Transforming Everyday Life
into Extraordinary Ideas

Canadian Longitudinal Study on Aging (CLSA) as a Platform for Research on Aging

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Concordia University, January, 2018, Montreal, CA

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CLSA Leads

Lead Principal Investigator
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Co-principal Investigator
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WORLD POPULATION

The world population is rapidly growing:

World Population: 1950-2050

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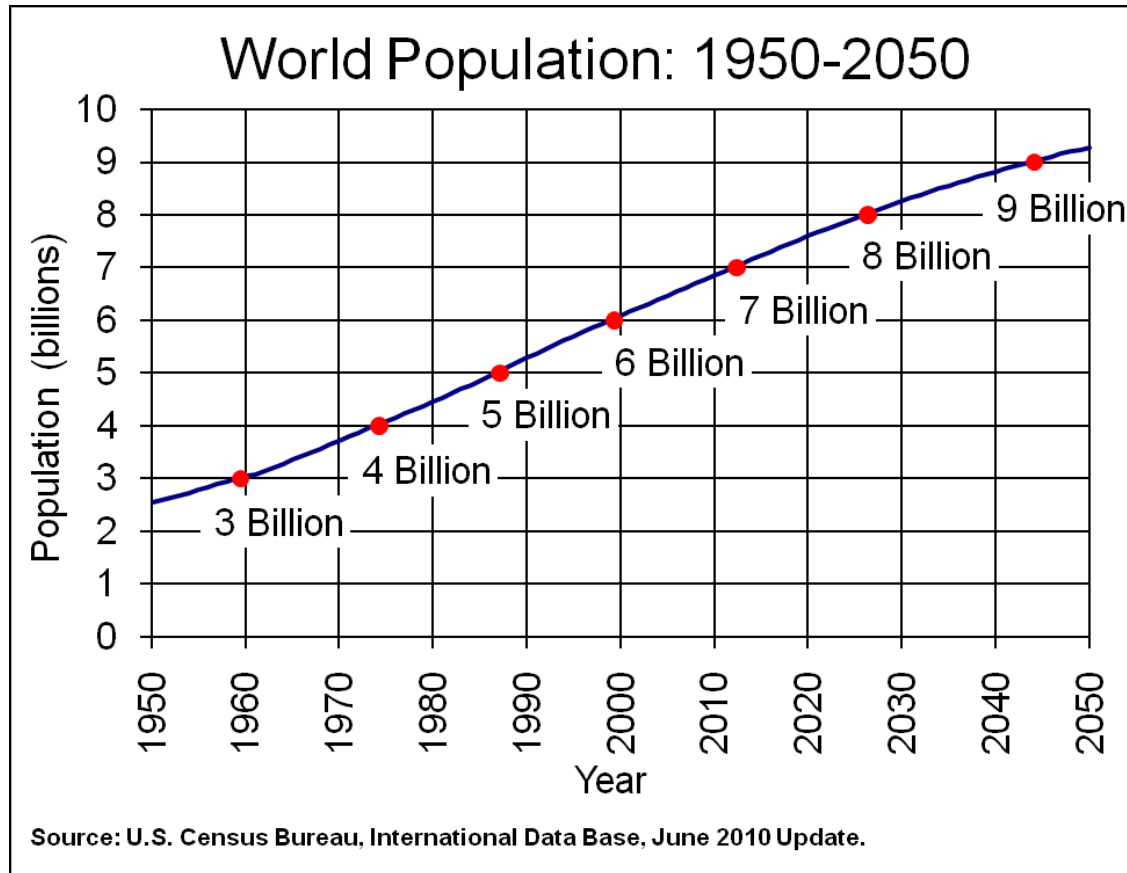
WORLD POPULATION AGING

- 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.

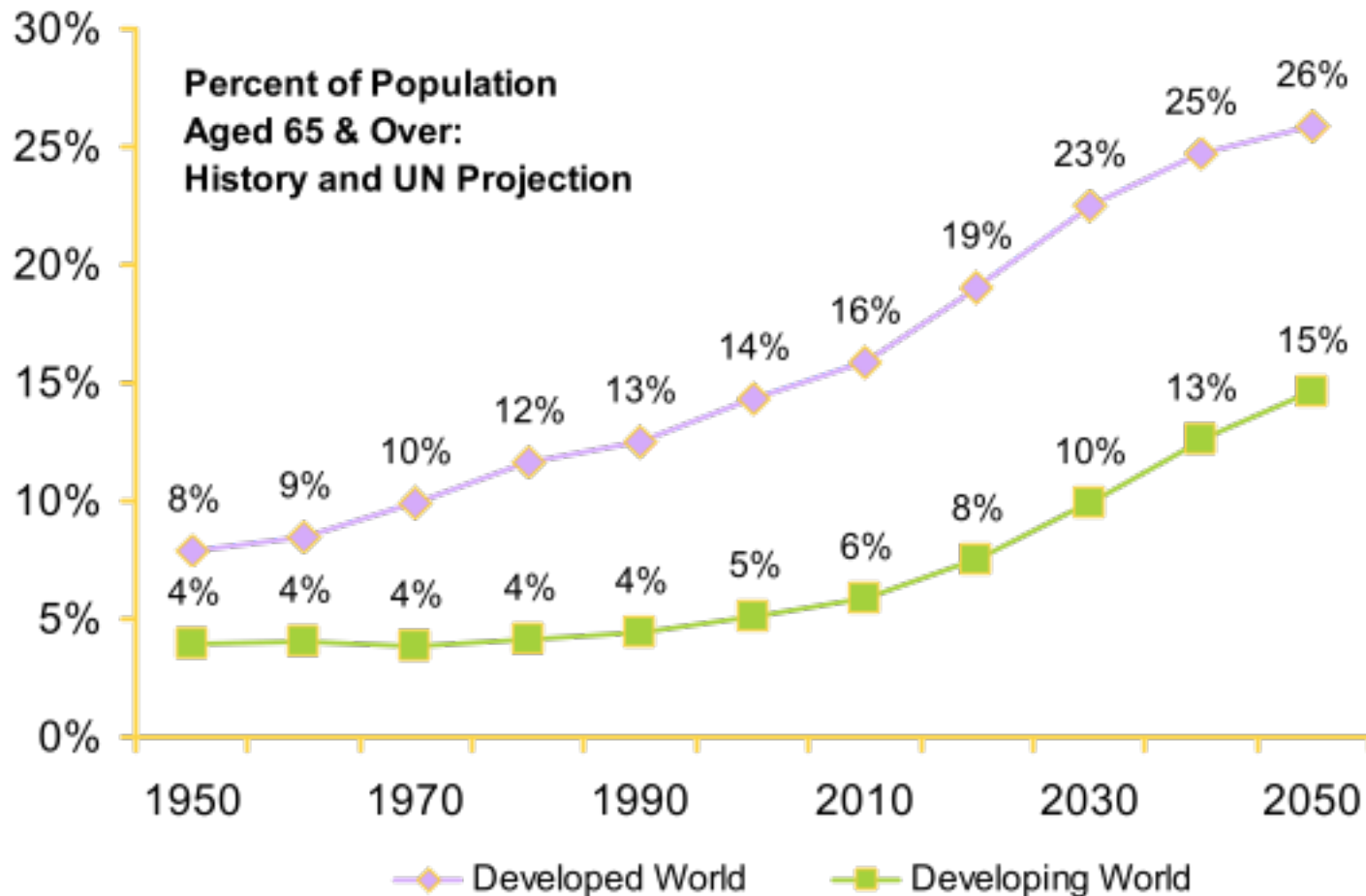 (<u>U.S. Census Bureau, International Data Base</u>)

