Showcasing the CLSA research platform

Latest updates on data collection, data availability and data access

May 27, 2025

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Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

Overview

- CLSA Research Platform
- Data Availability
- Data Access

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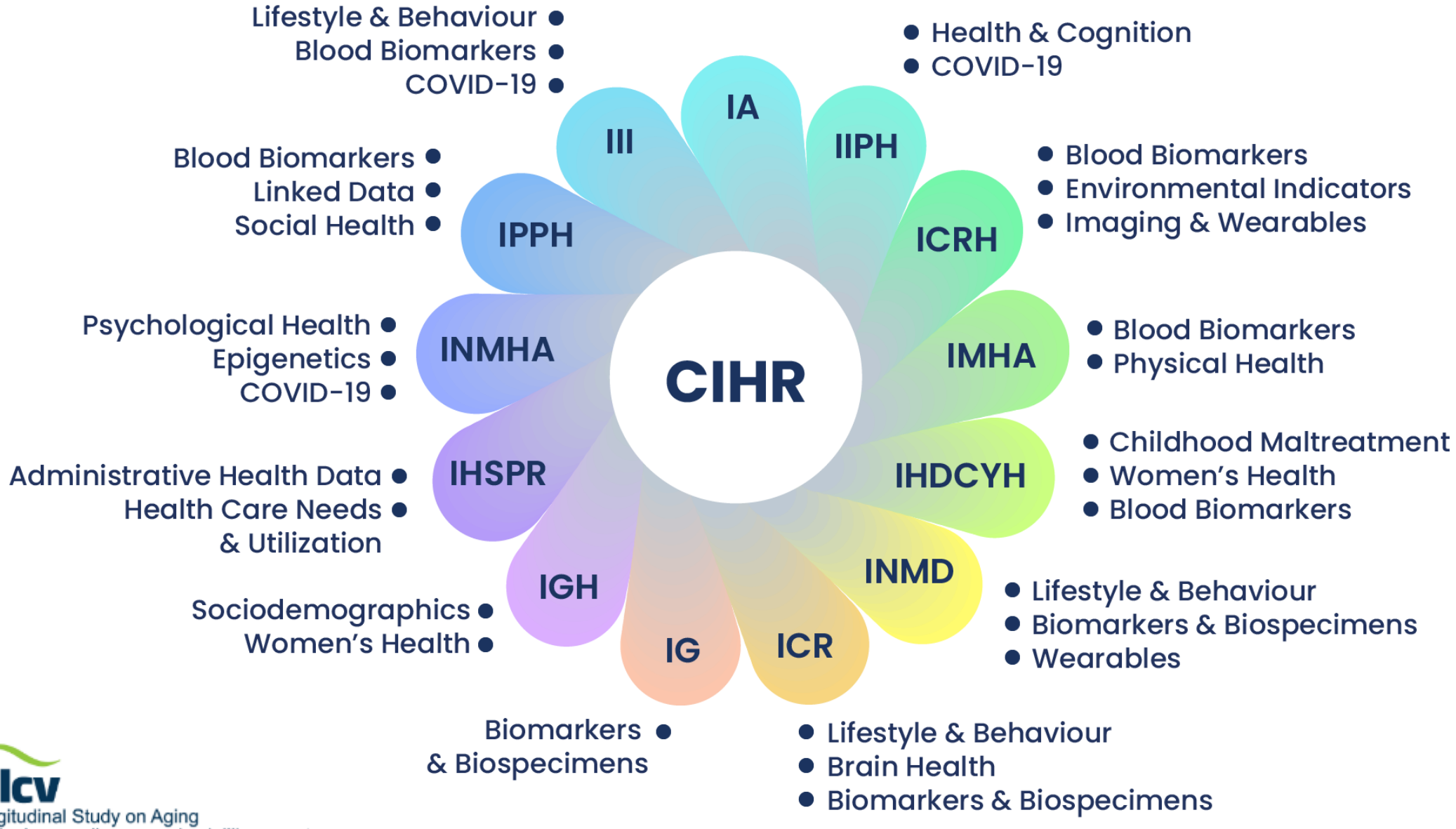
What is the Canadian Longitudinal Study on Aging?

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.

Alignment of CLSA Data with CIHR Institutes



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CLSA Research Platform

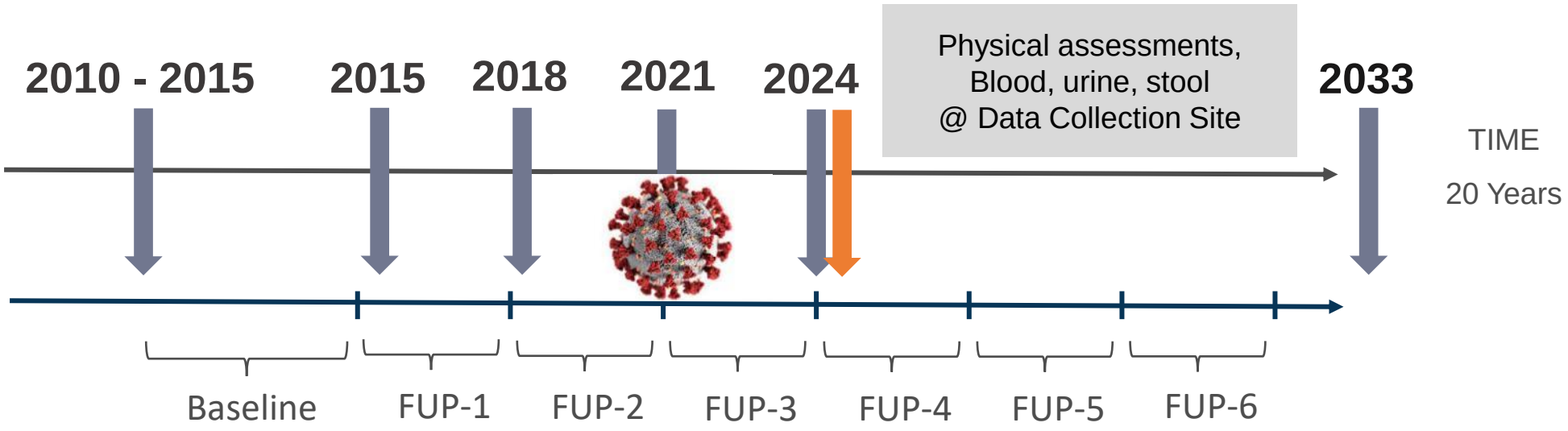
51,338 participants aged 45 - 85 at Baseline

CLSA Tracking
21,241 participants

CLSA Comprehensive
30,097 participants

Questionnaire
By telephone (CATI)

Questionnaire
In person, in home (CAPI)



Active follow-up (FUP) every 3 years

Linkage with Heath Administrative Data

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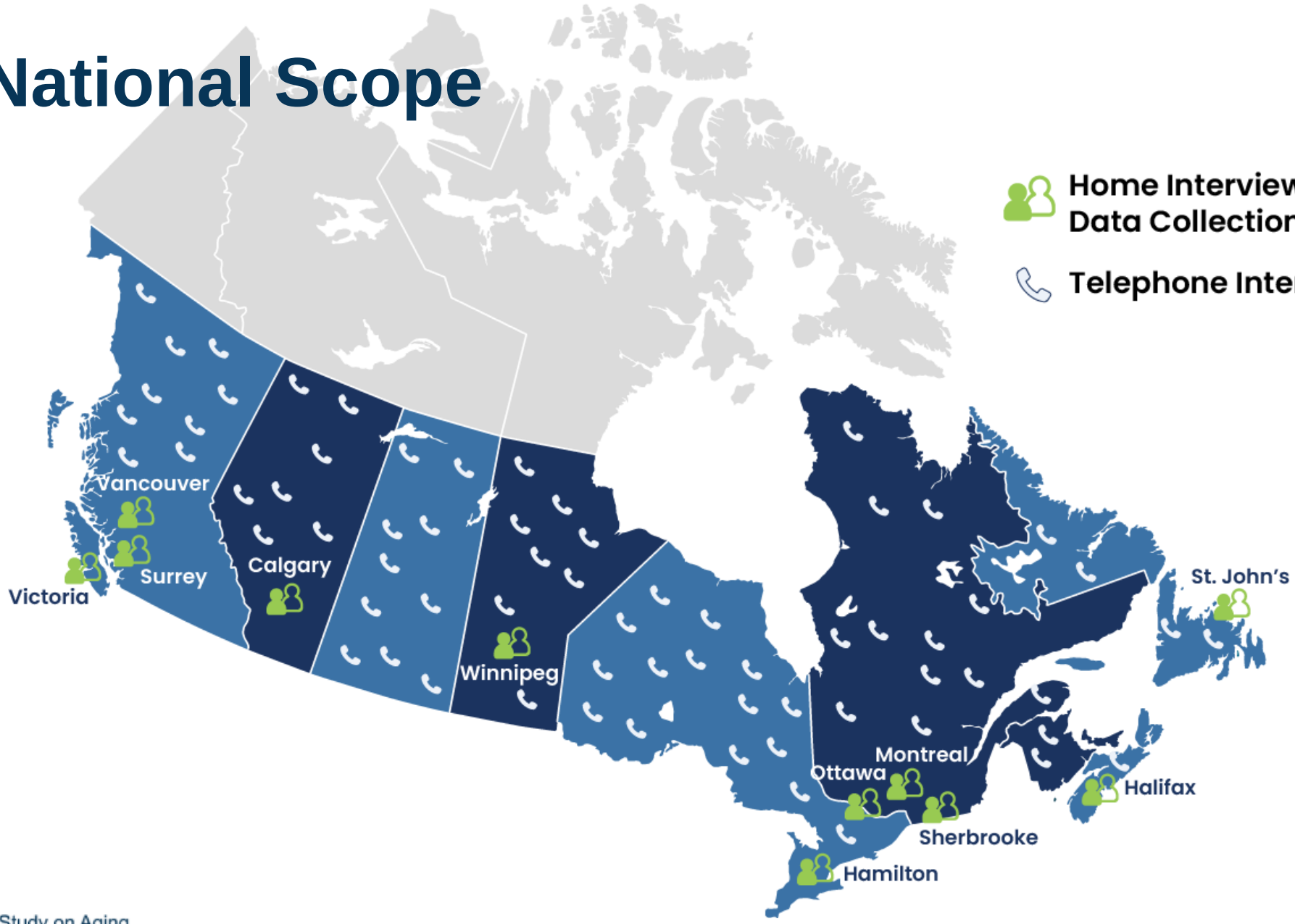
National Scope



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CLSA Network of Collaborating Institutions

SFU SIMON FRASER UNIVERSITY

UBC a place of mind THE UNIVERSITY OF BRITISH COLUMBIA

DALHOUSIE UNIVERSITY

University of Manitoba

McMaster University

UNIVERSITY OF CALGARY

McGill

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

SOINS CONTINUS Bruyère CONTINUING CARE — INSTITUT DE RECHERCHE BRUYÈRE RESEARCH INSTITUTE Affilié à l'Université d'Ottawa Affiliated with the University of Ottawa

uOttawa

University of Victoria

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UdS Université de Sherbrooke

MEMORIAL UNIVERSITY

Data Collection through Questionnaires

- Answer a variety of questions on physical, social and psychological health
- Questions largely remain the same, but new content has been added

Supplemental Questionnaire

- Web-based
- Healthy Sexuality
- Family History
- Chronic Conditions (CHF & arrythmia)
- All participants

Ageism Experiences

- Additional questions
- All participants

Cannabis Use

- Additional questions
- All participants

Introduced in Follow-up 3

Introduced in Follow-up 4

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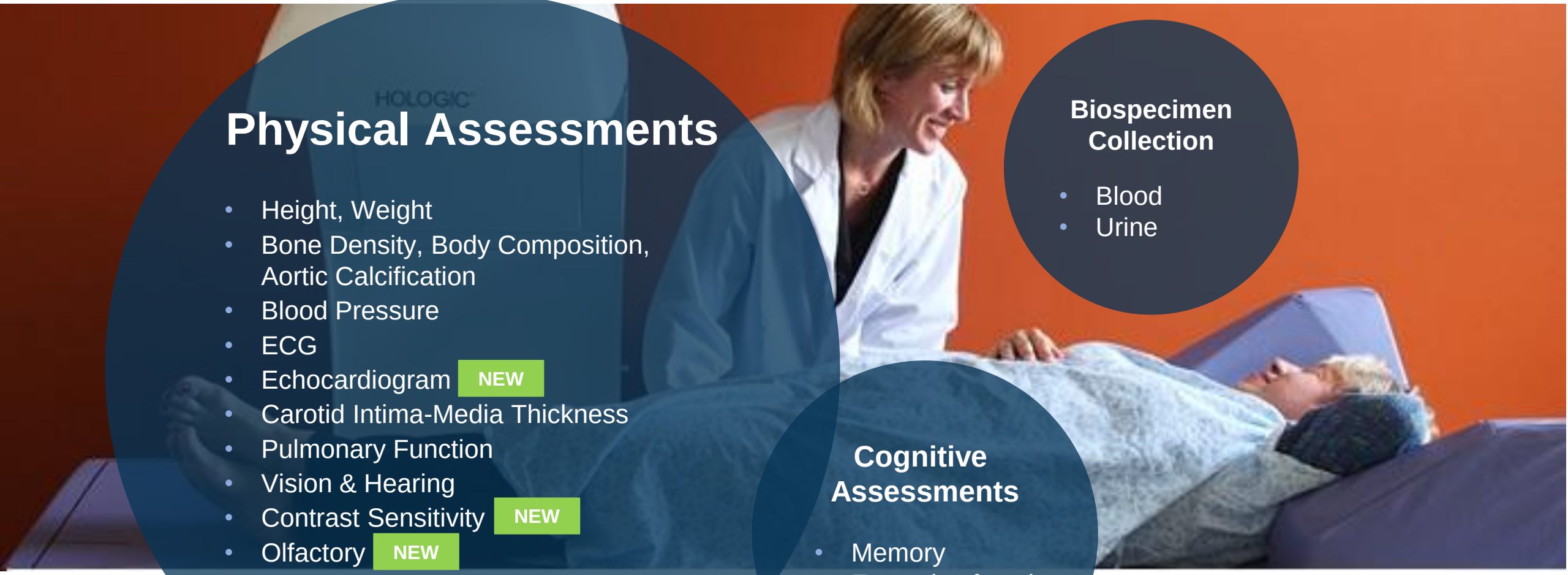
CLSA In-Person Data Collection

Data Collection Site



Physical Assessments

- Height, Weight
- Bone Density, Body Composition, Aortic Calcification
- Blood Pressure
- ECG
- Echocardiogram NEW
- Carotid Intima-Media Thickness
- Pulmonary Function
- Vision & Hearing
- Contrast Sensitivity NEW
- Olfactory NEW
- Performance testing
- Wearables NEW

Biospecimen Collection

- Blood
- Urine

Cognitive Assessments

- Memory
- Executive function
- Reaction time

Introduced in Follow-up 3

Introduced in Follow-up 4

FUP3 New Measures
Wearables

Sleep Trackers

- Muse headband
- ActiGraph (wrist)
- Sleep quality (e.g., duration, fragmentation, efficiency)
- EEG for sleep architecture
- Comprehensive participants (N=2,630)

Mobility Trackers

- GPS and triaxial accelerometer devices:
  - TicWatch
  - ActiGraph (thigh)
- Physical activity and sedentary behaviour
- Community mobility (e.g., driving)
- All Comprehensive participants

CLSA-Weston Healthy Brains, Healthy Aging Initiative (HBHA)

Began in September 2022

- Brain health initiative funded by the Weston Family Foundation
- 6,000 Comprehensive participants
- MRIs & fecal samples (N=2,250)
  - Additional cognitive measures, sleep, and handedness
- Fecal samples only (N=6,000)
- Two data collection events

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Dementia Disease Ascertainment Pilot

- Study funded through PHAC's Enhanced Dementia Surveillance Program
- Data collection: August 2022 – March 2024
- N= 597
- Estimate of undetected dementia in Canada by:
  - Validating CLSA dementia algorithm with clinical assessments*
  - Linking CLSA data with provincial health-care databases

*Outcome (major neurocognitive disorder) based on validated CLSA dementia algorithm will become part of the core CLSA dataset

Data Availability

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Core CLSA Data

	Baseline	FUP1	FUP2	FUP3
Questionnaire Data	✓	✓	✓	2025
Physical Assessments	✓	✓	✓	2026
Blood Biomarkers Hematology Chemistry	✓	✓	✓	~2026
Genomics	✓	-	-	-
Epigenetics	✓	-	-	-
Metabolomics	✓			

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Core CLSA Data
Questionnaire Data

	Baseline	FUP1	FUP2	FUP3
Questionnaire Data				
Socio-demographics	✓	✓	✓	✓
Lifestyle & Behaviour	✓	✓	✓	✓
Labour Force	✓	✓	✓	✓
Physical Health	✓	✓	✓	✓
Psychological Health	✓	✓	✓	✓
Social Health	✓	✓	✓	✓
Medications	✓	✓	✓	✓
Cognition	✓	✓	✓	✓

NEW at FUP2 and FUP3

- Weight perception
- Resiliency scale
- Aortic Valve Stenosis
- Munich ChronoType Questionnaire

- Generalized Anxiety Disorder
- Positive Mental Health
- Intimate Partner Violence
- Elder Abuse Suspicion Index

- Quality of Life

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Physical Assessments

Baseline & Follow-ups 1-3

- Weight and Height
- Body Mass Index
- Hip and Waist
- 4-Metre Walk
- Timed Get Up and Go
- Standing Balance
- Chair Rise: Balance and Coordination
- Grip Strength
- Pulse Rate and Blood Pressure
- Body Composition
- Basic Activities of Daily Living
- Instrumental Activities of Daily Living
- Functional Status
- Life Space Index
- Spirometry
- Hearing
- Canadian Digit Triplet Test
- Visual Acuity
- Tonometry
- Electrocardiogram
- Carotid Intima Media Thickness *
- Bone Density by DEXA:
  - Dual Hip
  - Forearm
  - Whole Body

* Not yet available for Follow-up 2. FUP3 data anticipated in 2026.

Core Biomarkers: Baseline & Follow-ups 1-3+

	Category	N*	Wave	Biomarkers
OMICS	**GENETICS** Genetic and Epigenetic Centre (GEC)	26,622	Baseline	• Genotypes (Affymetrix Axiom array, 794k SNPs) • Imputation (Haplotype Reference Consortium release 1.1, 39.2M SNPs)
OMICS	**EPIGENETICS** Epigenetic Centre (EC)	1,479	Baseline	• DNA methylation • DNA extracted from PBMCs • 850K Infinium MethylationEPIC BeadChip (Illumina)
OMICS	**METABOLOMICS**** Metabolon	~9,500	Baseline	• LC-MS/MS systems • ~1,300 metabolites
BLOOD BIOMARKERS	**CHEMISTRY**	~9,500	Baseline	• IL-6 • TNF-alpha
BLOOD BIOMARKERS	**CHEMISTRY**	~22,900	FUP1	• High-Sensitivity Troponin T (hsTnT) • NT-proBNP
BLOOD BIOMARKERS	**CHEMISTRY** Calgary Laboratory Services (CLS) (Analysis repeated every 3 years)	27,012	Baseline, FUP1, FUP2, FUP3	• Albumin • Alanine aminotransferase (ALT) • C-reactive protein (CRP) • Creatinine • Cholesterol • Ferritin • Free T4 • Hemoglobin A1c (n = 26,961) • HDL • LDL • Non-HDL • Triglycerides • 25-Hydroxyvitamin D • Thyroid stimulating hormone (TSH)
BLOOD BIOMARKERS	**HEMATOLOGY** Data Collection Sites (DCS)	25,427	Baseline, FUP1, FUP2, FUP3	• Erythrocytes • Hemoglobin • MCV • MPV • Granulocytes • Lymphocytes • MCH • RBC • Hematocrit • Platelets • MCHC • RDW

*N represents Baseline only. **Follow-up metabolomics planned for a subset, but not yet available. +Biomarkers from Follow-up 3 not yet available.

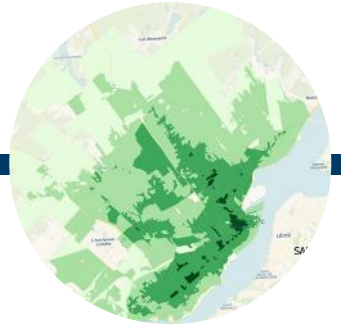
Mortality Data

- Data release update planned for June 2025 with information collected by May 2025
- **Decedent questionnaire data** (Details Surrounding Death, Living Arrangements Prior to Death, Function at 1 Month Before Death, About the Main Caregiver, Participant's Health Care Preferences and Decisions, and Quality of Death and Dying)

Environmental Indicators: Linked Data

Canadian Urban Environmental Health Research Consortium (https://canue.ca/) & Health Canada datasets: Baseline, Follow-up 1 & Follow-up 2

Spatial Accessibility Measures



Social & Material Deprivation Indices

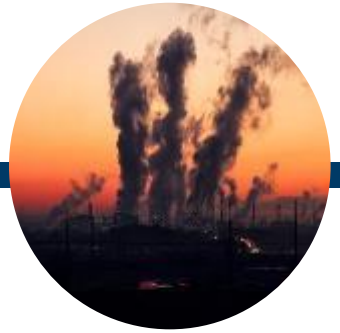
Greenness

Can-ALE Data

Weather & Climate

Public Transportation

Air Quality



Noise

Nighttime Light

Access to Employment

Proximity Measures

Data Access

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CLSA Data Access

- Data available to researchers and trainees based in academic settings and research institutes in Canada and elsewhere
- **Application deadlines:**
  - July 9, 2025
  - October 1, 2025
  - January 14, 2026
  - April 8, 2026
  - July 8, 2026
  - October 7, 2026
- For more information on the access process, please consult our website: **www.clsa-elcv.ca/data-access**

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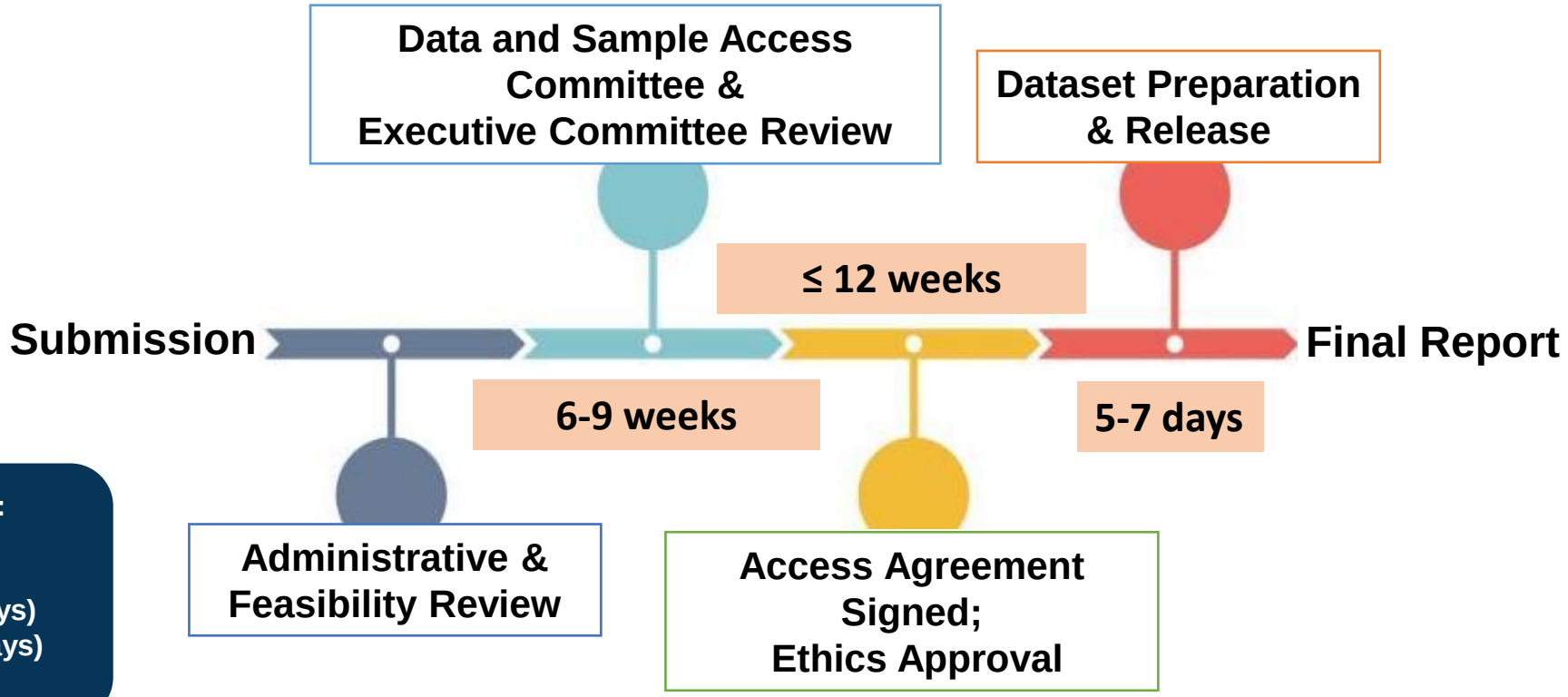
Data Access Process



Review outcomes:

Approved
Minor revision (7 days)
Major revision (21 days)
Not approved

Applicants advised to plan on receiving data <u>six months</u> after submission deadline

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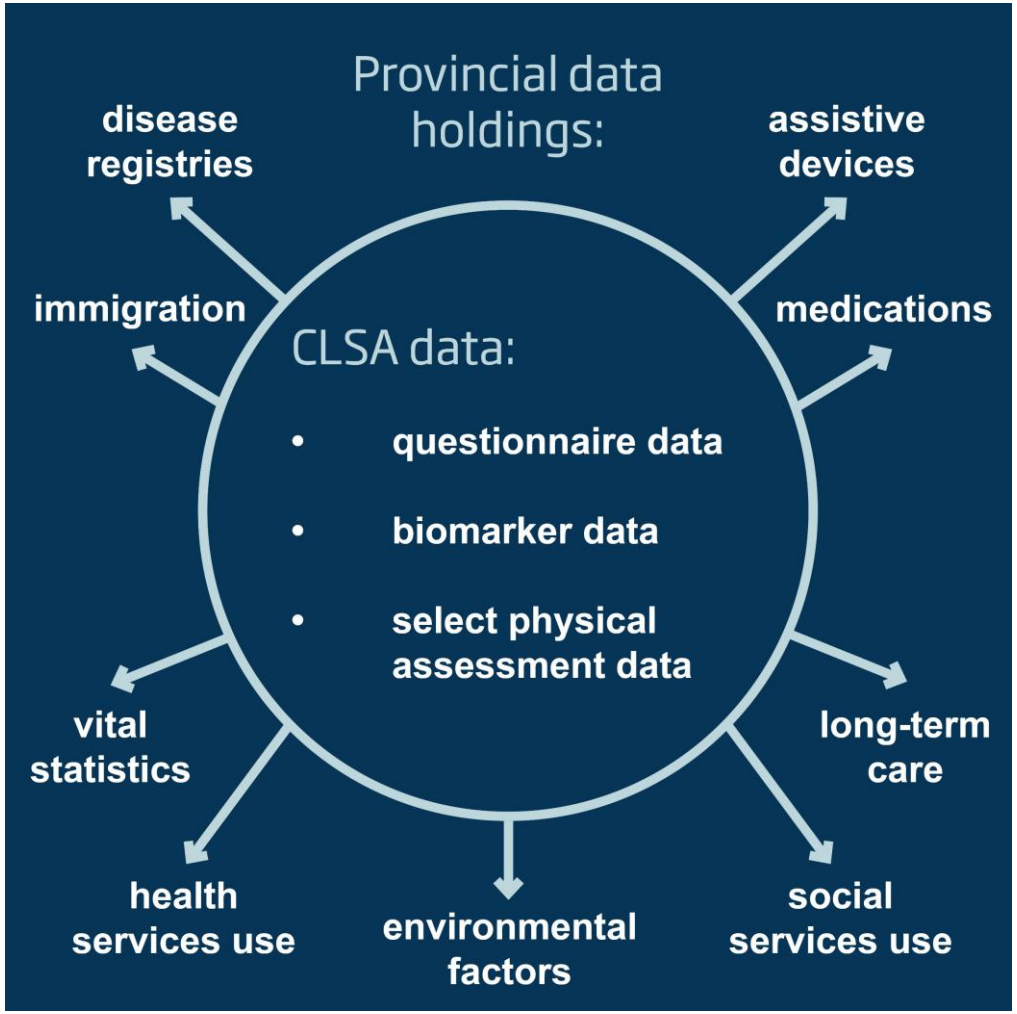
Special Considerations: Applying to access Indigenous-identifiers in Magnolia

- When proposing a project using/reporting on Indigenous identifiers, applicants must describe meaningful and respectful engagement with relevant Indigenous People
- Meaningful and respectful engagement =
  - Conduct work in service to community that supports community priorities
  - Respect existing Indigenous governance protocols
  - Recognize and promote sovereignty by ensuring Indigenous direction and governance throughout
  - Centre Indigenous values and communities in knowledge sharing
  - Strengthen and build data capacity within communities
  - Build on strengths, not deficits

Data Linkage

Administrative Health Data

- Linkage of CLSA data with multiregional provincial health data
- Provides opportunity to explore the intersection between aging and health-care utilization
- 92% (n=47,230) of CLSA participants provided consent to linkage
- Initiated a collaboration with Health Data Research Network (HDRN) Canada and its partners in 2021



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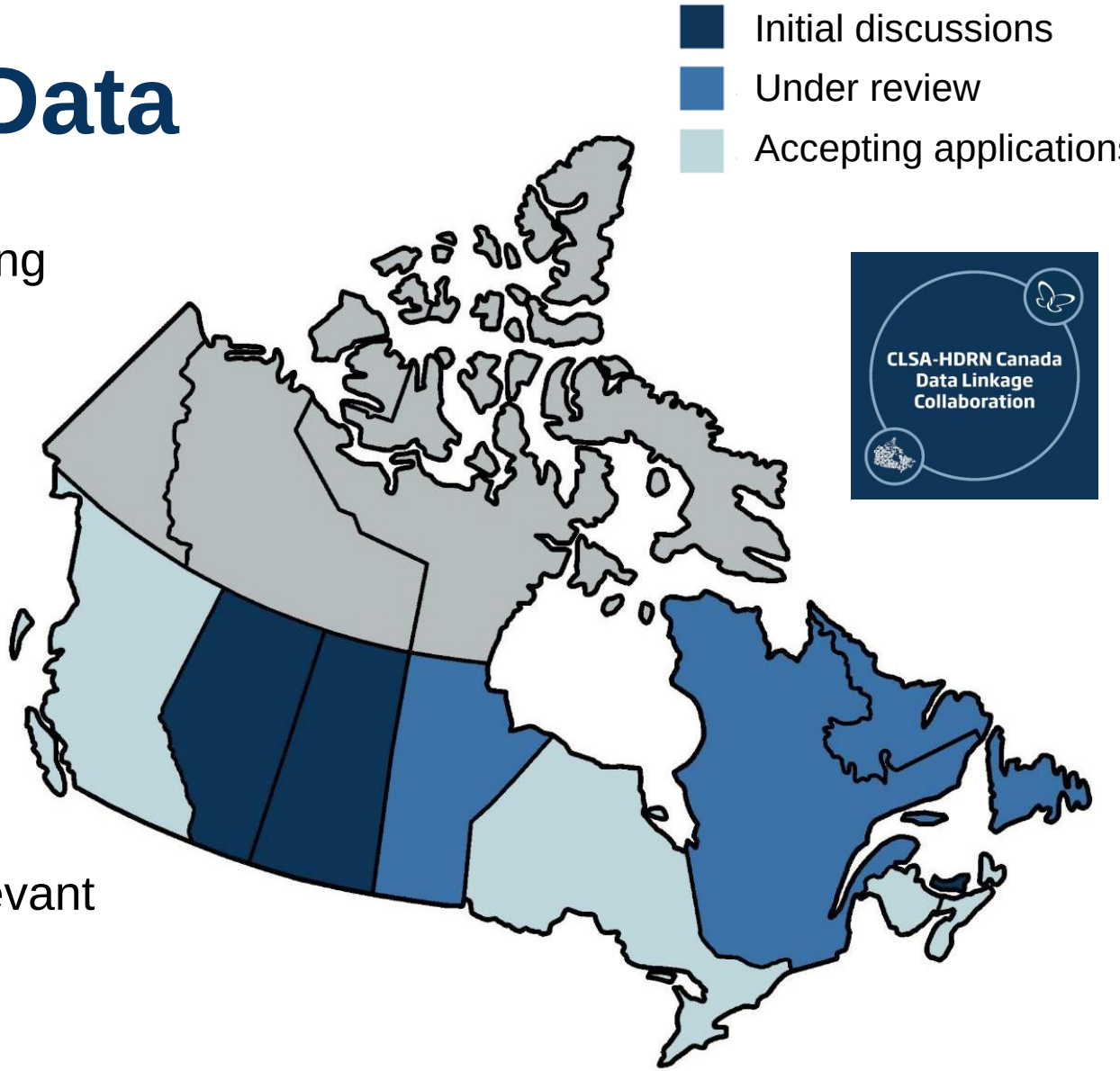
www.clsa-elcv.ca/administrative-health-data

Administrative Health Data

- Four provincial data centres currently accepting applications:
  - Population Data BC
  - ICES (Ontario)
  - New Brunswick Institute for Research, Data and Training (NB-IRDT)
  - Health Data Nova Scotia (HDNS)

- Multi-region requests facilitated through HDRN Canada's Data Access Support Hub (DASH): **www.hdrn.ca/dash**
- Single-region requests facilitated through relevant provincial data centre



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Réseau de recherche sur les données de santé du Canada
Health Data Research Network Canada

Documentation

- Data Access Policy & Guidelines
- Protocols, Cohort Profile & Reports
- Questionnaires
- Physical Assessments
- Data Dictionaries
- Sampling Weights Documents
- Derived Variables
- Data Support Documents
- Data and Biospecimens Documents
- **www.clsa-elcv.ca/researcher-resources**

CLSA Webinars

- Monthly from September to June
- 100+ recordings and slides are posted on the CLSA website, including:
  - Data access webinars on linked data, considerations for the access/use of Indigenous-identified data, CLSA sampling weights and more.
- **www.clsa-elcv.ca/webinars**

DataPreview Portal

- Summary statistics
- Explore data:
  - Variable by variable
  - Scales & measures
  - Areas of Information
- **www.clsa-elcv.ca/data-preview-portal**

Approved Projects & Publications

- Lay summaries of all approved projects
- Database of 500+ peer-reviewed publications
- Search engine
- **www.clsa-elcv.ca/approved-projects**
- **www.clsa-elcv.ca/publications**

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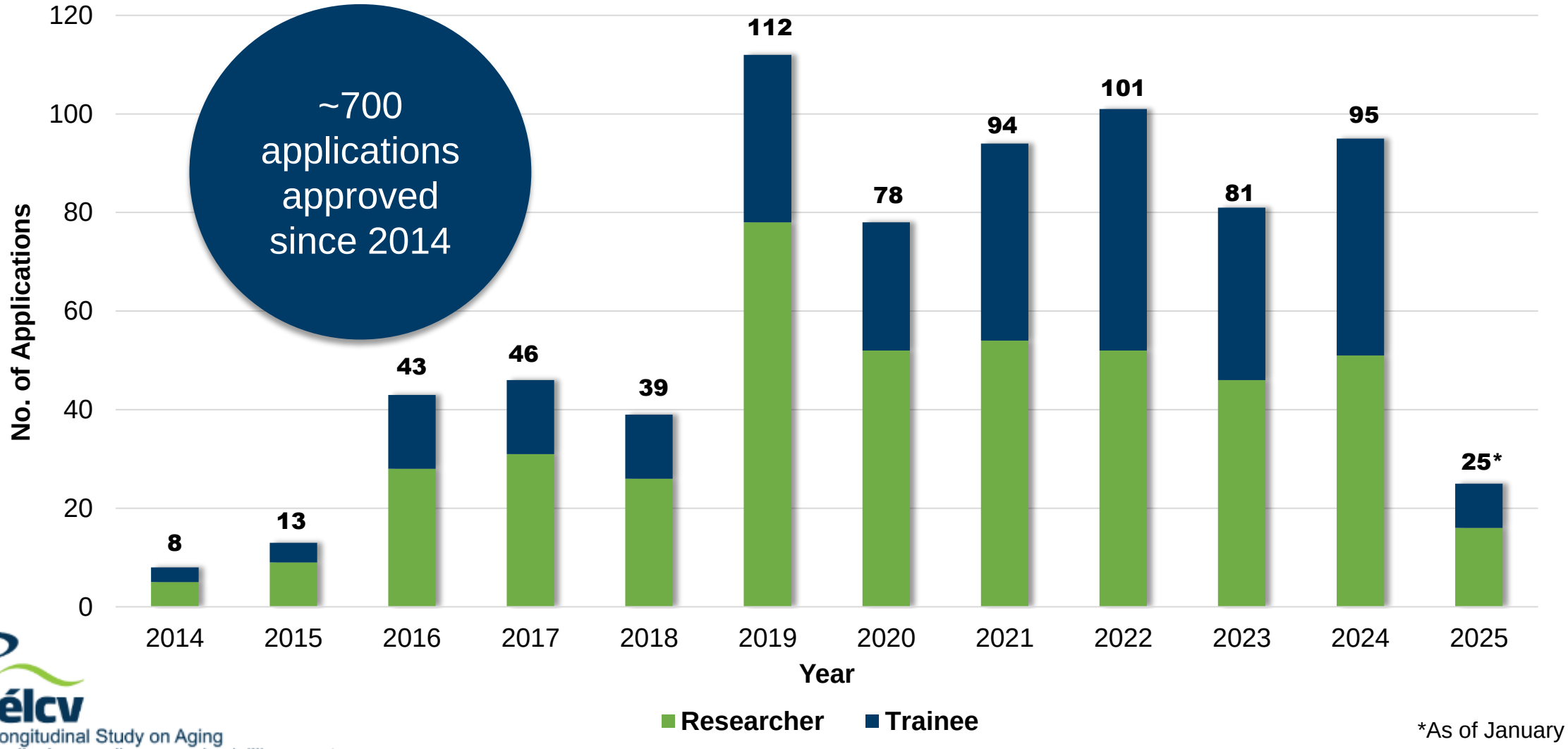
Researcher Resources

Approved Applications



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*As of January 2025

CLSA Research Team

Principal Investigators, Site Investigators, Working Group Leads, Key Co-investigators

UVic: Theone Paterson, Tarek Amer, Olave Krigolson
UBC: Teresa Liu-Ambrose, Michael Kobor
SFU: Andrew Wister, Theresa Pauly
UCalgary: Jacqueline McMillan, David Hogan, Eric Smith
USask: Megan O'Connell
UManitoba: Cara Brown, Philip St. John
McMaster: Parminder Raina, Cynthia Balion, Lauren Griffith, Andrew Costa, Laura Anderson, Marla Beauchamp, Michael Surette
UofT : Andrew Lim
UWaterloo: Mary Thompson, Changbao Wu, Mark Oremus, Bill McIlroy, Karen van Ooteghem
UOttawa/Bruyere: Vanessa Taler, Arne Stinchcombe
McGill: Christina Wolfson, Brent Richards, Mark Lathrop, Nicole Basta
USherbrooke: Benoît Cossette, Isabelle Dionne, Mélanie Levasseur, Karina Lebel
Dalhousie: Olga Theou, Lindsay Wallace, Susan Kirkland
Memorial: Zhiwei Gao
Eindhoven University of Technology: Edwin van den Heuvel

+ Scientific working group members and co-investigators

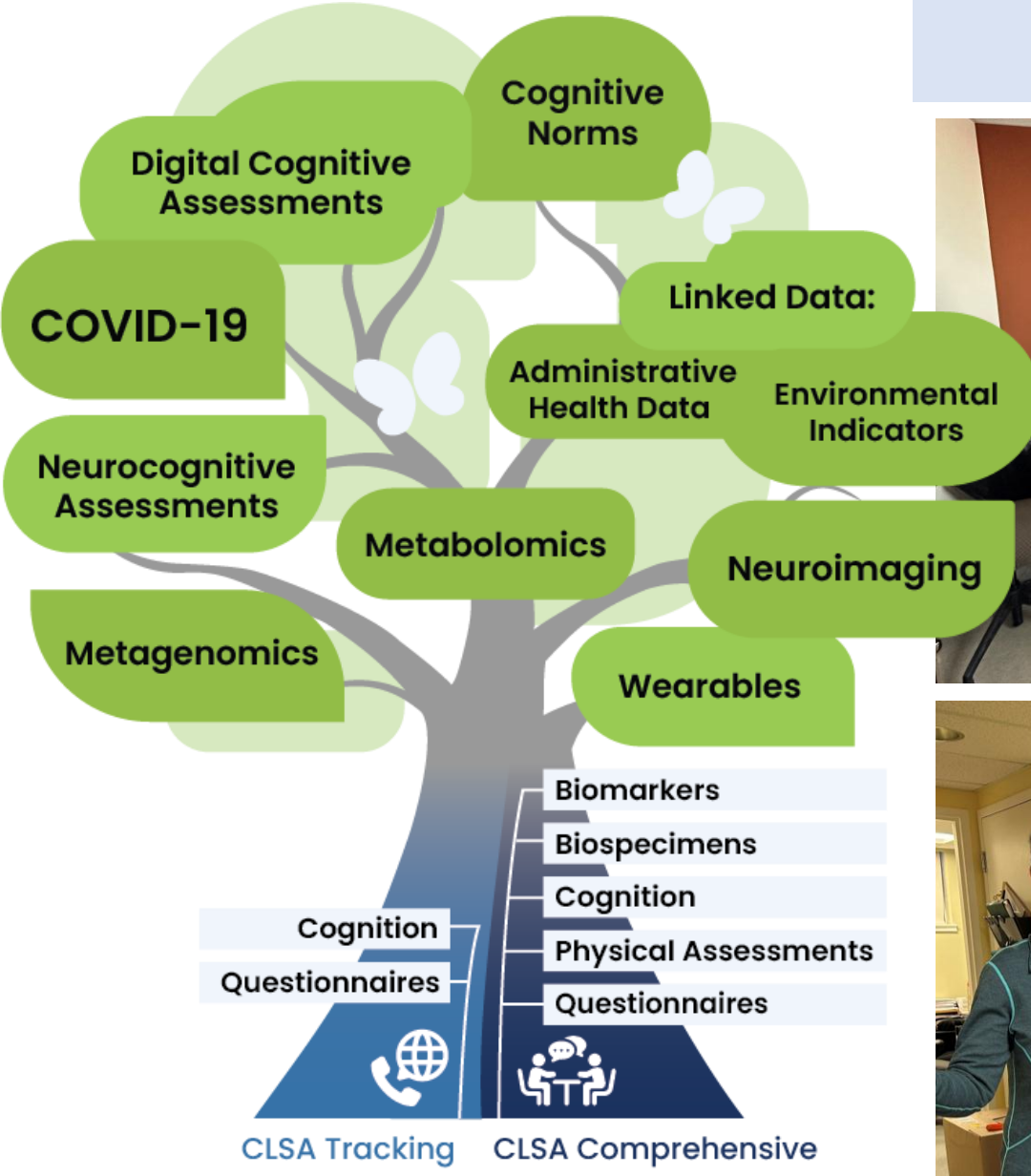
CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

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

Contact:
Data access support & inquiries: access@clsa-elcv.ca
General inquiries: info@clsa-elcv.ca

CLSA is funded by the Government of Canada through CIHR and CFI, and provincial governments and universities. Brain health research funding provided by the Weston Family Foundation.
Past funding includes: COVID-19 Immunity Task Force, Juravinski Research Institute, McMaster University, McMaster Institute for Research on Aging, Nova Scotia COVID-19 Health Research Coalition and the Public Health Agency of Canada.

Thank you to the study participants and CLSA team for their valuable contributions!



Images & Raw Data

	Baseline	FUP1	FUP2
Images and raw data (cIMT, DXA, ECG, Retinal scans, Spirometry, Tonometry, Raw cognition)	✓	✓	To be determined

- To request these data: applicants need to provide detailed justification explaining how these data will help to achieve proposed objectives and describe how they will be analyzed
- Users need to have the expertise and resources to work with these types of data
- The request for images and raw data usually incurs additional costs beyond the current data access fee
- It may take longer to receive these data

Magnolia Enhancements

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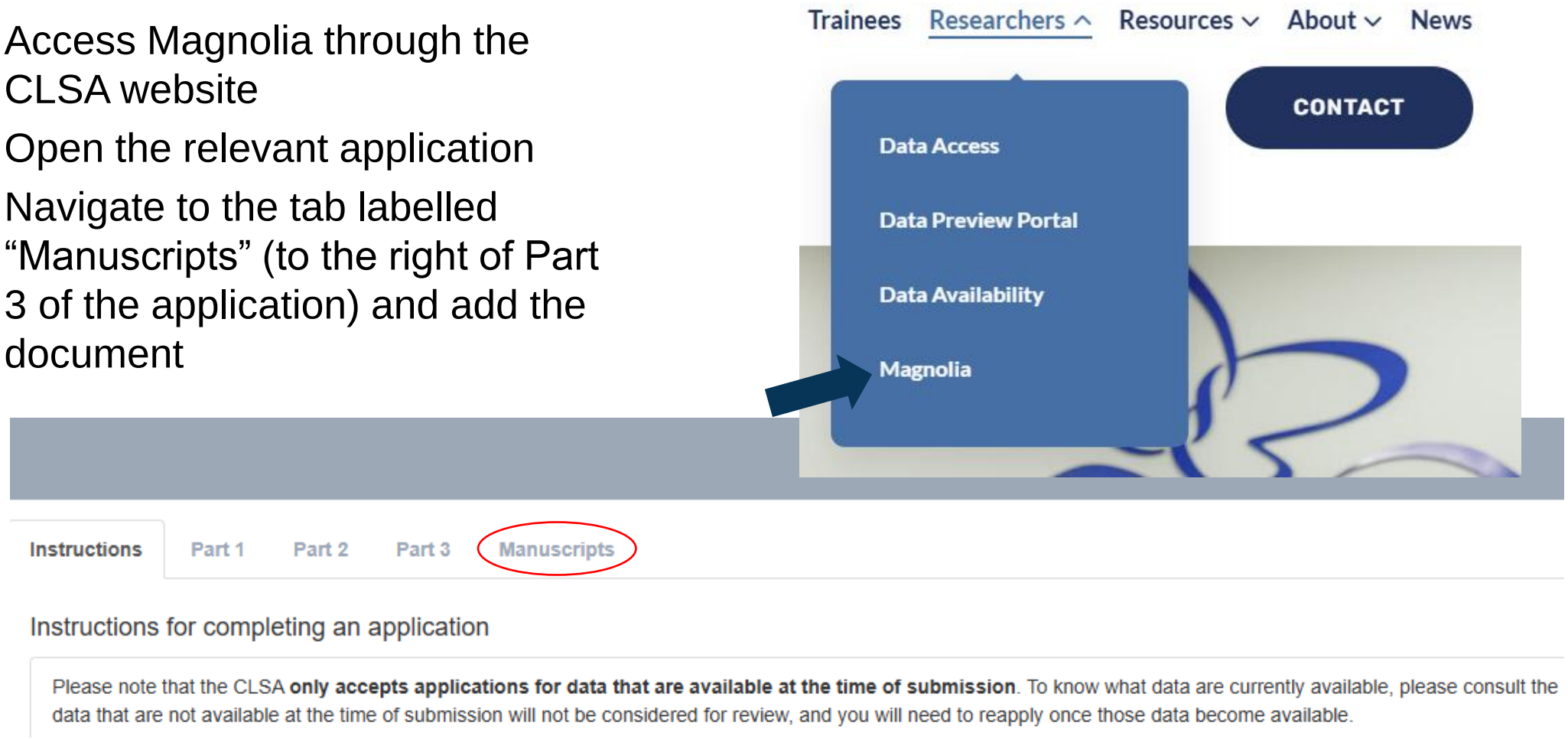
Manuscript submission process

- CLSA data users must now submit final drafts of manuscripts for review through Magnolia
- Final drafts of **all primary research outputs** must be submitted for review including: submissions to preprint servers, manuscripts, reports, and other types of media using CLSA data and/or biospecimens
- Drafts of abstracts, posters, and presentations do not need to be sent to the CLSA for review, but should follow the Guiding Principles outlined in the CLSA Publication and Promotion Policy

How do I submit a manuscript in Magnolia?

- Access Magnolia through the CLSA website
- Open the relevant application
- