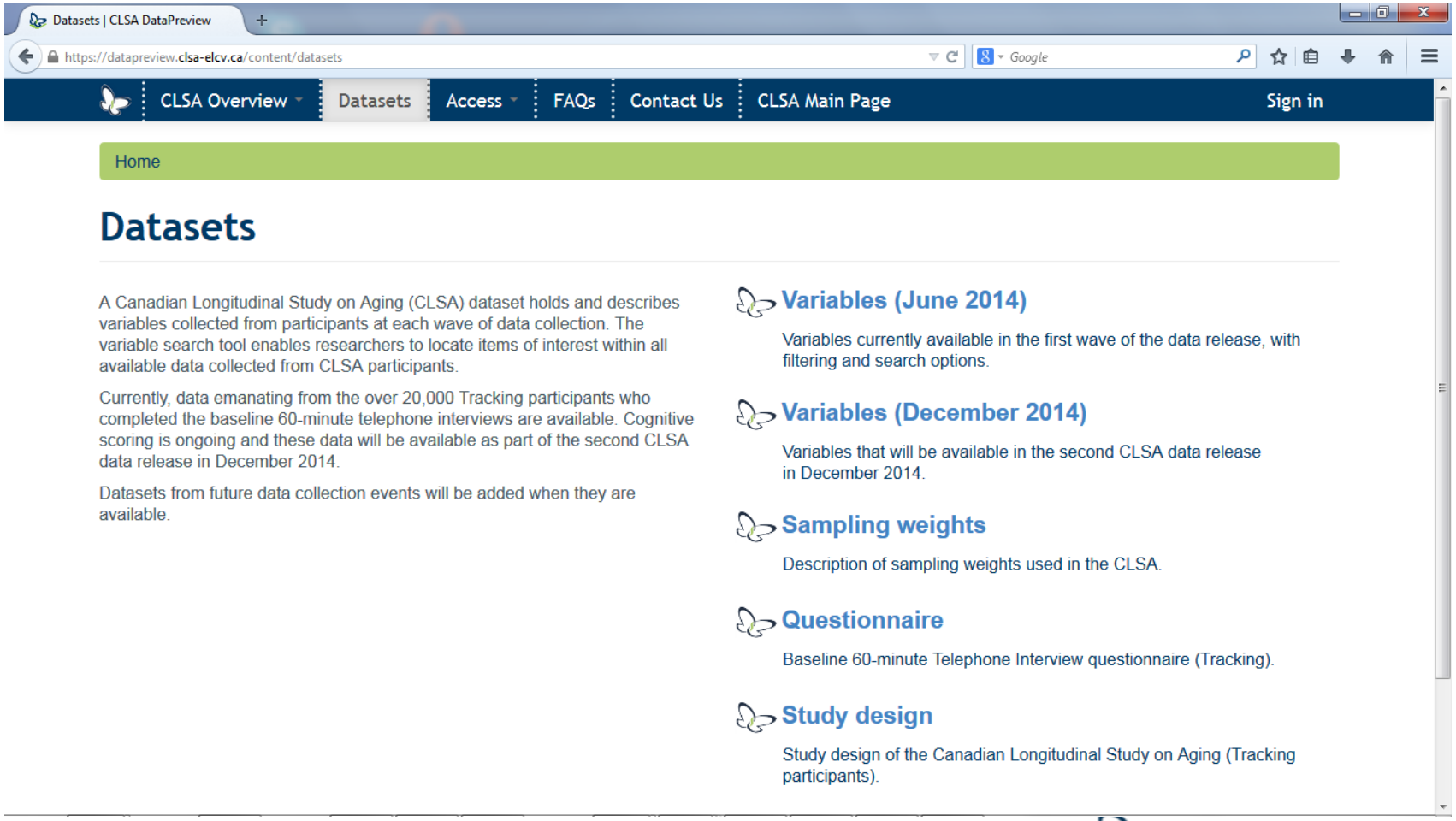
Data Access Continued

- Costing
- Cost Recovery (for alphanumeric data only)
  a. $1,000 for a straightforward alphanumeric dataset
  b. No cost for data for graduate student theses
  c. One free dataset for postdoctoral fellows
  d. No cost for data requests to conduct methodological projects that will directly benefit the CLSA
- DSAC Meetings 2015
  - February, April, June, September, December
- Application deadlines
  - March 23rd, **May 15th, August 14th, November 16th**

DataPreview Portal

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

DataPreview Portal



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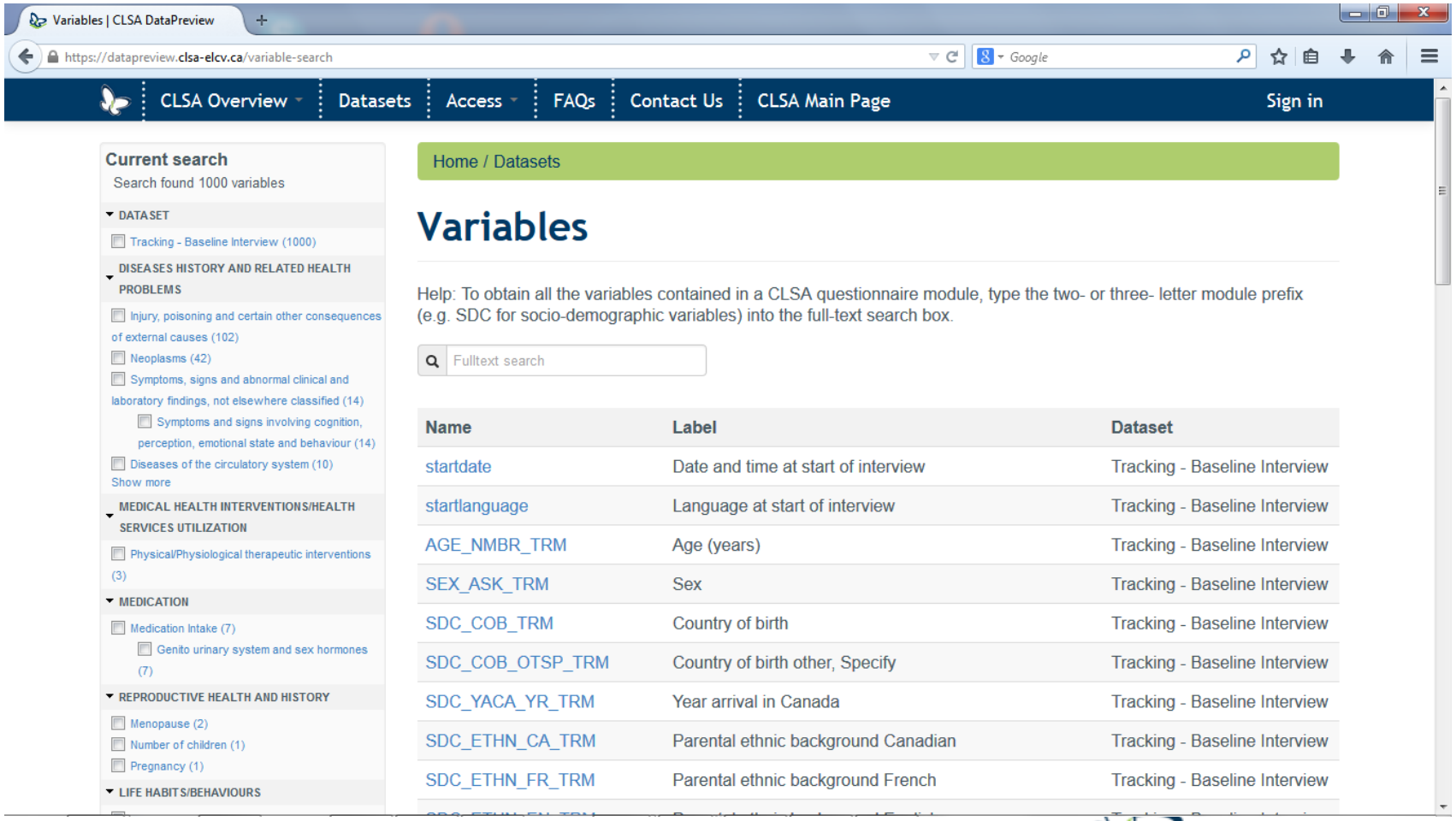
DataPreview Portal



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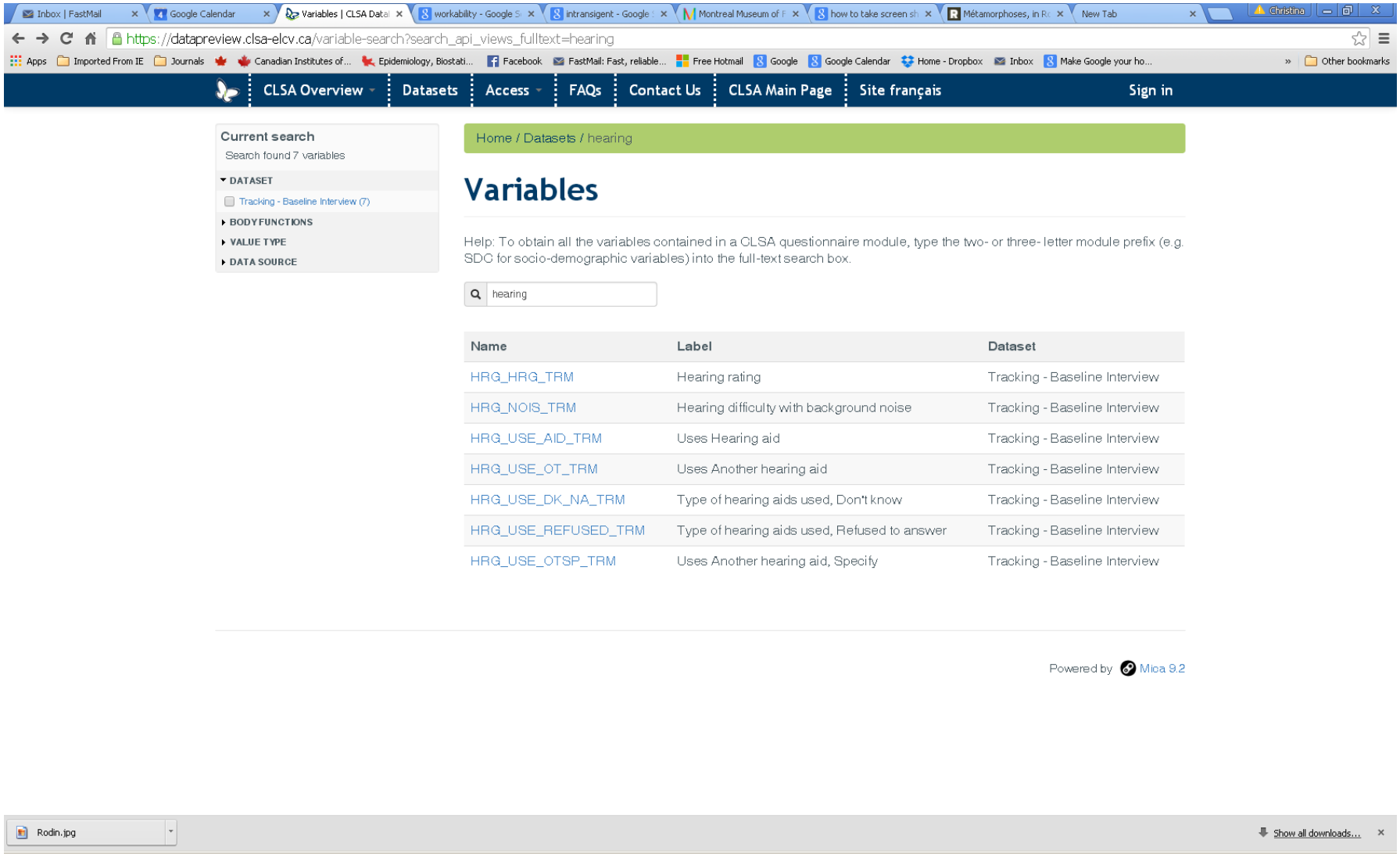
https://datapreview.clsa-elcv.ca/variable-search?search_api_views_fulltext=hearing
CLSA Overview
Datasets
Access
FAQs
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CLSA Main Page
Site français
Sign in
Current search
Search found 7 variables
DATASET
Tracking - Baseline Interview (7)
BODY FUNCTIONS
VALUE TYPE
DATA SOURCE
Home / Datasets / hearing
Variables
Help: To obtain all the variables contained in a CLSA questionnaire module, type the two- or three- letter module prefix (e.g. SDC for socio-demographic variables) into the full-text search box.
hearing
Name
Label
Dataset
HRG_HRG_TRM
Hearing rating
Tracking - Baseline Interview
HRG_NOIS_TRM
Hearing difficulty with background noise
Tracking - Baseline Interview
HRG_USE_AID_TRM
Uses Hearing aid
Tracking - Baseline Interview
HRG_USE_OT_TRM
Uses Another hearing aid
Tracking - Baseline Interview
HRG_USE_DK_NA_TRM
Type of hearing aids used, Don't know
Tracking - Baseline Interview
HRG_USE_REFUSED_TRM
Type of hearing aids used, Refused to answer
Tracking - Baseline Interview
HRG_USE_OTSP_TRM
Uses Another hearing aid, Specify
Tracking - Baseline Interview
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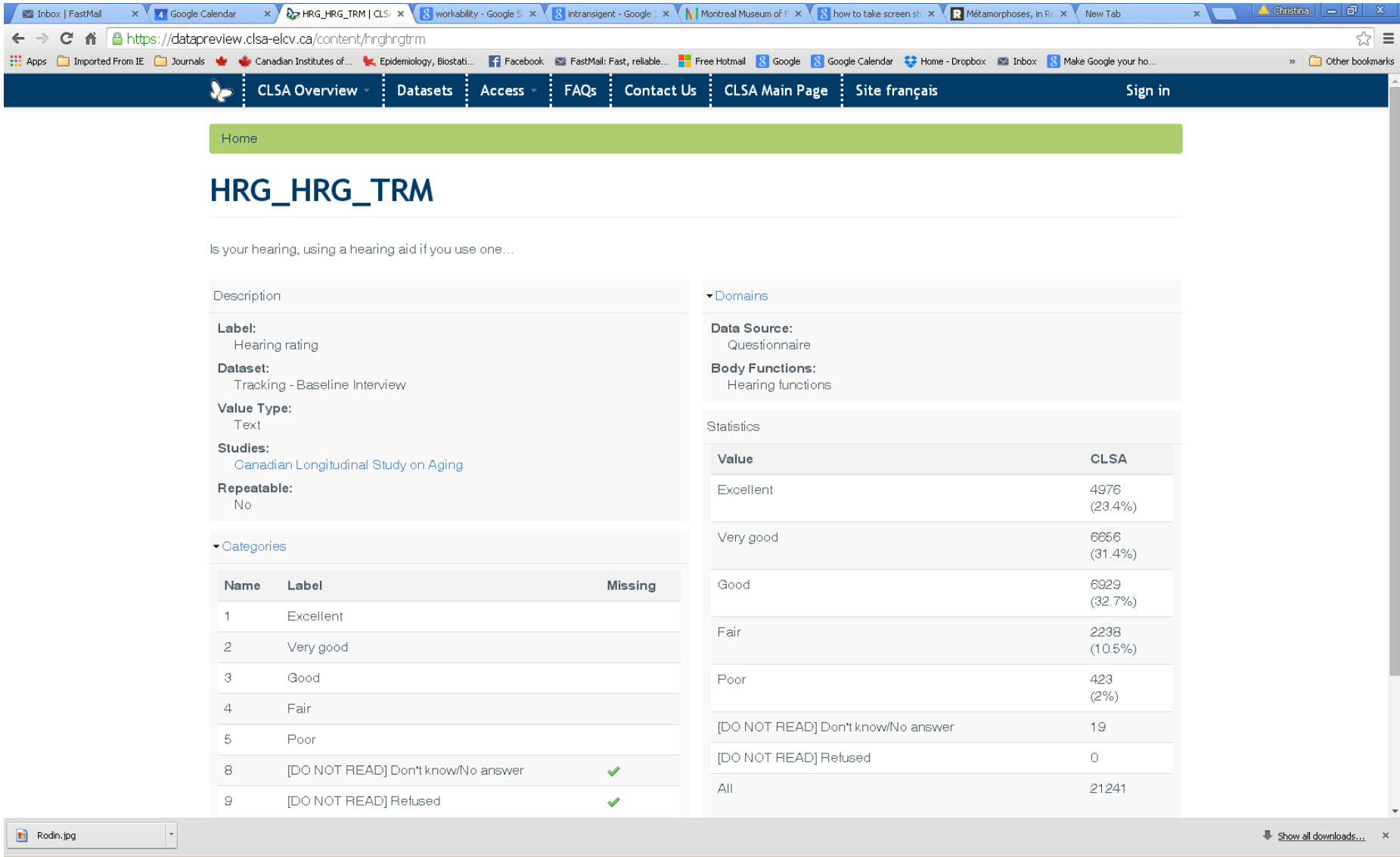
https://datapreview.clsa-elcv.ca/content/hrghrgtrm
CLSA Overview
Datasets
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CLSA Main Page
Site français
Sign in
Home
HRG_HRG_TRM
Is your hearing, using a hearing aid if you use one…
Description
Label:
Hearing rating
Dataset:
Tracking - Baseline Interview
Value Type:
Text
Studies:
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Repeatable:
No
Categories
Name
Label
Missing
1
Excellent
2
Very good
3
Good
4
Fair
5
Poor
8
[DO NOT READ] Don't know/No answer
9
[DO NOT READ] Refused
Domains
Data Source:
Questionnaire
Body Functions:
Hearing functions
Statistics
Value
CLSA
Excellent
4976 (23.4%)
Very good
6656 (31.4%)
Good
6929 (32.7%)
Fair
2238 (10.5%)
Poor
423 (2%)
[DO NOT READ] Don't know/No answer
19
[DO NOT READ] Refused
0
All
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Data and Sample Access Committee (Inaugural and Interim)

- Christina Wolfson (Chair)
- Cynthia Balion: *CLSA Biorepository and Bioanalysis Centre, McMaster*
- Max Cynader: *CLSA Lead Site Investigator, UBC*
- Pierrette Gaudreau: *CLSA Co-Investigator, Université de Montréal*
- Joan Lindsay: *Canadian Study of Health and Aging Investigator, Epidemiologist, Health Surveillance and Epidemiology Division, PHAC*
- Verena Menec: *Lead Health Services Working Group.CLSA Lead Site Investigator. University of Manitoba*
- Margaret Penning: *Past lead, CLSA Social Health Working Group, University of Victoria*
- Brent Richards: *CLSA Co-Investigator, McGill University*
- Harry Shannon: *Lead Methodology Working Group, McMaster University*
- CIHR representative – ex officio
- Jennifer Uniat: *Statistical Analysis Centre Manager*

Approved Applications

Applicant Title	Location
Consumer Product related senior falls and injury risk assessment	Ontario
CLSA Neurological conditions initiative (CLSA-NCI)	Quebec
Multiple chronic conditions in relation to disability and social participation	Ontario
The association between hearing loss and social function in older Canadians	British Columbia
The Veterans' Health Initiative within the CLSA (CLSA-VHI)	Quebec
Physical functioning and disability	Ontario (Postdoc)
Labour force participation: Retirement Transitions, Expectations and Planning	Ontario (Student)
Who is at risk of social isolation and loneliness?	Manitoba
Companion animals and the aging population	Alberta (Student)
Factorial invariance of the CES-D	Saskatchewan
The development of normative data and comparison standards for the cognition measures employed in the CLSA	British Columbia
Describing social networks and caregiver capacity in Nova Scotia	Nova Scotia
Menopause and mental well-being	Ontario (Postdoc)
Longterm exposure to ambient air pollution and effects on health	Ontario

18 applications received

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Linking CLSA Data
Work in progress

- Linkage is a key CLSA research strategy
  - Enormous potential for collection of information that is difficult to get from participants due to time, accuracy limitations; unknown to participants
- Types of databases
  - Individual level administrative provincial health databases (priority)
  - Disease registries
  - Population level databases of community characteristics, climate, pollution
  - Individual level economic characteristics

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*Selected Collaborations and Partnerships

- Canadian Consortium on Neurodegeneration in Aging (CCNA)
- Veterans Affairs Canada
- Canadian Institute for Military and Veteran Health Research
- LegerMarketing
- Health Charities Coalition of Canada
- Public Health Agency of Canada
- Health Canada
- Ontario Minister of Transport
- Statistics Canada
- Neurological Health Charities Canada
- CARP
- Maelstrom Research
- Calgary Laboratory Services
- Ontario Brain Institute
- Vocantas Inc.
- Canadian Mortgage and Housing Corporation
- ……

First Follow up

First Follow Up (2015-2018)

- 1st follow up Tracking (June 2015 to May 2018)
  - Re-contacting 21,242 participants for their follow up telephone interviews
    - Planning underway

- 1st follow up Comprehensive (June 2015-May 2018)
  - Re-contacting 30,000 participants for their follow up inhome interviews and DCS visits
    - Planning underway

First Follow Up - New Content

- Child maltreatment*
- Elder Abuse*
- Epilepsy
- Hearing
- Arterial stiffness
- Decedent information
  - date and cause of death, trajectory of functional decline, residential transitions, health care utilization in 3 months prior to death
- Workability
- Subjective cognitive decline
- Transportation*
- Health care use
- Preventive health behaviours

*External funding

First Follow-up
Additional Considerations

- Changing circumstances
  - Moving
  - Cognitive impairment
  - Physical impairment
  - Sensory impairment

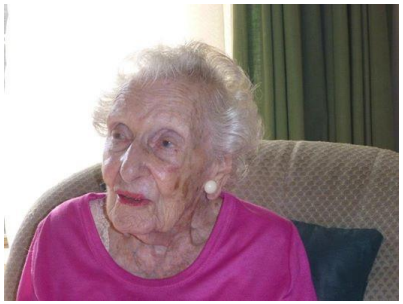
Governance and Advice

- Scientific Management Team
- International Scientific Advisory Board
- CLSA Advisory Council
- Knowledge Translation and Communications Cttee
- Training and Research Capacity Cttee
- Data and Sample Access Committee
- Ethical, Legal, Social Issues Advisory Committee (CIHR)

Take Home Messages

- The platform is up and running
- The data and biospecimens are being collected
- Alphanumeric data on more than 20,000 participants from across Canada are now available
- These data are free for student thesis research
- Visit the website https://datapreview.clsa-elcv.ca/
- Apply now!

Acknowledgements
CLSA Montreal



- **Data Collection Site**
  - Josee Mayer(Manager)
  - Katya Lopez
  - Claudia Greco
  - Sanjivlall Balgobin
  - Jessica Noseworthy
  - Shannon Sinclair
  - Roselene Baltus
- **In home Interviewers**
  - Amy Striemer
  - Christina DelGaudio
  - Claudia Greco
  - Liliane Mefanche
  - Elizabeth Grou
- **Statistical Analysis Centre**
  - Isabel Fortier (Assoc Director)
  - Jennifer Uniat (Manager)
  - Bin Zhu (Statistician)
  - Sarah Youssef (Data Curator)
  - Khaled Boulsaien
  - Caterina DeLeo (Research assistant)
- **Translation**
  - Marie-Eve Veilleux (Coordinator)
  - Laurie Torres
- **Administration**
  - Karen Zabowski

Transforming Everyday Life
into Extraordinary Ideas

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