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
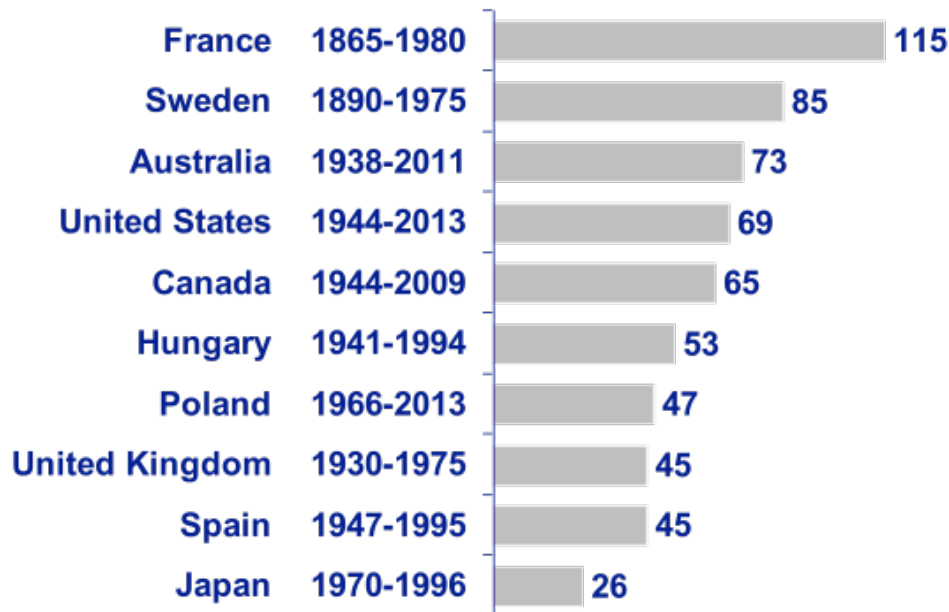

Percent of Population Aged 65 & Over: History and UN Projection

Developed World: 8%, 9%, 10%, 12%, 13%, 14%, 16%, 19%, 23%, 25%, 26%

Developing World: 4%, 4%, 4%, 4%, 4%, 5%, 6%, 8%, 10%, 13%, 15%

Years: 1950, 1970, 1990, 2010, 2030, 2050

Legend: Developed World, Developing World

Source: UN (2005)

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

More developed countries

Country	Years	
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	
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

THE GLOBE AND MAIL*

Canada shows its age as seniors outnumber children for first time

ERIC ANDREW-GEE

The Globe and Mail

Published Tuesday, Sep. 29, 2015 9:50PM EDT

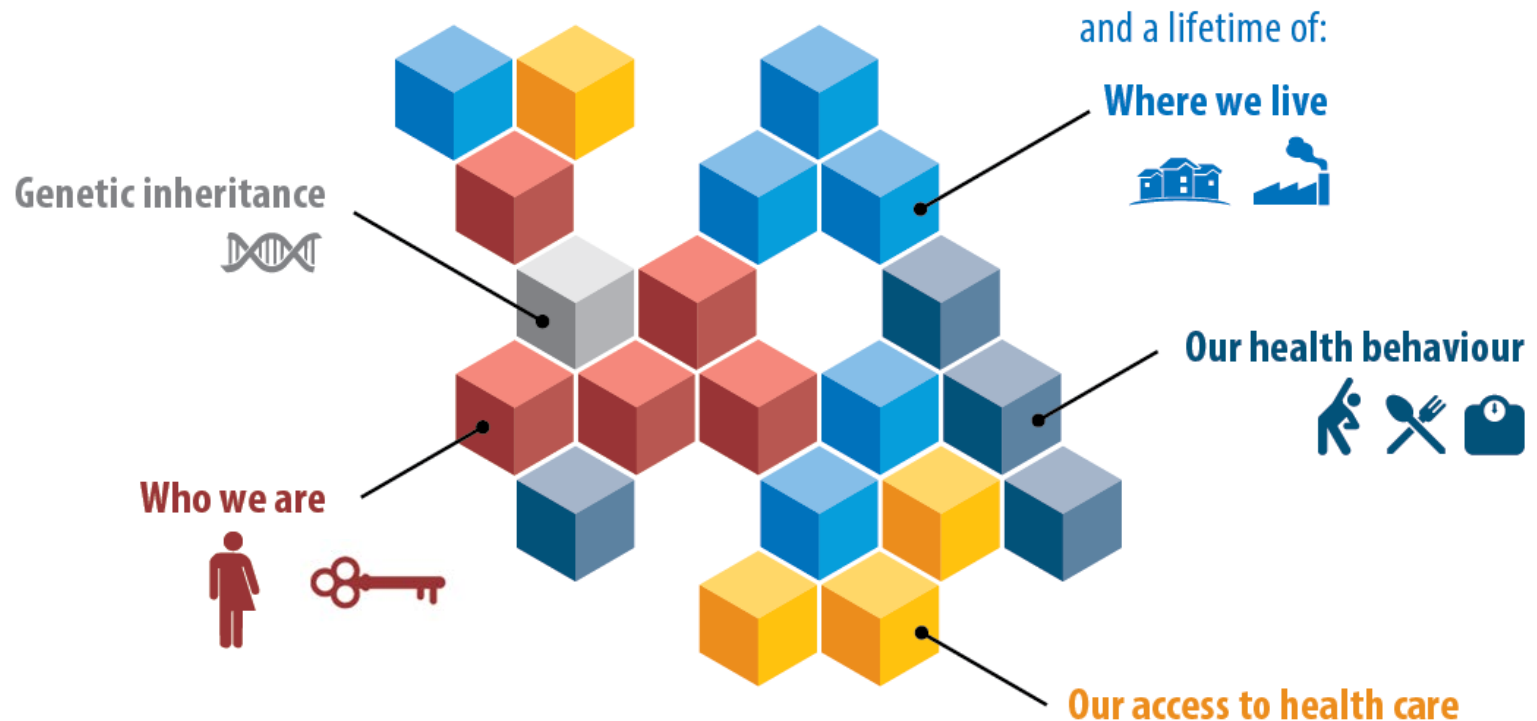Last updated Wednesday, Sep. 30, 2015 8:07AM EDT

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Canadian Longitudinal Study on Aging
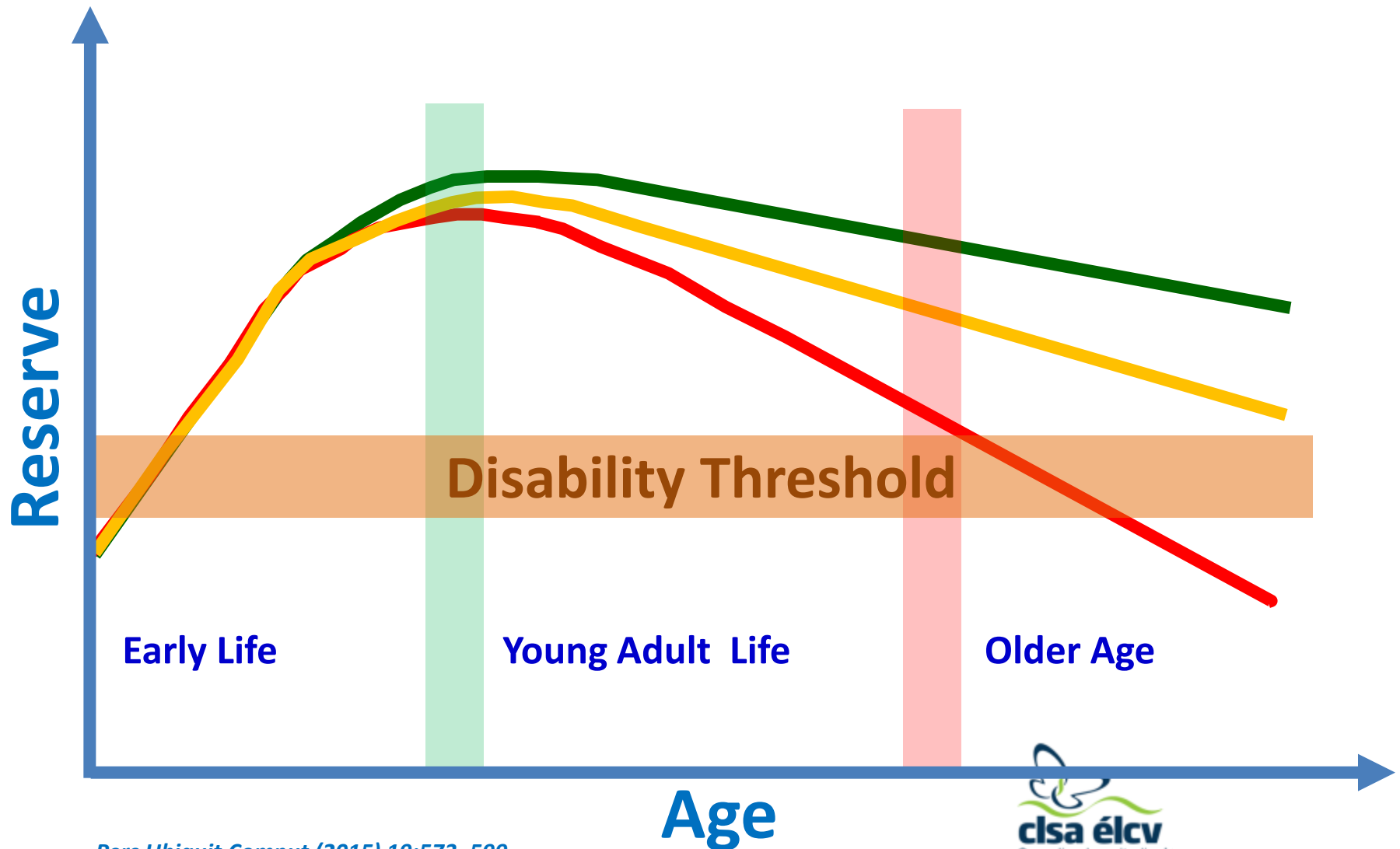Étude longitudinale canadienne sur le vieillissement

There is no "typical" older person

Health and Functional Abilities in older age are not random

What makes us age differently?

Genetic inheritance

Who we are

and a lifetime of:

Where we live

Our health behaviour

Our access to health care

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Heterogeneity of Aging

What do we know or don't know?

- Risk factors
  - Many factors contribute
  - Aging populations are not homogeneous
  - Environmental and Climate influences remain unexplained
  - Gender difference remains unexplained
  - Paradoxes in prediction
- New opportunities
  - Larger number of very old people
  - Longer term follow-up
  - Longitudinal data – identify optimal trajectory
  - Common risk factors

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Future Opportunities

- **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. (CLSA)

- **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. (PURE and Harmonization with international cohorts)
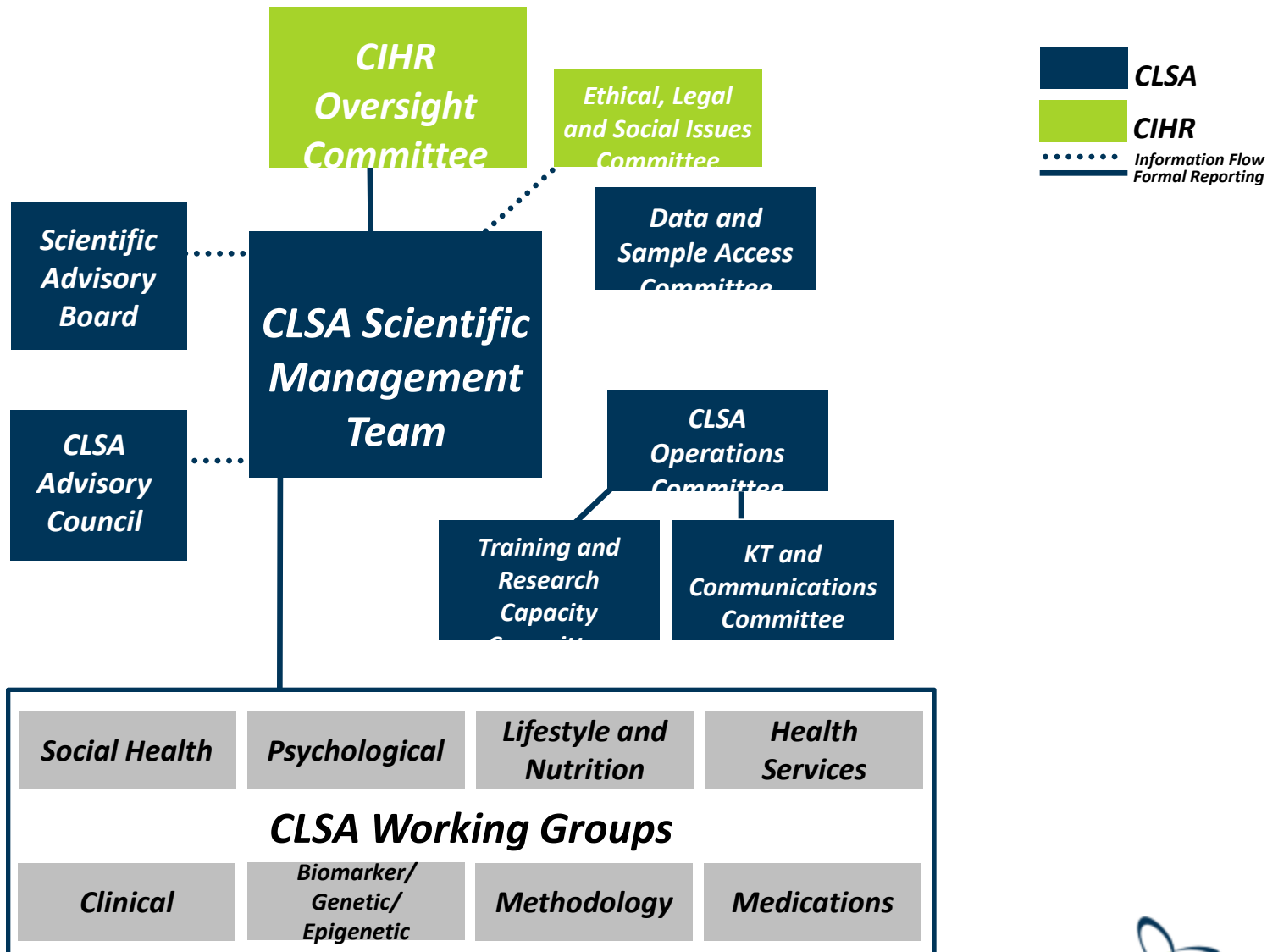
What is the Canadian Longitudinal Study on Aging (CLSA)?

"*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

Governance

CIHR Oversight Committee

Ethical, Legal and Social Issues Committee

Data and Sample Access Committee

Scientific Advisory Board

CLSA Scientific Management Team

CLSA Advisory Council

CLSA Operations Committee

Training and Research Capacity Committee

KT and Communications Committee

CLSA Working Groups

Social Health

Psychological

Lifestyle and Nutrition

Health Services

Clinical

Biomarker/ Genetic/ Epigenetic

Methodology

Medications

CLSA

CIHR

Information Flow
Formal Reporting

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The CLSA platform collects data and biospecimens from:

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

Questionnaires by telephone interview (~150 min) on 21,241 participants
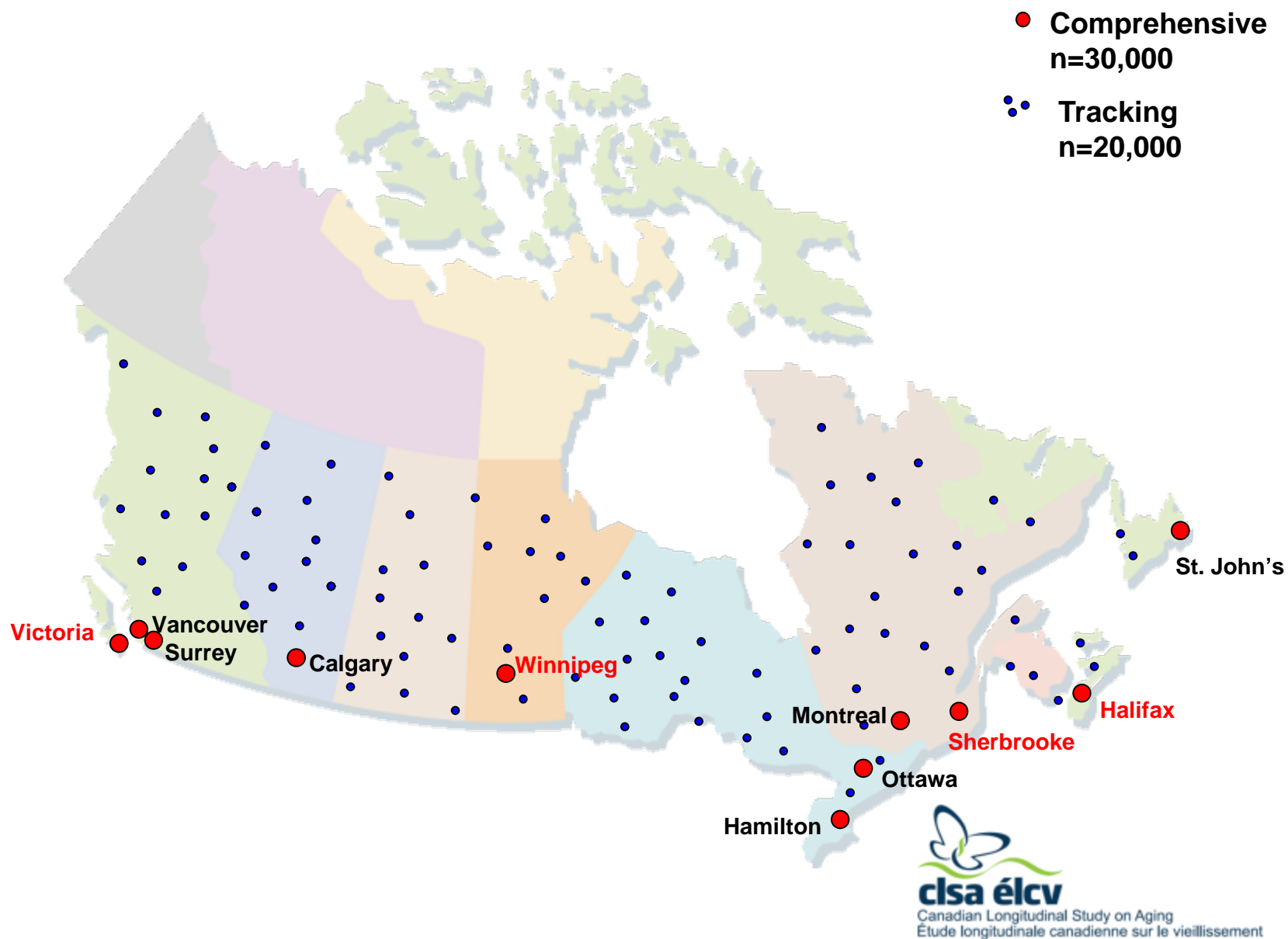
Randomly selected 10 provinces

Questionnaires by in-person interviews (~60 min) and physical assessments (~180 min) on 30,097 participants

Randomly selected 25-50 km of 11 sites in 7 provinces

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

Data Linkage with health care, mortality and disease registries

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Participant Recruitment

CLSA Overview

2010-2015   **2015**   **2018**   2021   2024   2027   2031

TIME
20 Years

Participants (51,338)

Enrolled — MC F MC F MC F MC F MC F MC F MC F

Questionnaire Data (telephone and in person interviews) (>50,000)

Physical Exam and Biological Specimen (>30,000)

Active Follow-up (**F**) Every 3 years
- Questionnaire
- Physical exam
- Biological samples

Maintaining Contact (**MC**) mid-wave
- Update contact information & implement Retention strategies

Active Follow-up Every 3 years
- Questionnaires
- Physical exams
- Biological samples
- Implement sub-studies

Data Linkage

Data and Biological Sample Repositories

Researchers

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How did we recruit our Sample

- **Telephone Interviews** Recruitment of **21,241 participants** (age 45-85) for telephone interviews:
  - ✓ Statistics Canada CCHS on Healthy Aging
  - ✓ Provincial Health Care Registries
  - ✓ Random Digit Dialing

- **Home Interviews and Data Collection Site Visits** Recruitment of **30,097 participants** (age 45-85) for Home Interviews and Data Collection Site Visits:
  - ✓ Provincial Health Care Registries
  - ✓ Random Digit Dialing

- Baseline data collection completed on 51,338 participants
- Data are available to researchers now, additional data and biospecimen release in 2017
- First follow-up ongoing and to be completed early 2018 (2/3rd completed)
    Retention rates to date are about 98%

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CLSA Data Processing

Telephone interview (n=20,000)

Home interview and data collection site visit (n=30,000)

Blood and urine stored in Biorepository and Bioanalysis Centre (BBC)

Questionnaire data processed

Data stored in National Coordinating Centre/ Statistical Analysis Centre (NCC/SAC)

Linkage to administrative data with consent

Major Challenge for a National Platform

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Depth and Breadth of Baseline CLSA

PHYSICAL & COGNITIVE MEASUREMENTS

- Height & weight
- Waist and hip measurements
- Blood Pressure
- Grip strength, timed up-and-go, chair raise, 4-m walk
  Standing balance
- Vision (retinal imaging, Tonometer & visual acuity)
- Hearing (audiometer)
- Spirometry
- Body composition (DEXA)
- Bone density (DEXA)
- Aortic calcification (DEXA)
- ECG
- Carotid Plaque sweep (ultrasound) (Only at baseline)
- Carotid intima-media thickness (ultrasound)
- Cognitive assessment (30 min. battery)
- Neuroimaging (Pilot sub-study) (Follow-up 2)

HEALTH INFORMATION

- Chronic disease symptoms **(disease algorithm)**
- Medication and supplements intake
- Women's health
- Self-reported health service use
- Oral health
- Preventative health
- Administrative data linkage health services & drugs & other administrative databases

PSYCHOSOCIAL

- Social participation
- Social networks and support
- Caregiving and care receiving
- Mood, psychological distress
- Veteran's Identifier & PTSD
- Coping, adaptation
- Injuries and consumer products
- Work-to-retirement transitions
- Retirement planning
- Social inequalities
- Mobility-life space
- Transportation
- Built environments & Contextual Factors
- Air Pollution
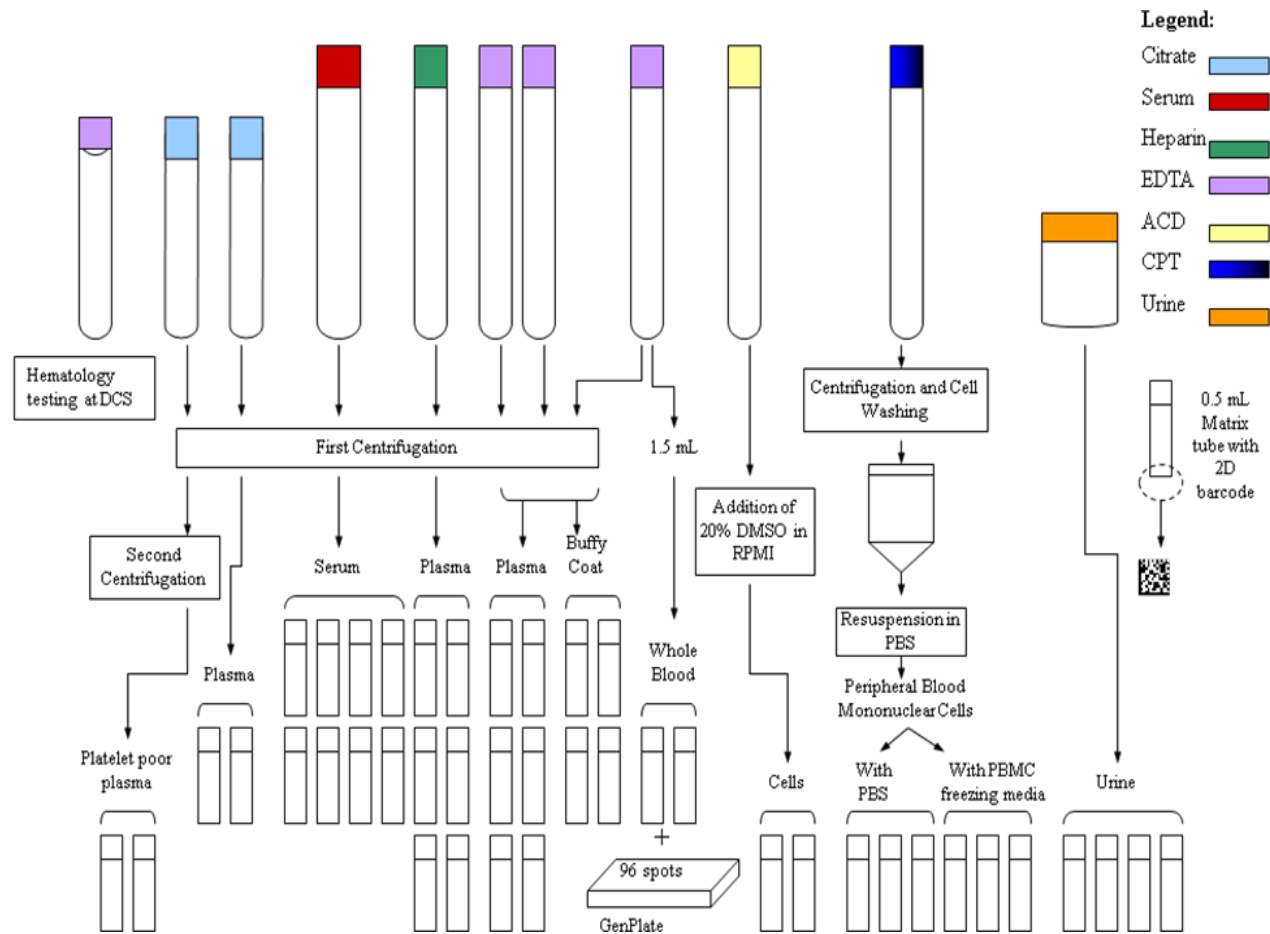- Income, Wealth and Assets

LIFESTYLE & SOCIODEMOGRAPHIC

- Smoking
- Alcohol consumption
- Physical activity (PASE)
- Nutrition (nutritional risk and food frequency)
- Birth location
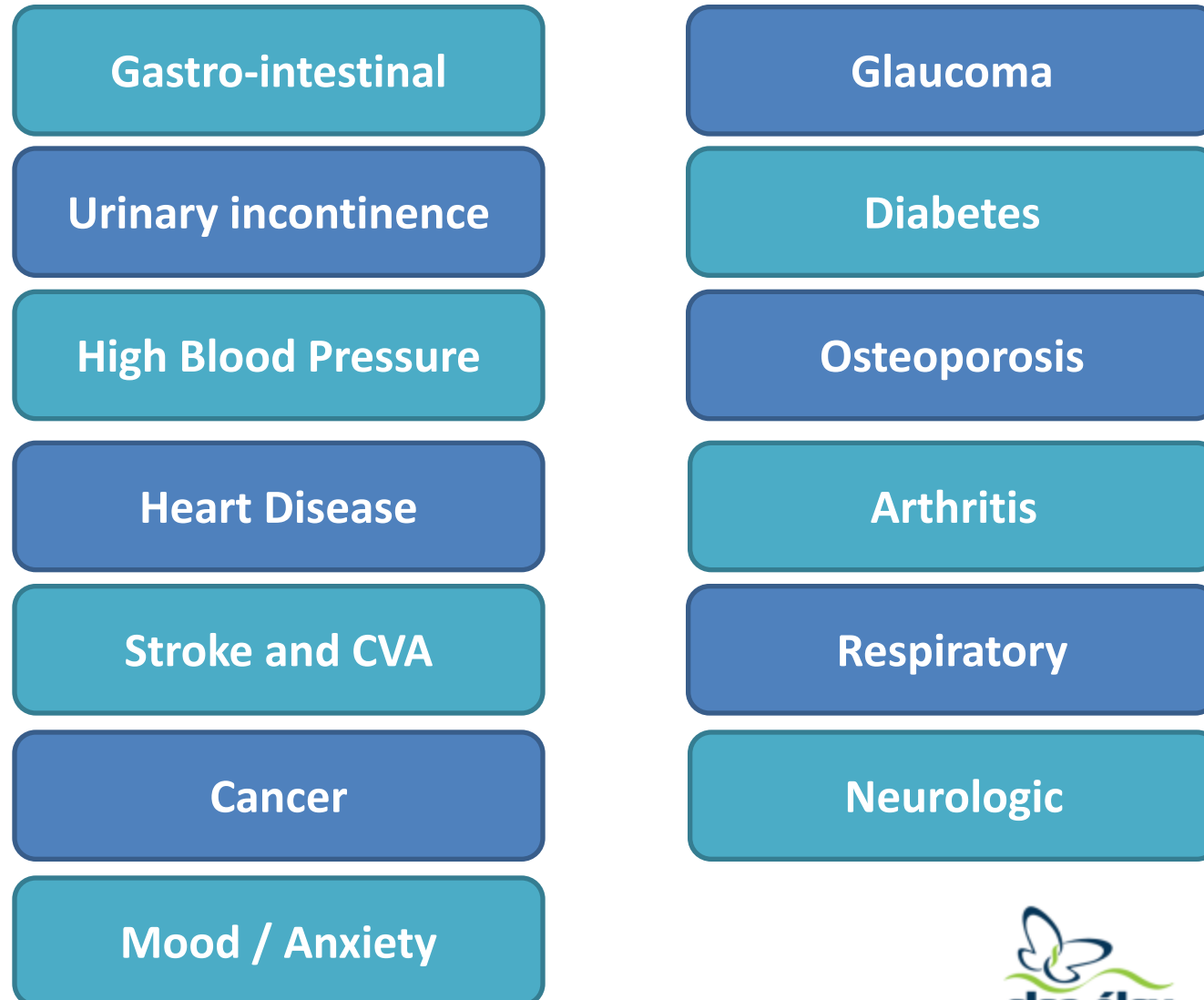- Ethnicity/race/gender
- Marital status
- Education

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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 •LDL •Alanine Aminotransferase • Non-HDL •Creatinine •Thyroid stimulating hormone •Ferritin •Triglycerides •Free T4 •25-Hydroxyvitamin D •Hemoglobin A1c •C-reactive protein •Cholesterol • HDL
	Genome-wide Genotyping McGill University and Génome Québec Innovation Centre	**20,000**	• DNA extracted on all 30,000 • 820K UK Biobank Axiom Array (Affymetrix)
	DNA Methylation Profiling UBC Genetics and Epigenetics Centre	1500	• PBMCs used for DNA extraction • 850K Infinium MethylationEPIC BeadChip (Illumina)
	Metabolomics Kyoto, Japan	1,000	• Mass spectrometry

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CLSA Data Available on Chronic Diseases:

Gastro-intestinal	Glaucoma
Urinary incontinence	Diabetes
High Blood Pressure	Osteoporosis
Heart Disease	Arthritis
Stroke and CVA	Respiratory
Cancer	Neurologic
Mood / Anxiety	

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Additional content 2015-2018
(based on Working Groups, Collaborations & Partnerships)

- Child Maltreatment and adverse events
- Elder Abuse
- Epilepsy
- Decedent Information
  - Link with provincial mortality data (completed in all provinces except for BC and QC (in progress)
  - Primary data collection for end-of-life
- Transition to Institutions
  - Primary data collection versus using InterRai or equivalent data
- Workability
- Subjective Cognitive Decline and Meta Memory
- Preventive Health Behaviours
- Sexual orientation and Gender Identity

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Additional content 2018-2021
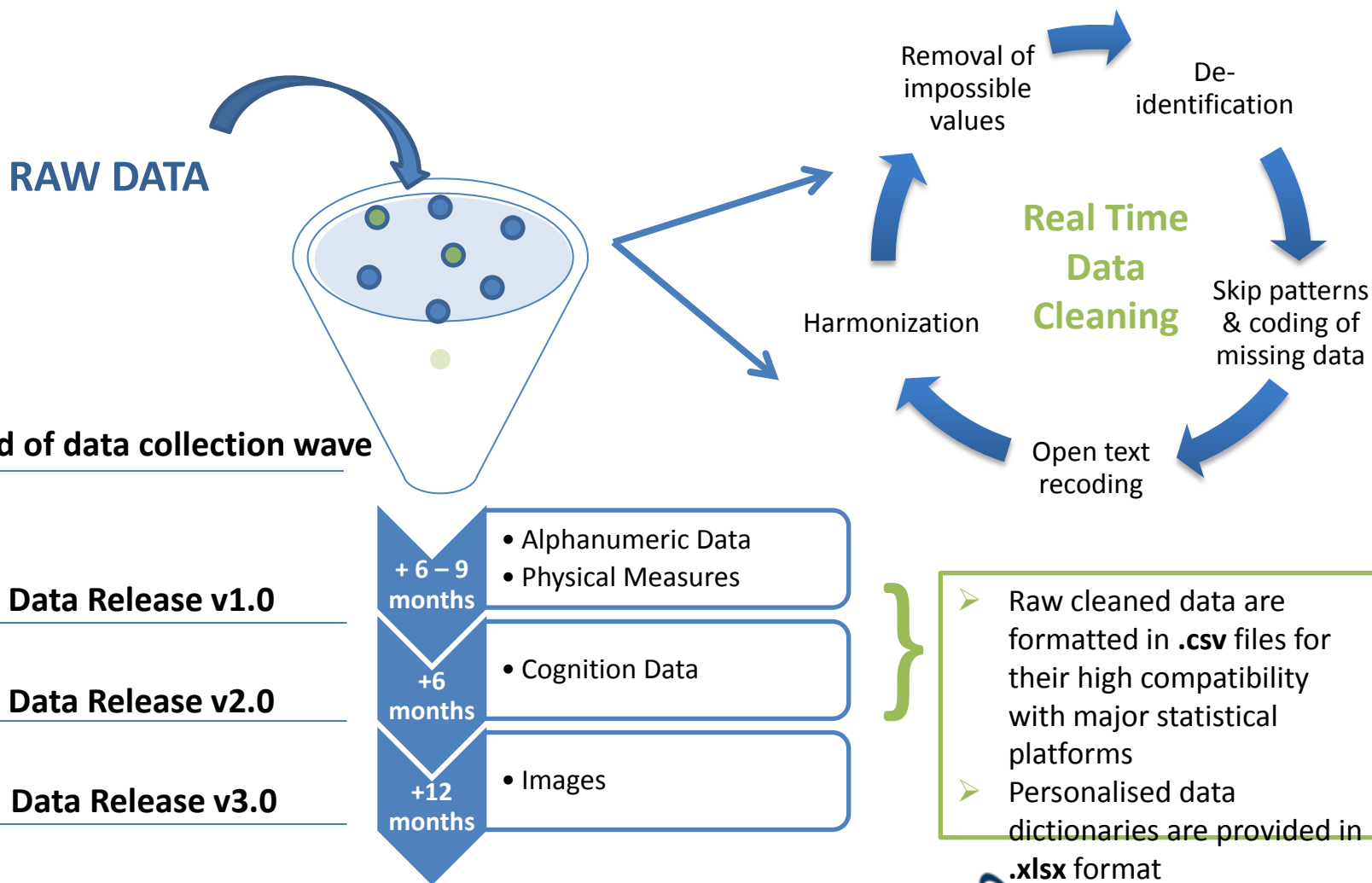## (based on Working Groups, Collaborations & Partnerships)

- New Modules
  - Intimate Partner Violence (PHAC)
  - Enhancing Mental Health (PHAC)
  - Anxiety (PHAC)
  - Dementia assessments
  - More enhanced modules on Hearing
  - Measures of Visceral fat

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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

Data Preparation

RAW DATA

3 Years – End of data collection wave

Data Release v1.0

Data Release v2.0

Data Release v3.0

+ 6 – 9 months
- Alphanumeric Data
- Physical Measures

+6 months
- Cognition Data

+12 months
- Images

Removal of impossible values

De-identification

Real Time Data Cleaning

Skip patterns & coding of missing data

Open text recoding

Harmonization

> Raw cleaned data are formatted in **.csv** files for their high compatibility with major statistical platforms
> Personalised data dictionaries are provided in **.xlsx** format

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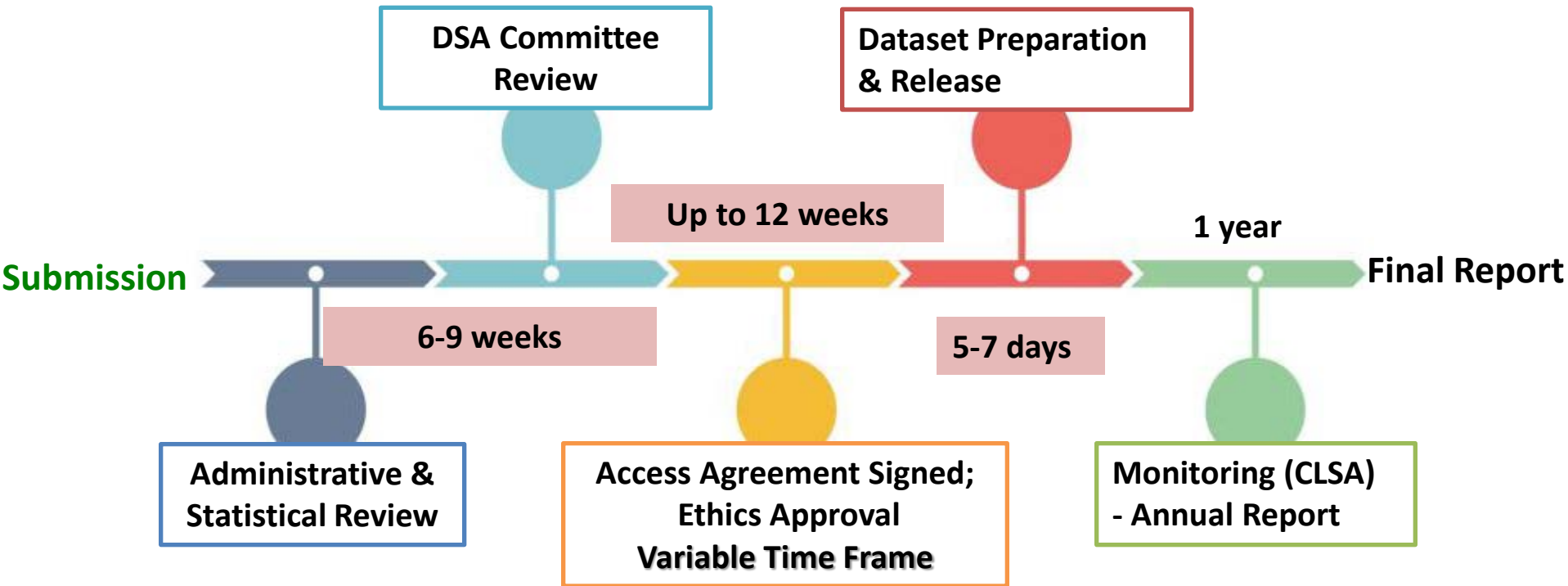# How to access the CLSA Research Platform?

Data and Biospecimen Access

- All data become part of the CLSA platform

- 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 must be used optimally to support research to benefit all Canadians.

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The process to access CLSA data

- via **CLSA DataPreview** portal
  - ➢ https://datapreview.clsa-elcv.ca/
- **Review**: Administrative → Data and Sample Access Committee → Scientific Management Team
- **Approval:** Preparation of CLSA access agreement, verification of ethics approval, cost recovery
- **Release:** Raw data provided to approved investigator
- **Enhance:** Return of derived variables to CLSA dataset as appropriate

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Data Access Timeline

DSA Committee Review

Dataset Preparation & Release

Up to 12 weeks

1 year

Submission

6-9 weeks

5-7 days

Final Report

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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Current use of the CLSA Research Platform

➢ To date 100+ research projects approved and ongoing using CLSA data (less than 2 years)

➢ 50+ partnerships/collaborations with federal and provincial governments, research organizations, associations, charities and industry to expand and enrich the CLSA Research Platform

➢ Over 50 HQP have been or are being trained

Keywords – All projects

Passive Data Collection Work in progress

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

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

www.clsa-elcv.ca

CLSA Funders and Partners