Transforming Everyday Life
into Extraordinary Ideas

Canadian Longitudinal Study on Aging: A Platform for Interdisciplinary Research

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Talk Outline

- **CLSA Study Design and Methodology (LG)**

- **Accessing CLSA Data (IMS)**

- **CLSA Projects: Perspectives from data users (MO+LG)**

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What is the Canadian Longitudinal Study on Aging (CLSA)?

"*The Canadian Longitudinal Study on Aging is the largest most comprehensive research platform and infrastructure available for aging research with longitudinal data that will span 20 years from over 50,000 Canadians over the age of 45*"

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

CLSA Leads

Lead Principal Investigator
Parminder Raina (McMaster)

Co-principal Investigator
Christina Wolfson (McGill)

Co-principal Investigator
Susan Kirkland (Dalhousie)

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Design Overview

51,338 women and men aged 45 - 85 at baseline

Tracking (21,241)
Randomly selected
10 provinces

Comprehensive (30,097)
Randomly selected
25-50 km of 11 sites in 7 provinces

Questionnaire
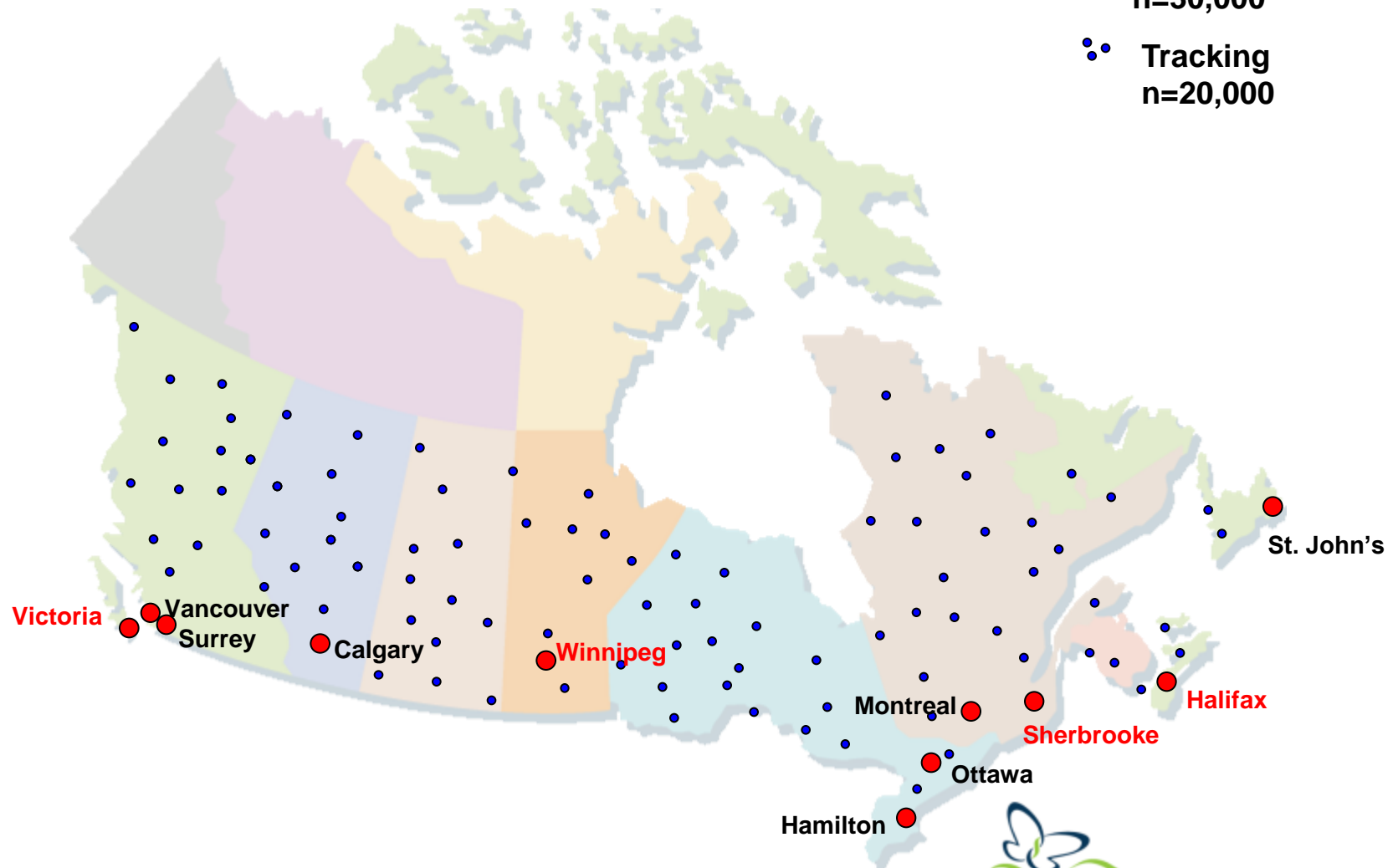**• By telephone Interviews**

Questionnaire
In home Interviews
And Physical Assessments
Blood, Urine
•At Data Collection Site

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

Data Linkage with health care, mortality and disease registries

Participant Recruitment

Comprehensive n=30,000

Tracking n=20,000

Victoria
Vancouver
Surrey
Calgary
Winnipeg
St. John's
Montreal
Sherbrooke
Halifax
Ottawa
Hamilton

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Exclusion Criteria at Baseline

1. Residents of the 3 territories
   - i.e. 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

- Unable to communicate in French or English

1 to 5 exclude <4% of the target population

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Recruitment & Data Collection
Telephone Interviews

- Recruitment of 21,241 participants for telephone interviews:
  - ✓ Statistics Canada CCHS on Healthy Aging
  - ✓ Provincial Health Care Registries
  - ✓ Random Digit Dialing

- **Baseline data collection is completed!**

- **Data are now available to research community**

- Maintaining contact interviews initiated in 2013 (**completed in early 2016, retention rate 95%**)

- First follow-up began 2015 and will be completed in late summer of 2018

Recruitment & Data Collection
Home Interviews and Data Collection Site Visits

- Recruitment of 30,097 for Home Interviews and Data Collection Site Visits:
  - ✓ Provincial Health Care Registries
  - ✓ Random Digit Dialing
- Baseline data collection 2012 to 2015: **Data collection completed**
- **Data are now available to the research community**
- Maintaining Contact Interviews initiated in 2014 (**completed, retention rate 96%**)
- First follow-up began 2015 and will be completed in mid-summer of 2018

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CLSA Questionnaire modules
All 51,338 participants

Demographic/Lifestyle

- Age
- Gender
- Education
- Marital status
- Sexual orientation
- Language
- Ethnicity
- Wealth/income
- Veteran Identifier
- Smoking, alcohol
- Nutritional risk
- Physical activity
- Health care utilization
- Medication use
- Supplement use

Health

- General health
- Women's health
- Chronic conditions
- Disease symptoms
- Sleep
- Oral health
- Injuries, falls
- Mobility
- Pain, discomfort
- Functional status
- ADL, IADL
- Cognition
- Depression
- PTSD
- Life Satisfaction
- Nutritional Risk

Social

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

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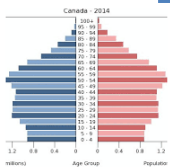
CLSA Data Collection
Data Collection Site

Physical Assessments:
- Height, Weight, BMI
- Bone Density, Body Composition, Aortic Calcification
- Blood Pressure, ECG, c-IMT
- Pulmonary Function
- Vision & Hearing
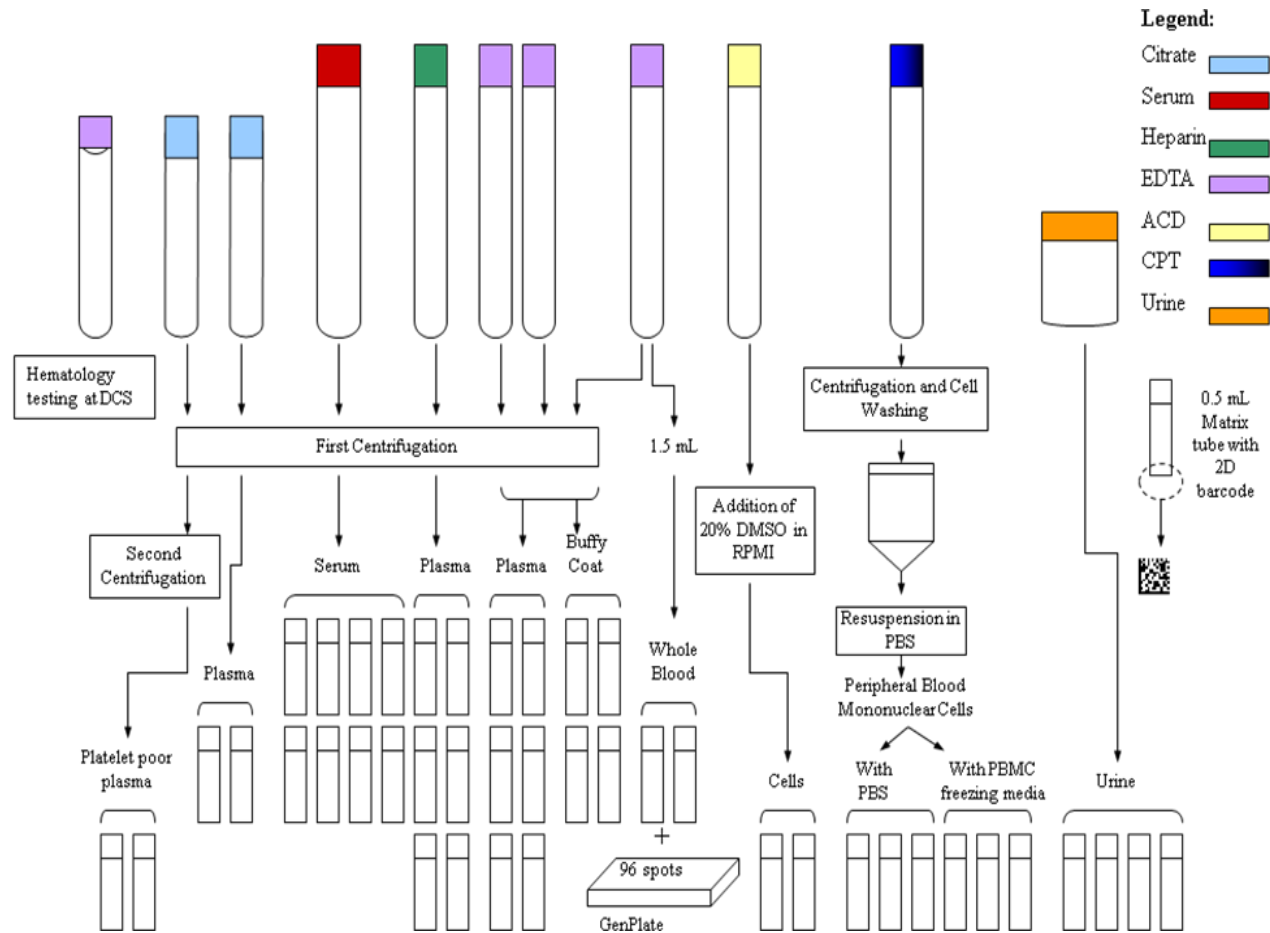- Performance testing
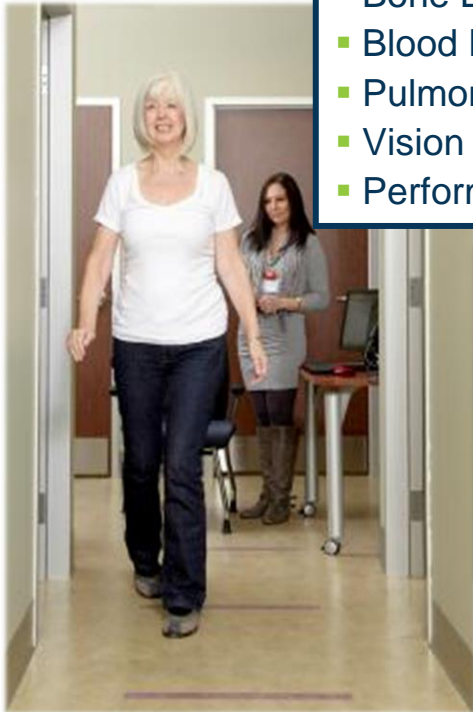
Biospecimen Collection:
- Blood
- Urine

Cognitive Assessments:
- Neuropsychological Battery
  - Memory
  - Executive function
  - Reaction time

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Biospecimens
42 aliquots per participant

Biomarker data in the CLSA

Available	**Hematology** Data Collection Sites	30,000	• Erythrocytes • Lymphocytes • MCHC • Granulocytes • Platelets • MPV • Hematocrit • MCV • RDW • Hemoglobin • MCV
Available in 2018	**Chemistry** Calgary Laboratory Services	30,000	• Albumin • HDL • Alanine • LDL Aminotransferase • Non-HDL • Creatinine • Thyroid stimulating • Ferritin hormone • Free T4 • Triglycerides • Hemoglobin A1c • 25-Hydroxyvitamin D • C-reactive protein • Cholesterol
	Genome-wide Genotyping McGill University and Génome Québec Innovation Centre	10,000	• DNA extracted on all 30,000 • 820K UK Biobank Axiom Array (Affymetrix)
	DNA Methylation Profiling UBC Genetics and Epigenetics Centre	2,000	• PBMCs used for DNA extraction • 850K Infinium MethylationEPIC BeadChip (Illumina)
	Metabolomics Kyoto, Japan	1,000	• Mass spectrometry

•Also increasing the sample size for Epigenetics to make this a largest resource at the population level

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CLSA Data Available on Chronic Diseases:

Diabetes

Chronic Airway Obstruction

Parkinsonism

Ischemic Heart Disease

Stroke/ Cerebrovascular Event

Hypertension

Depression

Hyperthyroidism/ Hypothyroidism

Osteoarthritis of the Hand

Osteoarthritis of the Hip

Osteoarthritis of the Knee

Osteoporosis

Over 40 Self-Reported Chronic Conditions

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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

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Demographic Characteristics of the CLSA Participants

	Tracking N=21,241	Comprehensive N=30,097	Total N=51,338
Age			
45-54	5832 (27.5)	7595 (25.2)	13427 (26.2)
55-64	6564 (30.9)	9856 (32.7)	16420 (32.0)
65-74	4634 (21.8)	7362 (24.5)	11996 (23.4)
75-85	4211 (19.8)	5284 (17.6)	9495 (18.5)
Sex			
Female	10835 (51.0)	15320 (50.9)	26155 (50.9)
Male	10406 (49.0)	14777 (49.1)	25183 (49.1)
Language			
English	17483 (82.3)	24291 (80.7)	41774 (81.4)
French	3758 (17.7)	5806 (19.3)	9564 (18.6)
Born in Canada	18513 (87.2)	24644 (81.9)	43099 (84.0)

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Social Participation and Loneliness by Age & Gender

Variable	Total % (age 45-85)	Age 65+ %	Males Age 65+ %	Females Age 65+ %
Desire to participate in more activities **(Yes)**	41.7	31.7	29.7	33.5
How often participant feels lonely **(Sometimes or more)**	22.7	23.7	19.1	28.5

Community-related Activities by Age & Gender

Frequency of any community-related activity participation	Total % (age 45-85)	Age 65+ %	Males Age 65+ %	Females Age 65+ %
At least once per day (daily)	15.5	16.1	16.3	16.0
At least once per week (weekly)	66.6	67.8	65.6	69.7
At least once per month or less (monthly or less)	17.9	16.3	18.2	14.3

Social Participation Types by Age & Gender

Frequency of participation in past 12 months	Total % (age 45-85)	Age 65+ %	Males Age 65+ %	Females Age 65+ %
Sports or physical activities with others	50.3	47.9	47.3	48.5
Family/friends activities outside household	50.2	46.2	47.0	52.9
Religious activities	22.4	32.3	28.2	35.9
Volunteer or charity work	16.9	22.1	18.1	25.7
Educational or cultural activities	10.3	11.6	10.1	12.9
Neighbourhood, community or social association activities	8.3	10.9	8.5	12.7
Service clubs or fraternal organization activities	5.2	7.2	7.5	6.8

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Perceived Barriers to Social Participation, by Age & Gender

Reason(s) preventing more participation	Total % (age 45-85)	Age 65+ %	Males Age 65+ %	Females Age 65+ %
Too busy	51.7	31.4	33.3	28.3
Health condition/limitation	15.9	23.2	20.4	25.3
Personal responsibilities	15.8	14.1	10.8	16.7
Going alone	10.2	12.2	12.0	12.5
Cost	8.7	7.4	7.9	7.0
Lack of activities in area	7.8	9.0	8.5	9.5
Transportation problems	3.5	5.3	2.3	7.5
Location accessibility	1.4	1.8	1.2	2.4
Language reasons	0.4	0.6	0.7	0.5

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Retirement Status

Retirement Status	45-64		65-85	
	Male	Female	Male	Female
Completely Retired	19.6%	25.3%	76.4%	84.5%
Partly Retired	10.5%	9.4%	15.1%	8.3%
Not Retired	69.9%	65.3%	8.2%	7.2%

	45-64		65-85	
	Male	Female	Male	Female
Retired and Returned to Work	9.6%	8.1%	26.7%	16.6%

Of those retired:	
Voluntary Retirement	n = 9,633 (78.7%)
Health/Disability/Stress contributed to decision to retire	n = 2,922 (23.5%)

Prevalence of Chronic Diseases (%) in the CLSA by Age and Sex (n=51,338)

Males (n=25,183)

Age:	45-54	55-64	65-74	75-89
Respiratory	13.3^4	13.9^5	12.7	14.1
Arthritis	18.4^2	29.7^2	36.5^2	42.0^2
Osteoporosis	1.1	2.4	4.2	5.4
HBP	20.8^1	36.4^1	48.5^1	54.0^1
Diabetes	10.0	17.7^3	23.0^4	25.9^5
CVD	5.6	13.3	23.4^3	33.4^3
Cancer	5.2	10.7	18.8^5	30.2^4
GI	11.0^5	11.0	13.8	13.3
Stroke or CVA	0.8	1.4	2.6	4.7
Urinary incontinence	1.4	3.1	6.9	12.5
Glaucoma	0.8	3.0	6.4	9.3
Mood/Anxiety	17.8^3	16.4^4	12.3	7.7

Females (n=26,155)

Age:	45-54	55-64	65-74	75-89
Respiratory	16.5^3	17.9^4	17.5	17.2
Arthritis	24.9^1	42.7^1	51.9^1	57.9^2
Osteoporosis	4.5	13.0	23.2^3	30.0^3
HBP	16.7^2	30.7^2	45.6^2	59.0^1
Diabetes	9.4	14.5	17.3	18.2
CVD	3.6	7.3	13.1	21.5^5
Cancer	8.4	14.2	19.9^5	22.7^4
GI	14.1^4	16.0^5	17.4	18.5
Stroke or CVA	0.4	1.3	1.7	2.9
Urinary incontinence	7.8	10.5	13.4	18.4
Glaucoma	1.5	2.8	6.0	11.3
Mood/Anxiety	24.9^1	26.9^3	20.4^4	14.5

[n]Ranking

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Number of Chronic Condition in the CLSA by Age and Sex (n=51,338)

Broad inclusion of CCs

Legend: None, One, >=Two
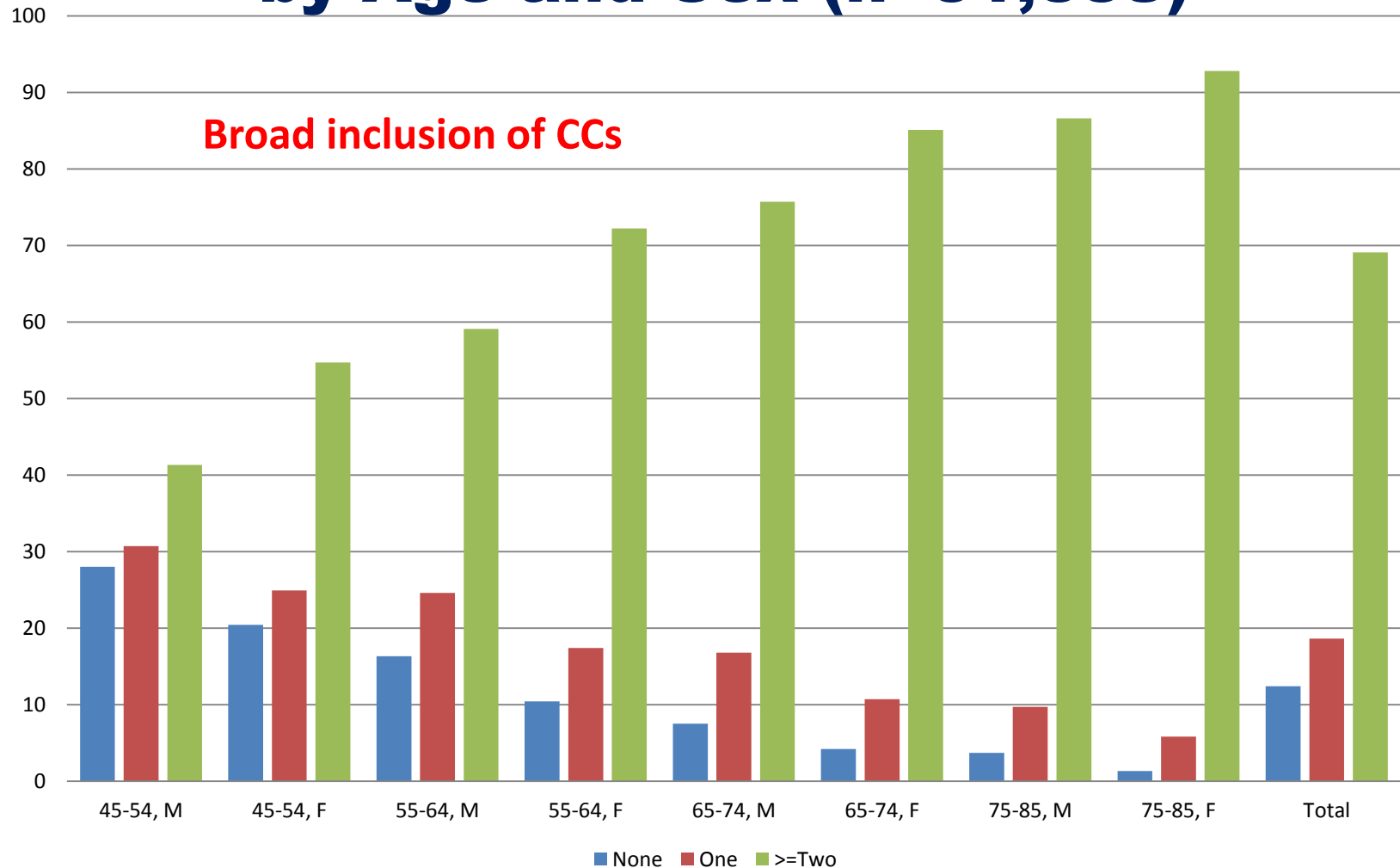
CLSA Funders and Partners

Questions?

Data Access in the CLSA:
We're open for research!

Istvan Molnar-Szakacs, PhD
Data Access Officer
Canadian Longitudinal Study on Aging

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Did you know?

- **20 years**

- **26 Canadian universities**

- **160 collaborators**

- **51,338 participants**

- **140,000 telephone interviews**

- **210,000 home interviews**

- **5 million bio-specimen aliquots**

- **126 million questions asked during telephone interviews**

- **300 million anticipated data points that will form the CLSA research platform**

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What data are available?

- **The CLSA platform includes data on health status, diseases, cognition, psychological well-being and mental health, social well-being, economic aspects of aging, physical assessments and blood-based biological markers.**

- **The Baseline alphanumeric dataset is currently available, including:**

    - **Questionnaire data on all 51,338 participants**

    - **Comprehensive physical assessment data and basic haematology results on approximately 30,000 participants**

- **Biospecimen availability is planned for 2018.**

- **Follow-up 1 is currently under way. Follow-up data collection events will be repeated every three years for 20 years.**

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How to access CLSA data?

- **What are the principles of data access?**
  - **Privacy, Security & Benefit to All**
- **Who can apply?**
  - **Researchers**
  - **Graduate students & Post-doctoral fellows**
- **How do I apply?**
  - **Application paper-based**
  - **Available for download on our website: www.clsa-elcv.ca**

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CLSA Data Access Application – Part 1

Application ID / N° de la demande
(office use only / usage interne seulement)

CLSA Data and Biospecimen Request Application

Demande d'accès aux données et aux échantillons de l'ÉLCV

Components of the Application – Part 1:

- **Project Team**
- **Lay Summary**
- **Project Description (3 pages)**
- **Timeline**
- **Ethics Approval**
- **Scientific Review**
- **Fee Waiver**
- **Signatures**

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CLSA Data Checklist – Part 2

Interview module *Module de l'entrevue*	Tracking (Telephone Interview) **Évaluation de surveillance** *(Entrevue téléphonique)*	Comprehensive (Face-to-face Interview - In-home or DCS visit) **Évaluation globale** *Entrevue en personne - à domicile ou au DCS)*
Medications / *Médicaments* (MEDI)	Not applicable / *Ne s'applique pas*	Not yet available / *Pas encore disponible*
Functional Status / *Capacités fonctionnelles* (FUL)	☐	N = 137 (DCS by telephone / *DCS par téléphone*)[2]
Life Space Index / *Évaluation de l'aire de mobilité* (LSI)	Not applicable / *Ne s'applique pas*	☐
Sleep / *Sommeil* (SLE)	Not applicable / *Ne s'applique pas*	☐
Basic Activities of Daily Living / *Activités de base de la vie quotidienne* (ADL)	☐	☐
Instrumental Activities of Daily Living / *Activités instrumentals de la vie quotidienne* (IAL)	☐	☐
Cognition – metadata & scores / ***Cognition – métadonnées et cotation* (COG)**	/////////	/////////
REYI / *REYI*	☐	☐
Animal Fluency Test / *Test de fluence (animaux)*	☐	☐
Mental Alternation Test / *Test d'alternance mentale*	☐	☐

Data Access Timeline

Submission

DSA Committee Review

Dataset Preparation & Release

Up to 12 weeks

1 year

Final Report

6-9 weeks

5-7 days

Administrative & Statistical Review

Access Agreement Signed; Ethics Approval
Variable Time Frame

Monitoring (CLSA) - Annual Report
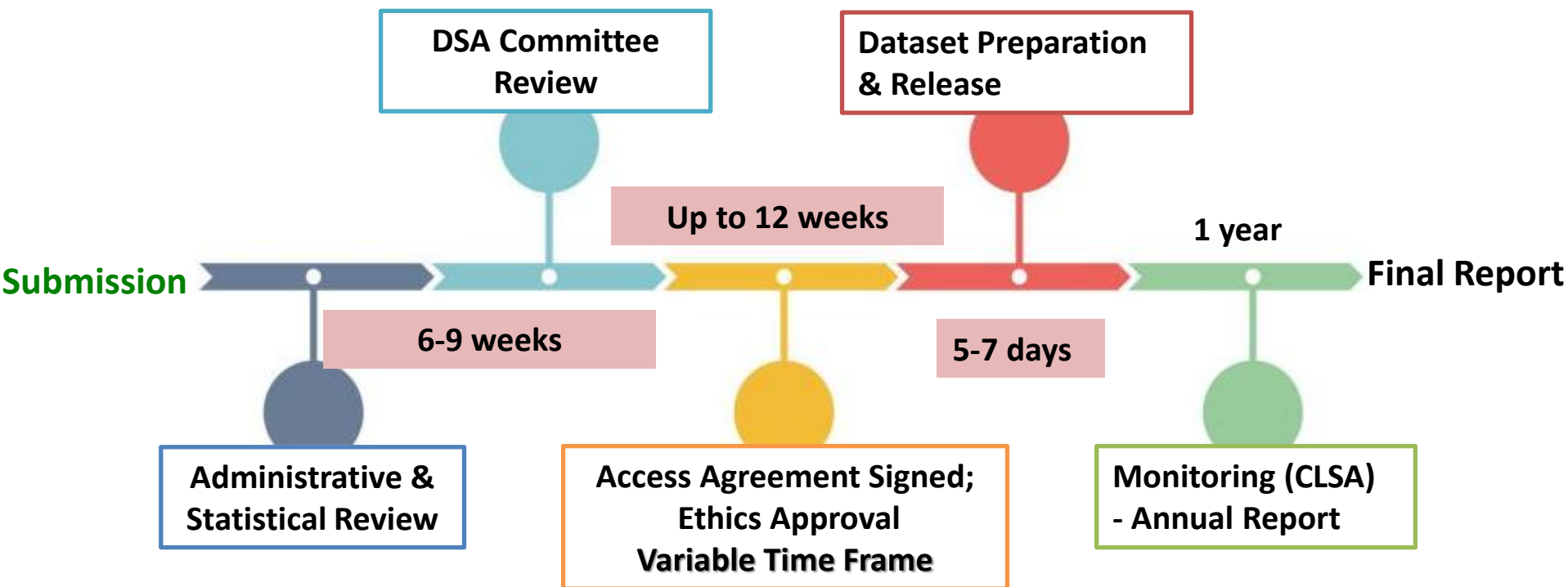
- **Plan on a receiving data 6 months after submission deadline**

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Data Access Fees

- **Costing (Alphanumeric Data)**
    - **Partial Cost Recovery Model**
    - **$3,000 for a prepared raw alphanumeric dataset**
    - **Graduate student - No cost for dataset to be used solely for thesis research**
    - **Postdoctoral fellow – No cost for <u>one</u> dataset to be used solely for the postdoctoral project**
- **Biospecimen Costing**
    - **In development**

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What do you get?

- **Alphanumeric data on all 51,338 participants**
  - **Additional raw data on certain variables may be requested (cognition, ECG, spirometry, etc.)**
- **De-identified open text for selected variables**
- **Sampling weights**
- **Additional data (i.e. linked Air Pollution, Meteorological data, Forward Sortation Areas) may be requested**

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Data Access – Resources for Researchers

www.clsa-elcv.ca

Information for Researchers

Tools for Researchers

Data Preview Portal

Need More Information?

We're Open for Research!

- **The CLSA platform is up and running**

- **Baseline data and biospecimens have been collected**

- **Alphanumeric data from questionnaires, physical assessments and basic haematology 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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Questions?

(Come see us at the Exhibitor Booths!)

CLSA Projects: Perspectives from data users

Lauren Griffith, PhD
McMaster University

Mark Oremus, PhD
University of Waterloo

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Who has applied for data?

Approved Projects Cluster by City:

Hamilton: 15

Winnipeg: 8

Montreal: 8

Halifax: 6

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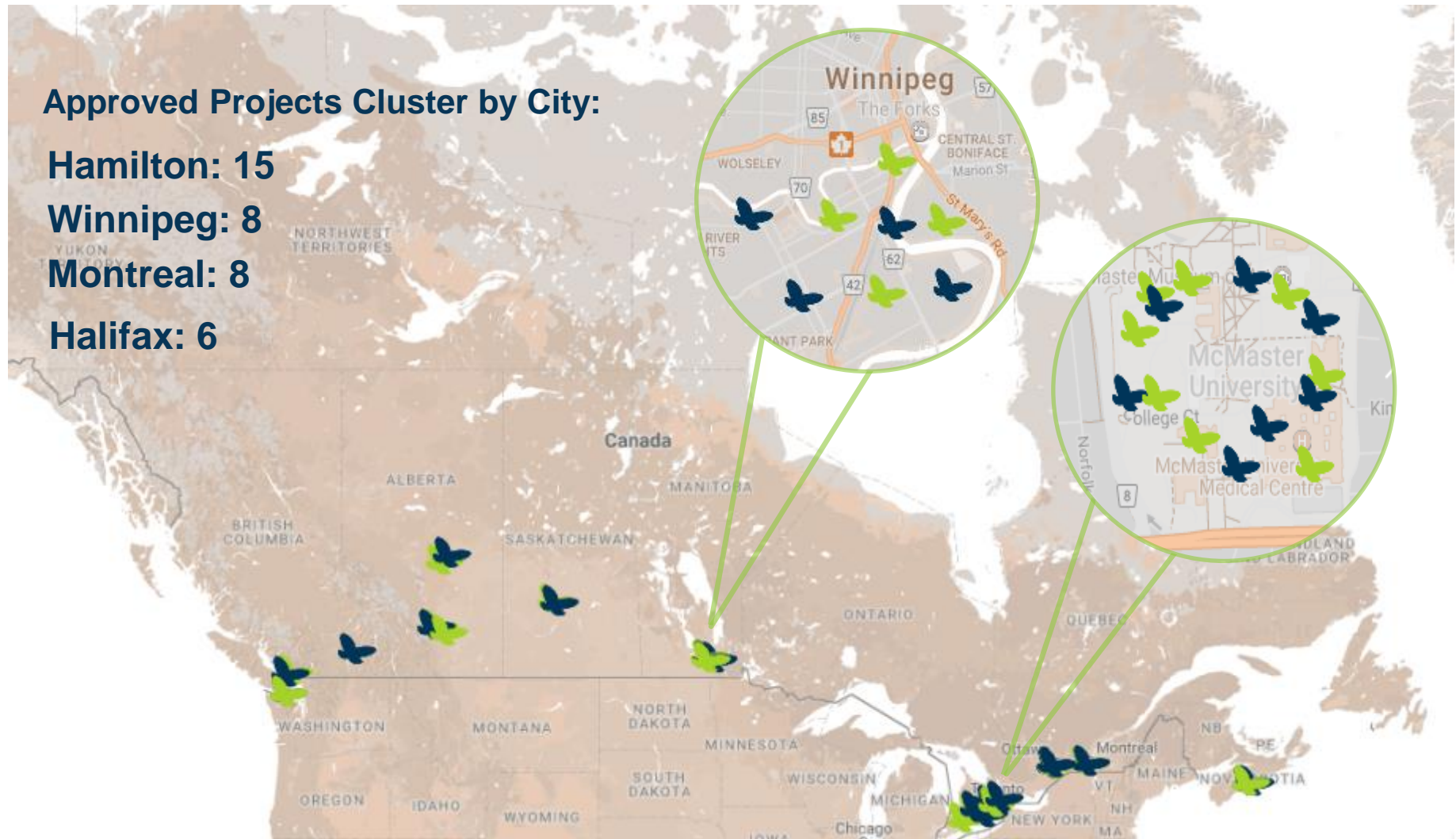
Selected Approved Projects 2016

- A Comparison of Functional Status in Rural and Urban Community Dwelling Older Adults
University of Saskatchewan

- Accumulation of Health Deficits Frailty Index in Wave 1 of the CLSA
Dalhousie University

- Understanding inequalities and inequities in health and wellness among older Canadians
Dalhousie University

- Factors associated with social participation and community ambulation in older adults with stroke and osteoarthritis
University of Manitoba

- Health Profile of Francophone Seniors in Manitoba: Canadian Longitudinal Study on Aging
Université de Saint-Boniface

- The "Motoric Cognitive Risk" syndrome in the Canadian population: Analysis of baseline assessment of the Canadian Longitudinal Study on Aging
McGill University

- Investigating relationships between nutrition, exercise, mood and hippocampus-dependent cognition in older adults in the Canadian Longitudinal Study on Aging
McMaster University

- Relationship between sarcopenia and low back pain in older adults - A cross-sectional analysis of the Canadian Longitudinal Study on Aging data
University of Ottawa

Selected Approved Projects 2016

- The early retiree divests the workforce: A quantitative analysis of early retirement among health professionals
  University of Alberta

- Long-term Exposure to Ambient Air Pollution and Effects on Cardiovascular, Respiratory and Neurocognitive Health
  Health Canada

- The clinical implications of spirometric impairment in the elderly
  McMaster University

- Association between air pollution and chronic bronchitis in two elderly populations
  Research Institute of the MUHC

- Sleep and its Covariates in the CLSA
  McGill University

- The Prevalence of Visual Impairment, its Risk Factors, and its Consequences in Canada
  University of Ottawa

- Defining age appropriate BMI cut points for the aging population
  McMaster University

- Assistive device use and its impact on social participation in Canada
  Dalhousie University

- A Multi-National Study to Understand the Upstream Risk Factors for Atrial Fibrillation
  McMaster University

- The burden of neurological disease in an older Canadian population
  Université de Montréal

Selected Approved Projects 2017

- [The gender difference in vascular risk factors, early cognitive impairment and progression to dementia](#)
  University of Calgary

- [Exploring the Associations between Lung Function and Sedentary Time among Middle-Aged and Older Canadian Men and Women](#)
  University of Ontario Institute of Technology

- [What makes people live long and keep well? Advancing the science of 'healthy aging' through examining the lay perspectives of older adults in the Canadian Longitudinal Study on Aging (CLSA)](#)
  Dalhousie University

- [A tale of eight cities, Age Friendliness and the CLSA](#)
  University of Ottawa

- [Examining Personal and Environmental Factors Associated with Social Isolation and Loneliness Among Canadians](#)
  University of Manitoba

- [A Biopsychosocial Approach to Understanding the Impact of Osteoarthritis on Social Participation: A Population-based Study](#)
  Krembil Research Institute

- [Examining the relationship between oral health, nutrition, and frailty in older adults](#)
  McMaster University

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Keywords – All projects

Questions?
&
Discussion