Transforming Everyday Life
into Extraordinary Ideas

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Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

Advancing the Science of Population Health and Aging through Interdisciplinary Research: Canadian Longitudinal Study on Aging

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The Canadian Association of Population Therapeutics, Toronto, Ontario
**November 18th, 2013**

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DEMOGRAPHY AND AGING

"Population aging is unquestionably the most important demographic force of the first half of the twenty-first century".

(Schoeni FR, Ofstedal MB. *"Key Themes in research on the Demography aging"* Demography, 47, 2010: S5-S15)
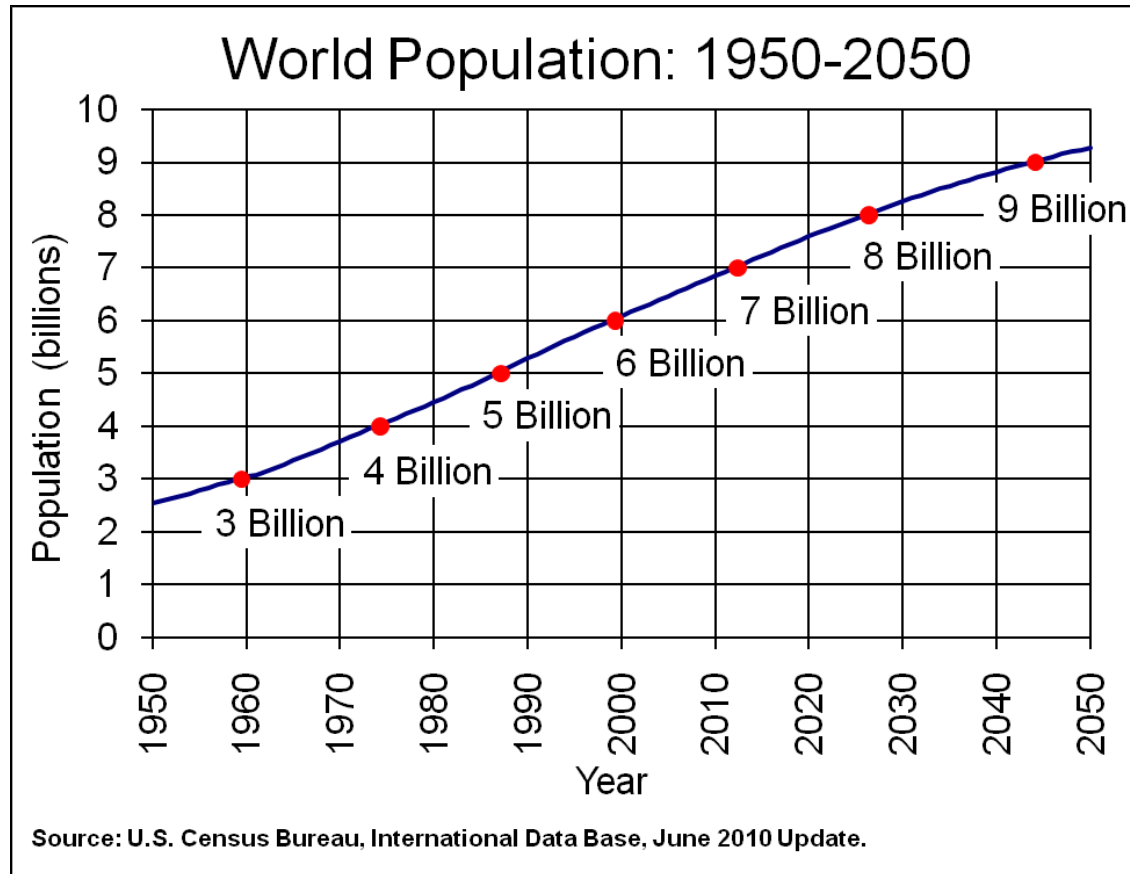
THE DEMOGRAPHIC TRANSITION

THE DEMOGRAPHIC TRANSITION MODEL

(**www.marathon.uwc.edu**)
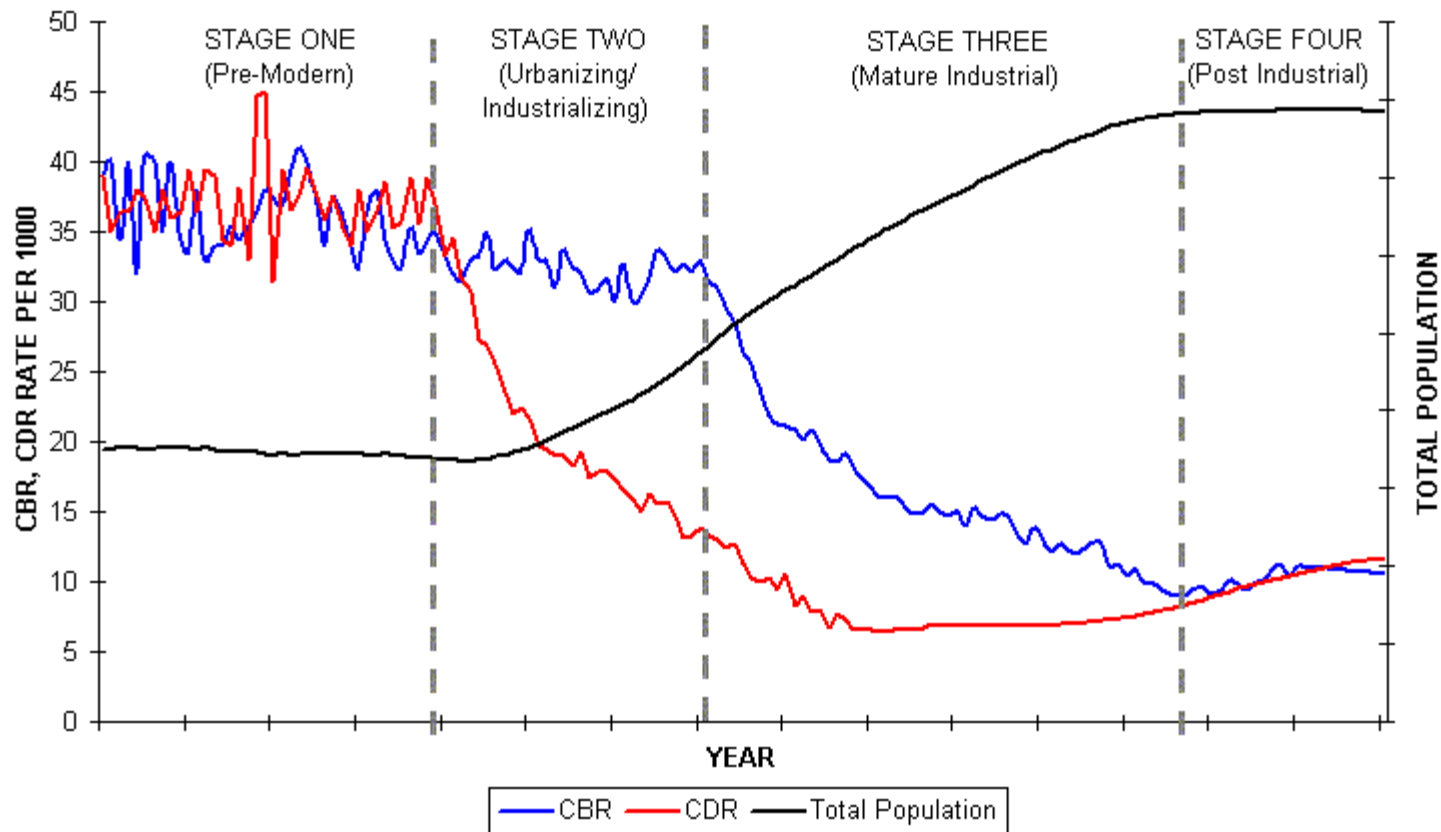
WORLD POPULATION

The world population is rapidly growing:

World Population: 1950-2050

Source: U.S. Census Bureau, International Data Base, June 2010 Update.

WORLD POPULATION AGING

- World population is especially growing older:

  ➔ the <u>share of the population aged 65+</u> is expected to double between 2010 and 2040, from 7.8% to 14.7%

  ➔ the <u>number of older people</u> will increase from 530 million in 2010, to 1.3 billion by 2040.

  (<u>U.S. Census Bureau, International Data Base</u>)

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WORLD POPULATION AGING

- Another aspect of world population aging is the aging of the older population; the share of the older at ages 80+ (the "oldest-old") is growing more rapidly than the older population itself.

- This growth will translate into a large increase of oldest-old within the world's older population, from 16% in 2000 to 24% in 2040.
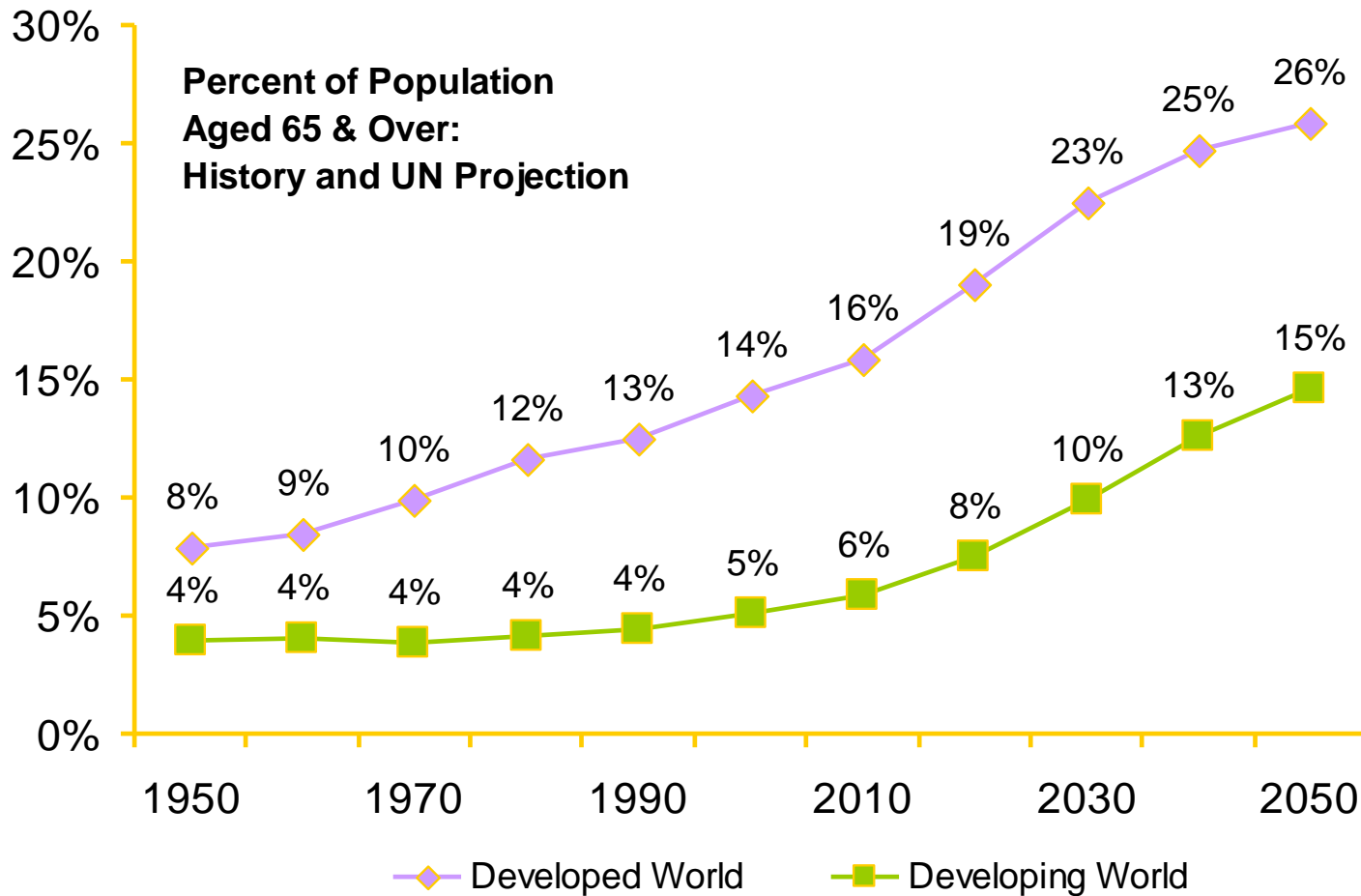 (U.S. Census Bureau, International Data Base)
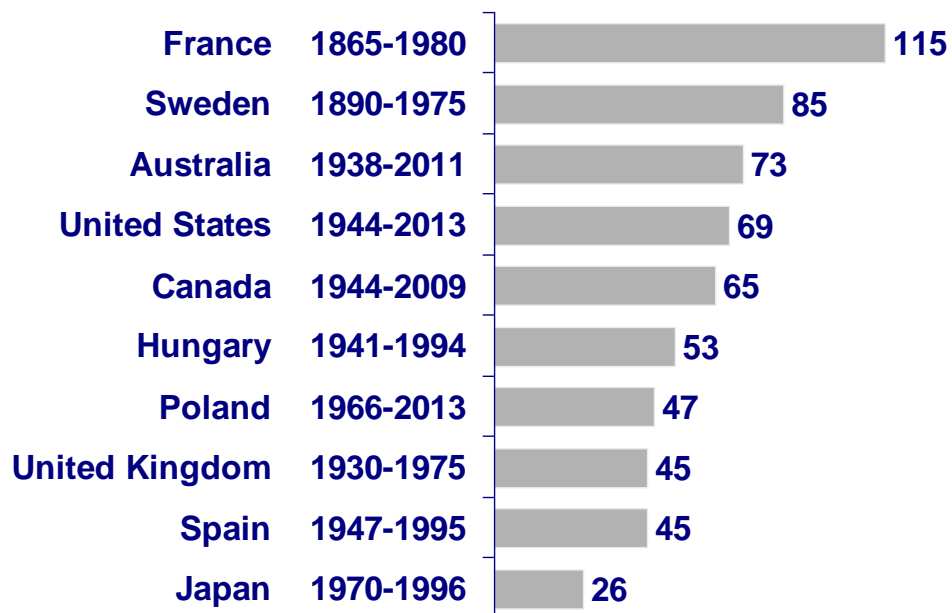
Gender and Aging

- NUMBERS
- MORBIDITY
- POVERTY

Trends in Global Aging

Percent of Population Aged 65 & Over: History and UN Projection

Source: UN (2005)

Number of Years for Percent of Population Age 65 or Older to Rise from 7% to 14%

More developed countries

Country	Years	Value
France	1865-1980	115
Sweden	1890-1975	85
Australia	1938-2011	73
United States	1944-2013	69
Canada	1944-2009	65
Hungary	1941-1994	53
Poland	1966-2013	47
United Kingdom	1930-1975	45
Spain	1947-1995	45
Japan	1970-1996	26

Less developed countries

Country	Years	Value
Azerbaijan	2000-2041	41
Chile	1998-2025	27
China	2000-2026	26
Jamaica	2008-2033	25
Tunisia	2008-2032	24
Sri Lanka	2004-2027	23
Thailand	2003-2025	22
Brazil	2011-2032	21
Colombia	2017-2037	20
Singapore	2000-2019	19

* Dates show the span of years when percent of population age 65 or older rose (or is projected to rise) from 7 percent to 14 percent.
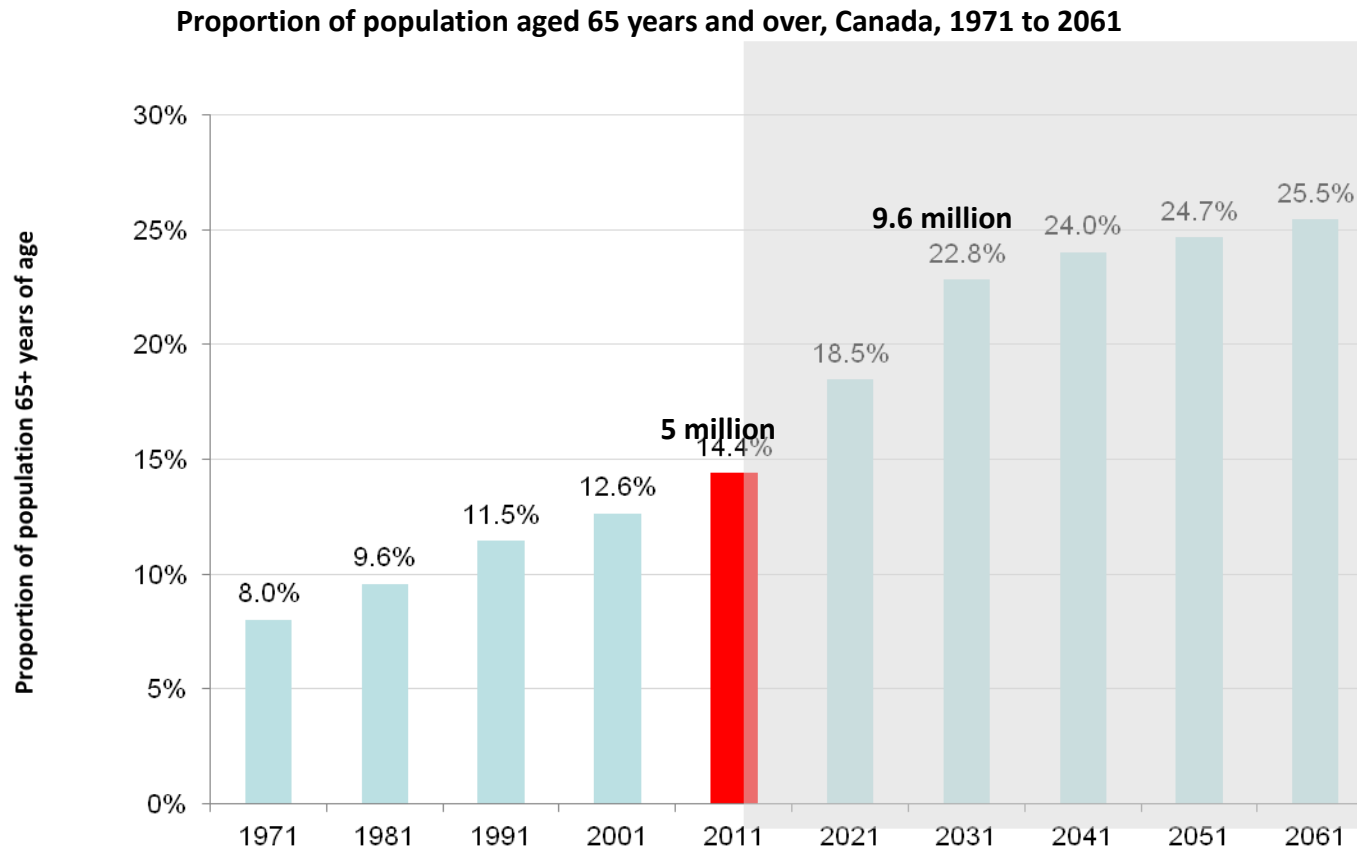Source: K. Kinsella and Y.J. Gist, *Older Workers, Retirement, and Pensions: A Comparative International Chartbook* (1995) and K. Kinsella and D. Phillips, "The Challenge of Global Aging," *Population Bulletin* 60, no. 1 (2005).

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Population Totals in Canada by Age Group and Year

AGE	MALES	BOTH SEXES	FEMALES
80+	229898	670192	440294
75-79	255599	622194	366595
70-74	364298	833991	469693
65-69	497996	1084588	586592
60-64	578596	1190087	611491
55-59	618096	1238387	620291
50-54	673295	1339986	666691
45-49	844194	1674182	829988
40-44	1076892	2138777	1061885
35-39	1173491	2344675	1171184
30-34	1311991	2597873	1285882
25-29	1282190	2528572	1246382
20-24	1067593	2108978	1041385
15-19	984993	1925780	940787
10-14	980292	1912979	932687
5-9	998293	1953079	954786
0-4	1000393	1953280	952887
1991 TOTALS	13938100	28117600	14179500

Population aging

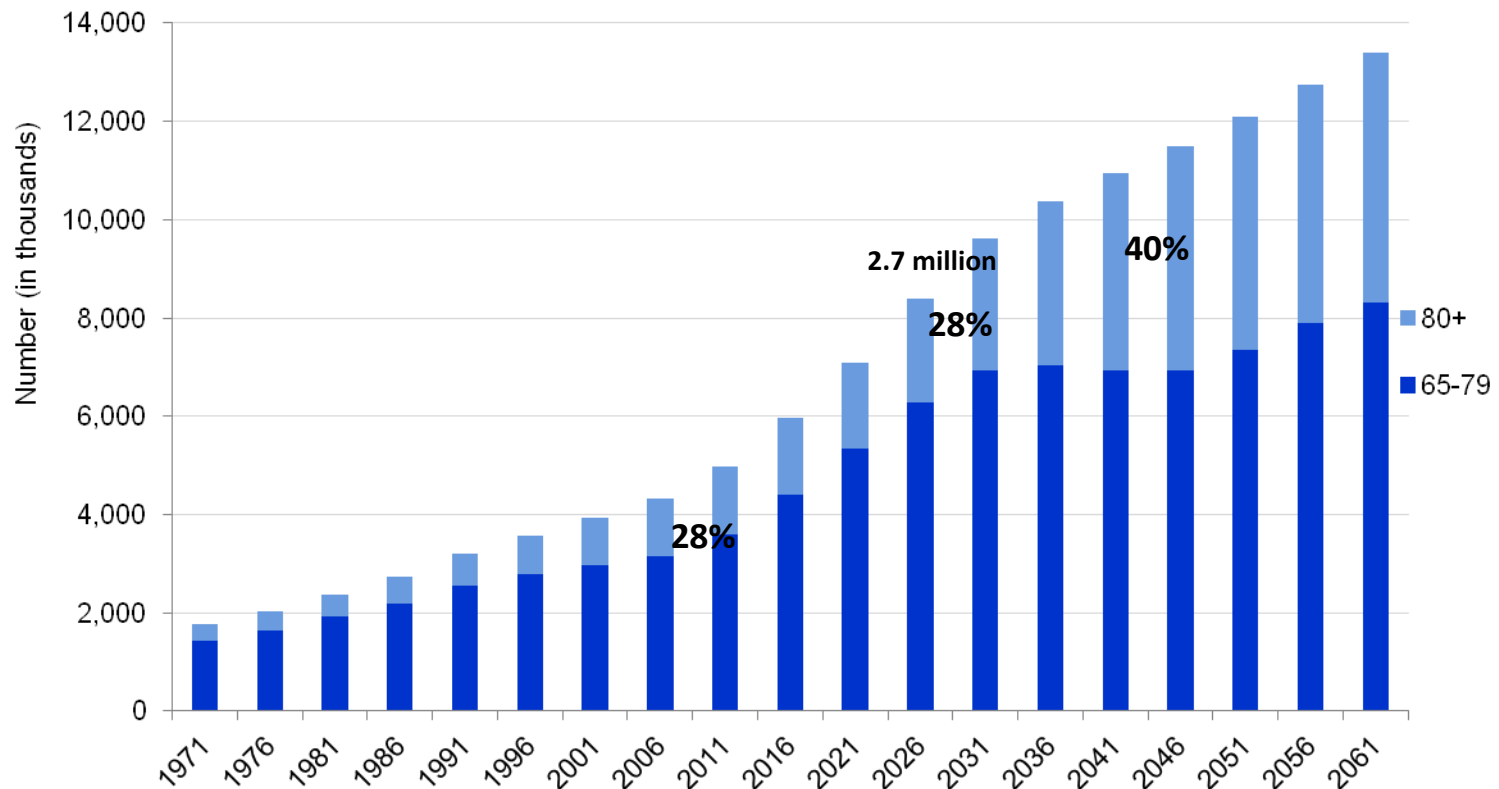## 65+ representing a larger proportion of population and growing

Proportion of population aged 65 years and over, Canada, 1971 to 2061

Source: Census 1971-2011 (projected estimates). Demography Division, Statistics Canada.

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Population aging

80+ representing larger proportion of seniors and also growing

Observed (1971 to 2011) and projected (2016 to 2061) number of people aged 65 to 79 years and 80 years and over, Canada

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EPIDEMIOLOGY OF AGING: DISEASES

- The leading cause of death among elderly:
  - heart disease
  - cancer
  - stroke
  - chronic lower respiratory tract disease
  - Alzheimer's disease

  (Minino et al. National Vital Statistics Reports 2007; 55(9):1-120)

EPIDEMIOLOGY OF AGING: DISEASES

The leading Causes of Morbidity:

- Hypertension

- Osteoprosis

- Osteoarthritis

- Vision/Hearing Problems

- Falls and Fractures

  - Disease in older population is the norm

    - And many have multiple morbidities: Need more research in this area

  - Use of multiple medications

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RESEARCH ON AGING

- The demographic causes of aging of the population, in terms of fertility rates and mortality rates, are generally predictable. A variety of population projections are available, prepared by UN, EU and National Statistic Institutes.

- What is less predictable is the interaction of these forces with social context, health status, economic changes, cultural influences and hence international migrations.

Risk factors for Disease, Disability and longevity

- Risk factors
  - Many factors contribute
  - Gender difference remains unexplained
  - Loss of prediction
  - Paradoxes in prediction
- New opportunities
  - Larger number of very old people
  - Longer term follow-up
  - Longitudinal data – identify optimal trajectory
  - Common risk factors

RESEARCH ON AGING

- For this reason further research on biodemography, dynamic of health, epidemiology, economics, psychology, social sciences and aging are needed.

- Longitudinal data are essential in order to sort causal relationships among demographic, biological, psychosocial and economic factors, and health.

- Cross-national comparison are important, considering variability across societies, in terms of status and well-being of older persons, experiences of health and mortality, family and social support.

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The Canadian Longitudinal Study on Aging (CLSA)

- A key strategic initiative of CIHR
  - The Canadian Longitudinal Study on Aging

- More than 160 researchers - 26 institutions

- Multidisciplinary - biology, genetics, medicine, psychology, sociology, demography, economics, epidemiology, nursing, nutrition, health services, biostatistics, population health
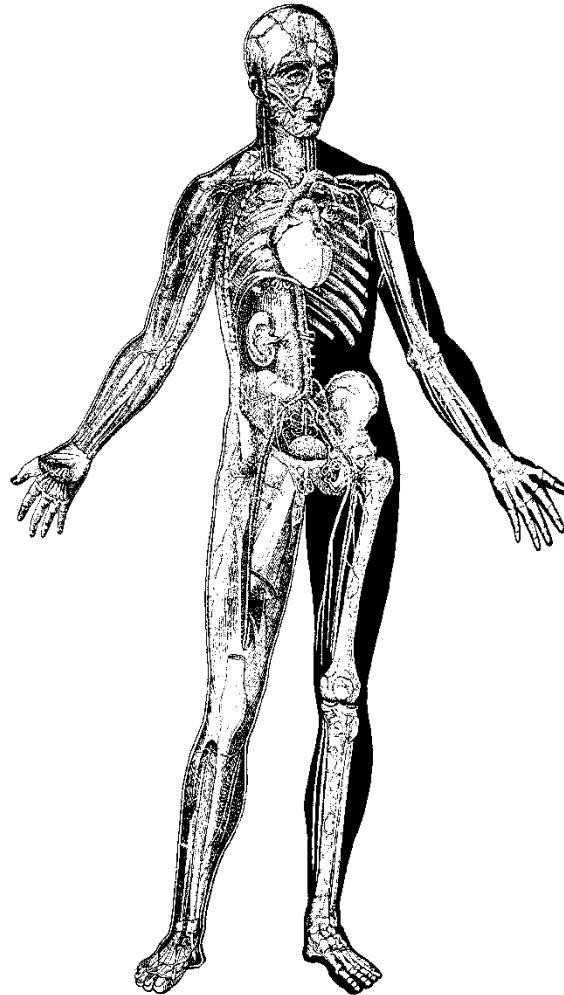
Canadian Longitudinal Study on Aging (CLSA)

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.

Innovation - Cell to Society

- Mid life to old age
- Quantitative traits
  - Physical
  - Social
  - Psychological
- Gene-environment interactions
- Disease, disability, psychosocial consequences
- Adaptation

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Overall Aims of the CLSA

- The progression of **health** from middle-age to early old age to older old age
- The determinants of **well-being and quality of life**
- Risk Factors (including genetics and epigenetics) of **Chronic diseases**
- **Multi-morbidity and its consequences**
- **Medication and pharmacogenomics**
- **Cognitive functioning** and **mental health**
- **Disability** and the compression of morbidity
- Biomarkers of Healthy Aging, Frailty, and Longevity
- The examination of socioeconomic and health **inequalities** in an aging population
- **Social participation, social relationships and care giving** in an aging population
- Veteran's Health and Aging
- **Retirement** and **post retirement** labor market activity

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Study Overview

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

| **n=20,000**
Randomly selected within Provinces | **n=30,000**
Randomly selected
within 25-50 km of 11 sites |

Questionnaire
- **By telephone (CATI)**

Questionnaire
- **In person, in home (CAPI)**

Clinical/physical tests
Blood, urine (consent)
- **At Data Collection Site**

Interim contact, Follow up every 3 years

Data Linkage (consent)

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National Scope

Data collection Sites

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

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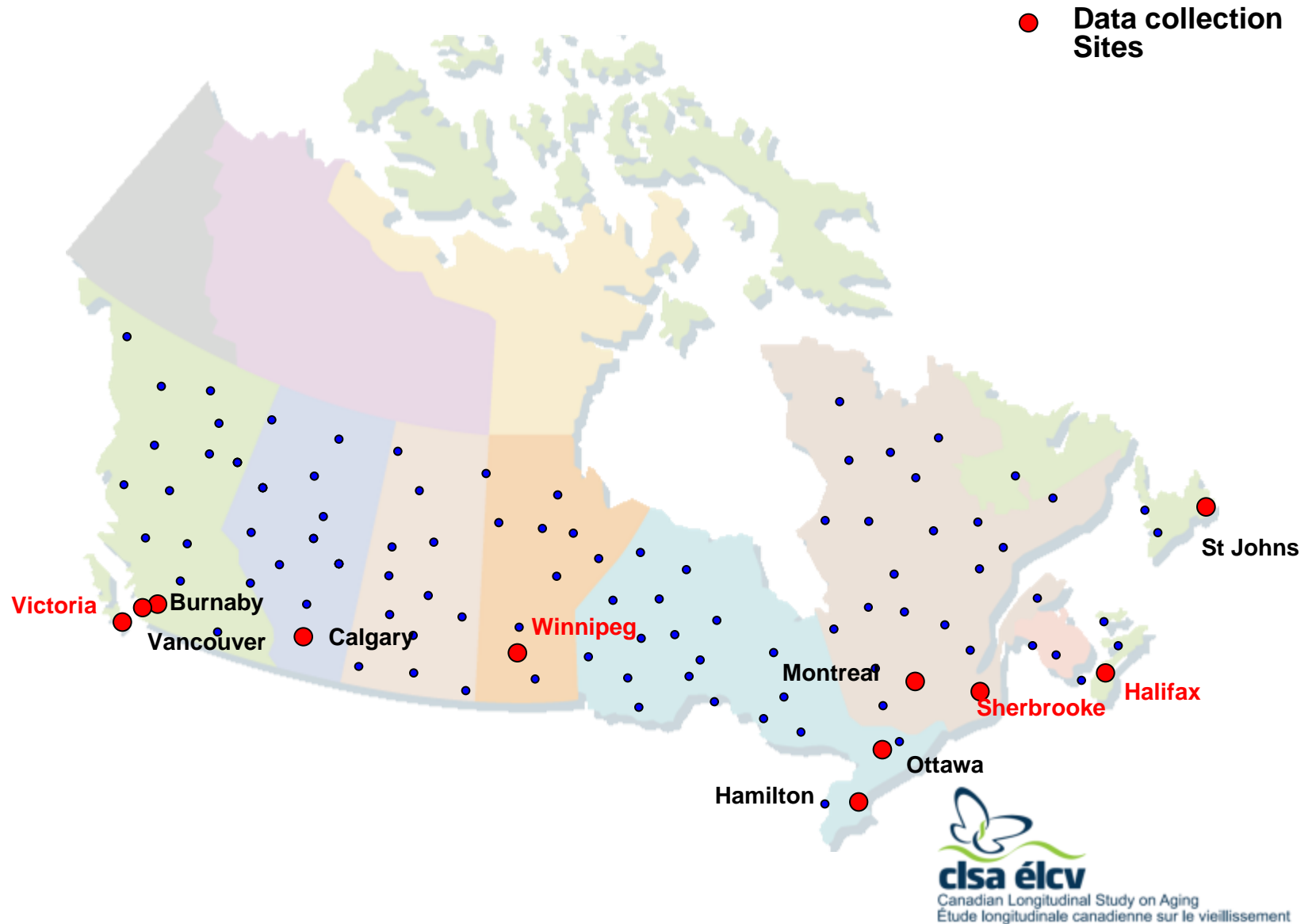
Representative sample frame

- Statistics Canada: Canadian Community Health Survey Cycle 4.2 Healthy Aging

- Ministries of Health: Provincial health billing records

- Random Digit Dialing

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Standardized, Centralized Process

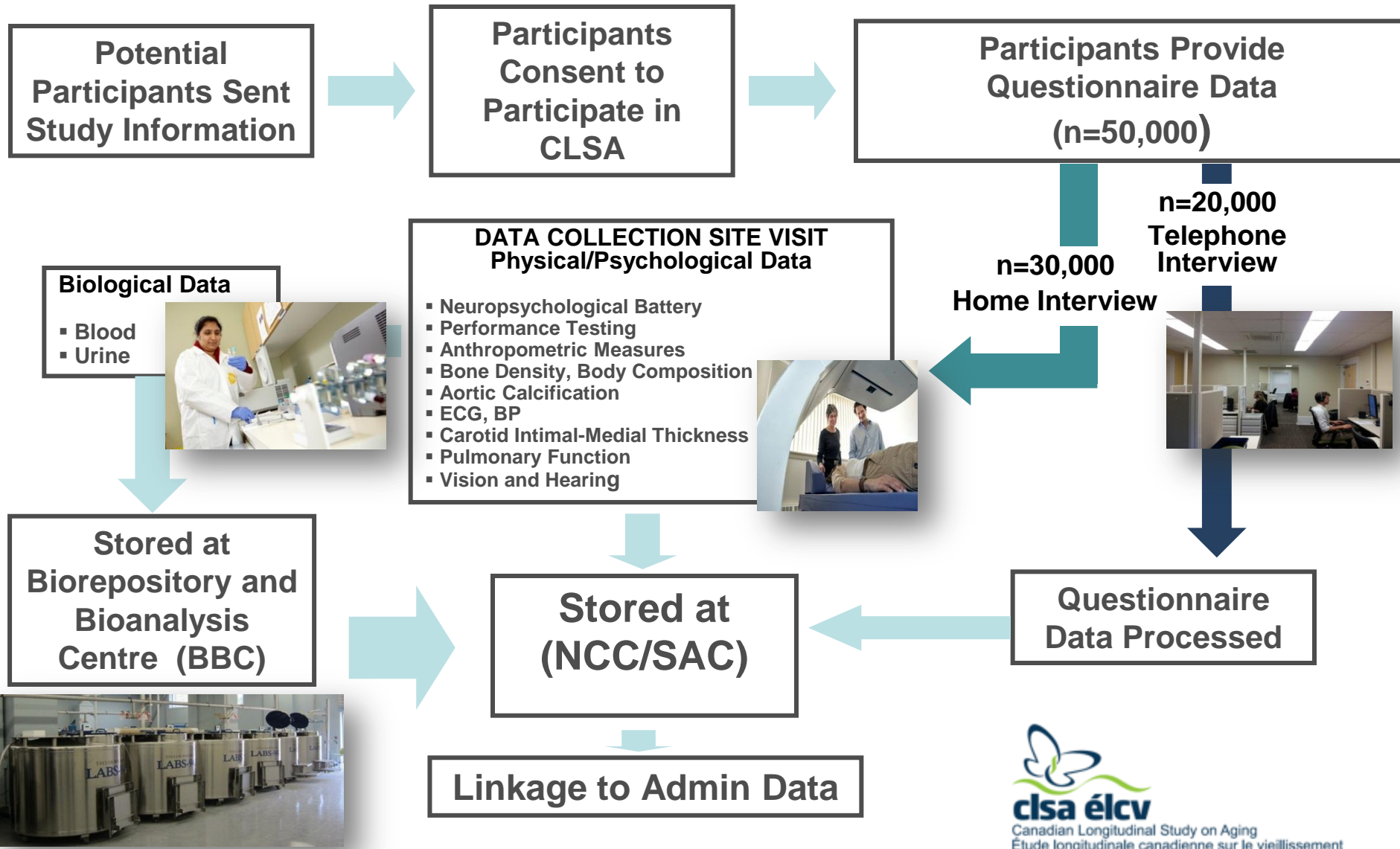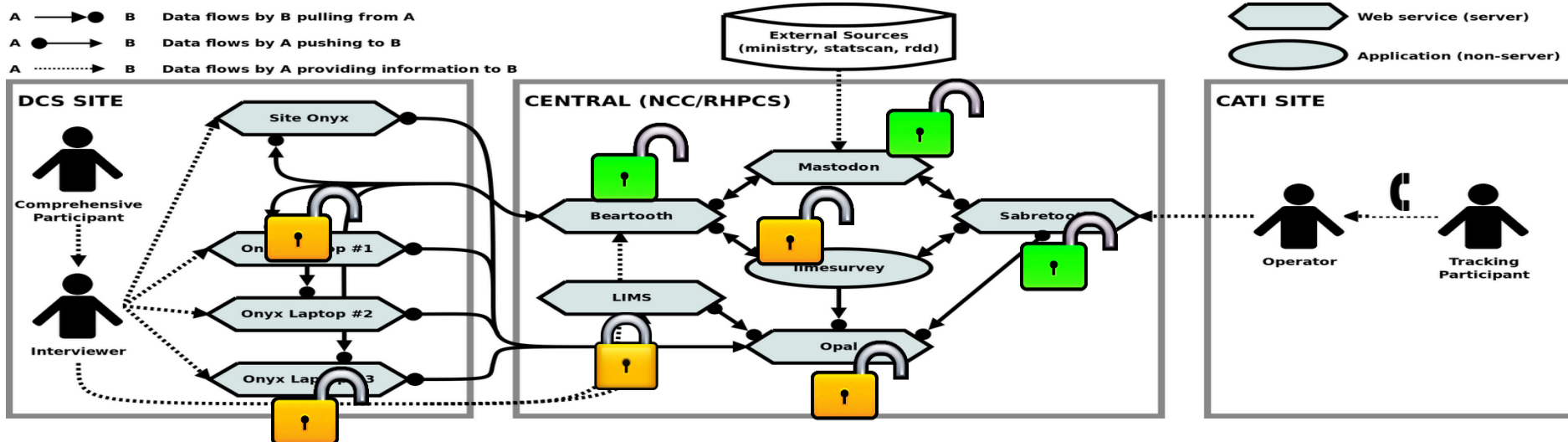**Potential Participants Sent Study Information** → **Participants Consent to Participate in CLSA** → **Participants Provide Questionnaire Data (n=50,000)**

n=30,000 Home Interview

n=20,000 Telephone Interview

Biological Data
- Blood
- Urine

DATA COLLECTION SITE VISIT
Physical/Psychological Data
- Neuropsychological Battery
- Performance Testing
- Anthropometric Measures
- Bone Density, Body Composition
- Aortic Calcification
- ECG, BP
- Carotid Intimal-Medial Thickness
- Pulmonary Function
- Vision and Hearing

Stored at Biorepository and Bioanalysis Centre (BBC) → **Stored at (NCC/SAC)** ← **Questionnaire Data Processed**

Linkage to Admin Data

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CLSA Software Architecture, IT Integration Systems for Paperless Data Collection

Mastodon - manages interactions with participants and securely stores identifying information

Sabretooth & Limesurvey – CATI software manages participant data collection, Interview scheduling and tracks the status of the interviews through to completion

Beartooth & Onyx – CAPI software used by the Data Collection Sites to coordinate the collection of questionnaire responses, physical measurements and biospecimens from participants

Opal – Central Data Repository – or databank – stores and manages all non-identifying data collected using Sabretooth, Beartooth and Onyx

CLSA Infrastructure

- National Coordinating Centre (McMaster)
- Biorepository and Bioanalysis Centre (McMaster)
- Statistical Analysis Centre (McGill)
- Genetics and Epigenetics Centre (UBC)
- 4 Computer-Assisted Telephone Interview Sites
  - Victoria, Winnipeg, Sherbrooke and Halifax
- 11 Data Collection Sites
  - Victoria, Vancouver, Surrey, Calgary, Winnipeg, Hamilton/Toronto, Ottawa, Montreal, Sherbrooke, Halifax and St John's

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Questionnaire Modules

- Demographics
- Veteran ID
- Height, Weight
- Smoking
- Alcohol
- Physical Activity
- Nutritional risk/Nutrition
- General health
- Women's health
- Vision, Hearing
- Oral Health

- Chronic conditions
- Injuries
- Pain, discomfort
- Health care utilization
- Medication/Supplement use
- Functional status
- ADL, IADL
- Cognition (Rey, MAT, AN)
- Parkinsonism module
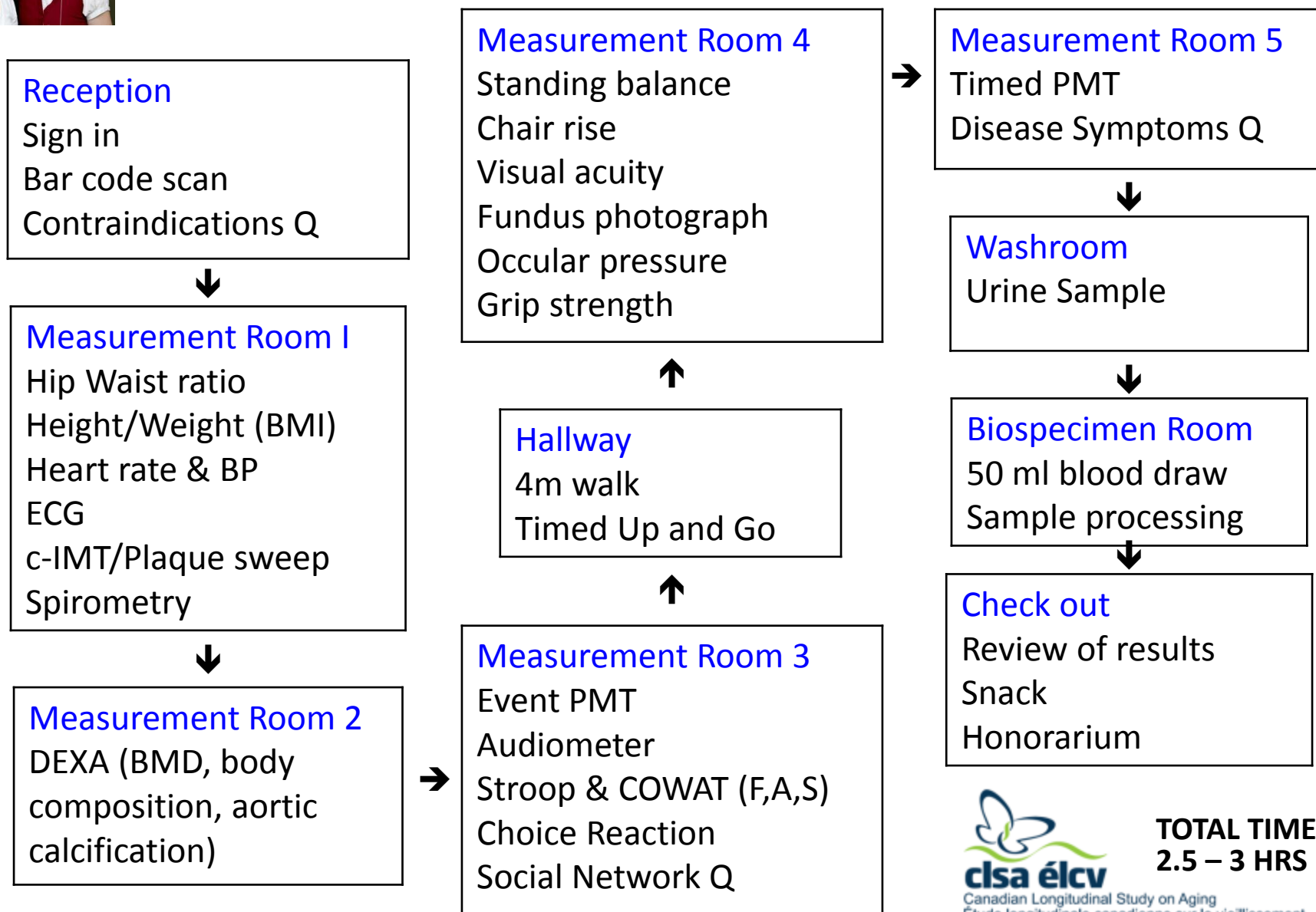- Depression
- PTSD

Questionnaire Modules

- Satisfaction with life
- Psychological distress
- Personality traits
- Social networks
- Social support
- Social participation
- Online social networking
- Social inequality
- Care receiving
- Care giving

- Labour force participation
- Retirement planning
- Transportation
- Mobility, Migration
- Built environments
- Income, Wealth
- Home ownership

At the Data Collection Site

Reception
Sign in
Bar code scan
Contraindications Q

↓

Measurement Room I
Hip Waist ratio
Height/Weight (BMI)
Heart rate & BP
ECG
c-IMT/Plaque sweep
Spirometry

↓

Measurement Room 2
DEXA (BMD, body composition, aortic calcification)

→

Measurement Room 4
Standing balance
Chair rise
Visual acuity
Fundus photograph
Occular pressure
Grip strength

↑

Hallway
4m walk
Timed Up and Go

↑

Measurement Room 3
Event PMT
Audiometer
Stroop & COWAT (F,A,S)
Choice Reaction
Social Network Q

→

Measurement Room 5
Timed PMT
Disease Symptoms Q

↓

Washroom
Urine Sample

↓

Biospecimen Room
50 ml blood draw
Sample processing

↓

Check out
Review of results
Snack
Honorarium

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TOTAL TIME 2.5 – 3 HRS

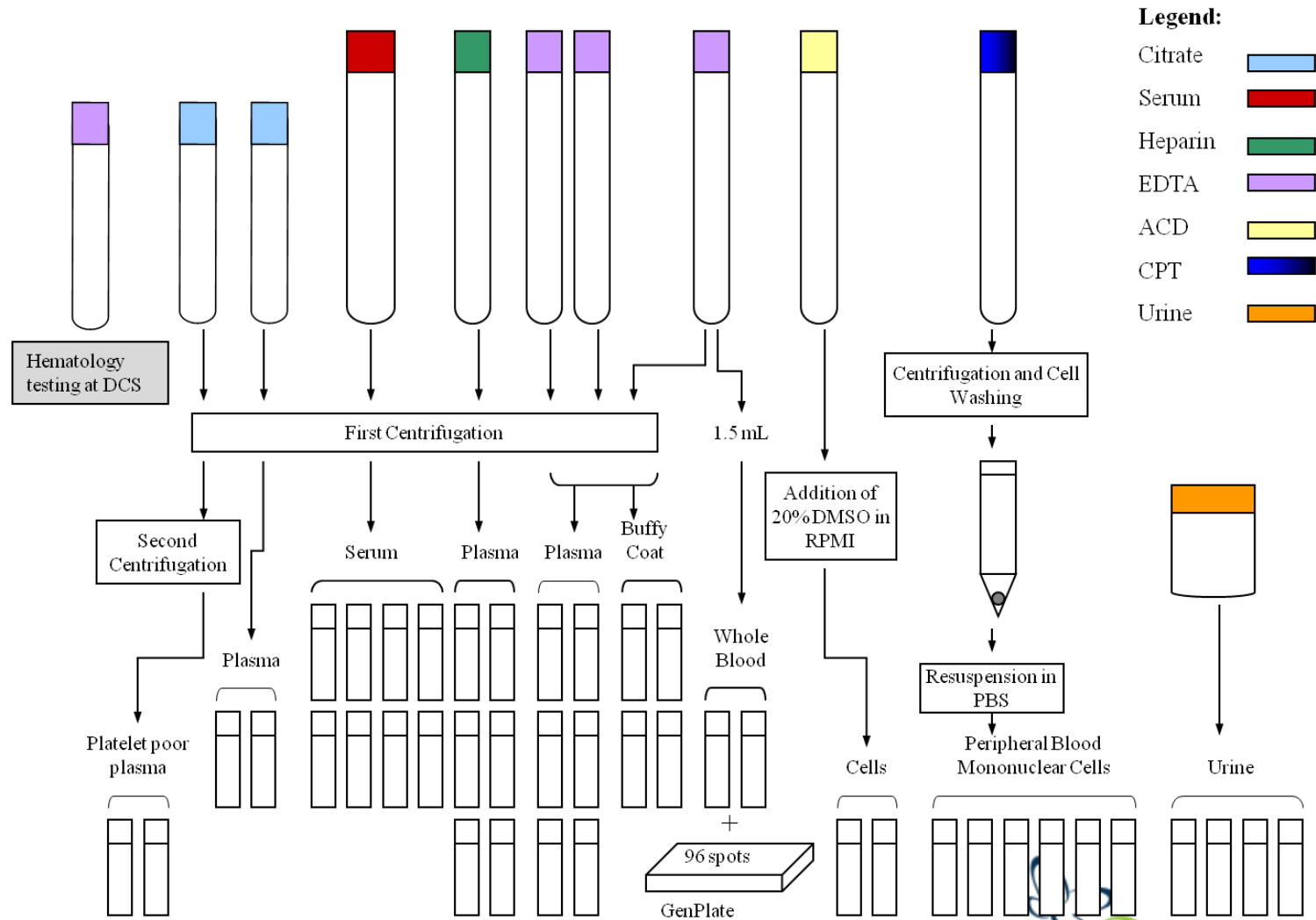# Biospecimen Room
Collection, processing, analysis

- ❑ 5 – 6 participants per day
- ❑ 50 mL blood
- ❑ Urine sample
- ❑ Hematology tests
- ❑ Collection to storage time 2 hour

AcT DIFF, Beckman Coulter

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Biospecimen processing:
42 aliquots per participant

Disease Ascertainment Algorithms

- Diseases will not diagnosed by clinicians
- DAAs developed by CLSA Clinical Working Group
- Validated by pilot studies[1,2]

  - Osteoarthritis-knee, hip, hand
  - Parkinsonism
  - CAO
  - Diabetes
  - Hypo- and Hyperthyroidism
  - Ischemic heart disease

  - HBP
  - Stroke/Cerebrovascular event
  - Osteoporosis
  - Depression
  - Dementia

[1]*Raina PS, et al. Can J Aging 2009;28(3):275-85*

[2]*Oremus M, et al. Can J Aging 2013;32(3):232-9*

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Proposed Data Linkages

- Regular linkage with mortality databases between waves of data collection
  - Decedent Questionnaire implemented for first follow-up
- Air pollution data (in collaboration with Health Canada)
- Environmental Biomarker and Aging (INSPQ)
- Administrative data linkage health services & drugs & other administrative databases for participant who provide consent

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Proposed Sub Studies

- Neuroimaging (collaboration with CCNA)
- Genetic analysis (NueroXChip)
- Mobility and Aging (funded through CIHR)
- Environmental Biomarker and Aging (INSPQ)
- Veterans Health and Aging (Veteran's Affairs Canada)
- Falls and Consumer Products (PHAC)
- Neurological disorders of Aging (PHAC)

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CLSA Recruitment: Where are we now?

Telephone-Administered Questionnaires

- Goal: Completion of all 20,000 baseline interviews by early 2014

- As of last week:
  - ➤ 20,376 completed 60-minute baseline interview
  - ➤ 885 completed maintaining contact interview (mid wave)

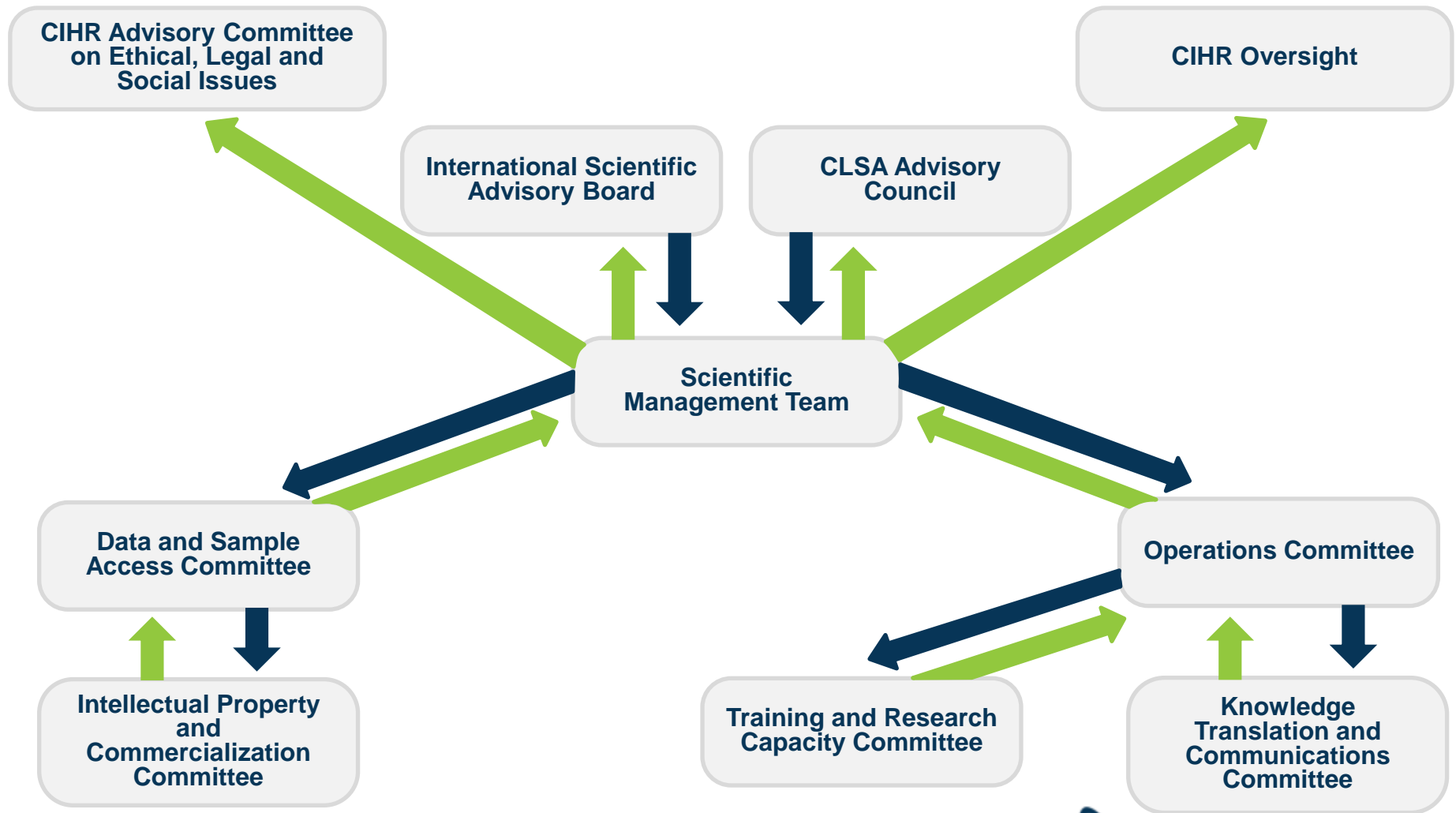***In-home Interviews and DCS Visits***

- Goal: complete first 30,000 baseline DCS visits by March 2015

- As of last week:
  - ➤ 15,298 In home interviews completed
  - ➤ 12,777 DCS visits completed

Preparing for the next wave that begins in April 2015

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What is required to create a centralized platform like CLSA?

- Good governance

- Coordinated ongoing ethics approval process

- Transparent Data and Sample Access Policies

- Transparent Data Ownership and IP Policies

- Integrated and secure IT infrastructure

CLSA Governance Structure

CIHR Advisory Committee on Ethical, Legal and Social Issues

CIHR Oversight

International Scientific Advisory Board

CLSA Advisory Council

Scientific Management Team

Data and Sample Access Committee

Operations Committee

Intellectual Property and Commercialization Committee

Training and Research Capacity Committee

Knowledge Translation and Communications Committee

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Data and Sample Access

- Data and samples 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 biological samples* must be safeguarded at all times
  - CLSA data and biological samples are resources that will be used optimally to support research to benefit all Canadians.

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What is the process to access data?

- 20,000 CATI Interviews: anticipate data to be available mid-2014

- Application process via CLSA website portal

- Review: Administrative, Data and Sample Access Committee recommendation

- Approval, data/sample sharing agreements

- Raw data and/or samples to investigator

- Return of derived variables to CLSA dataset

Harmonization and Global Observatory on Aging

- ## International collaboration and CLSA
  - EU FP7 funded Project: Creating a network of about 30 cohorts across Canada, Europe, Israel, China, and USA
  - CHANCES: Healthy Aging (already funded by EU): 10 Cohorts
  - Frailty Consortium (submitted to EU)
  - NIH funded harmonization consortium of cognitive aging

- ## Individual level pooled analysis and cross-national comparison

- ## Technical and methods development for harmonization

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CLSA CORE TEAM

Lead PI	Parminder Raina **(McMaster)**
CO-PI	Christina Wolfson **(McGill)** and Susan Kirkland **(Dalhousie)**
Key Senior Co-Investigators	Gerry Mugford, Patrick Parfrey **(Memorial)**, Helene Payette **(Sherbrooke)**, Ron Postuma **(McGill)**, Vanessa Taler, Larry Chambers **(Ottawa)**, Harry Shannon, Cynthia Balion, Christopher Patterson, Lauren Griffith and Mark Oremus **(McMaster)**, Mary Thompson and Chang Bo **(Waterloo)**, Debra Sheets, Lynne Young, Holly Tuokko, **(Victoria)**, Verena Menec **(Manitoba)**, David Hogan and Marc Poulin **(Calgary)**, Max Cynader, Michael Hayden and Michael Kobor **(UBC)** and Andrew Wister, Scott Lear **(SFU)**
Scientific Working Group	**See our website – www.clsa-elcv.ca**

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Canadian Longitudinal
Study on Aging

32,735 Participants so far

50,000 goal

Sherbrooke Launch April 2012

Our Mission

Transforming everyday life into extraordinary ideas

The Canadian Longitudinal Study on Aging (CLSA) is a large, national, long-term study that will follow approximately 50,000 men and women between 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's 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.

Dr. Parminder Raina (McMaster University, Hamilton) is the lead principal investigator of the CLSA. Dr. Christina Wolfson (McGill University, Montreal) and Dr. Susan Kirkland (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.

For more information, please contact us at info@clsa-elcv.ca.

News

Oct 8th
Montreal site reaches 1,000 visits
The Canadian Longitudinal Study on Aging (CLSA) achieved a milestone at the Montreal Data Collection Site this week when the site welcomed its 1,000th participant.

Oct 1st
Living Longer, Living Better: Is there a secret to longevity?
Join us for "Living Longer, Living Better: Is there a secret to longevity?" on Oct. 16, 2013 in Halifax, Nova Scotia.

Sep 26th
Winnipeg: A thousand participants and counting
By sharing his experience as he ages, Alex Waywood is committed to helping Canadians age better in the future.

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Provincial & Institutional Partners

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UBC McMaster University Bruyère

Funders

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CIHR IRSC INNOVATION.CA

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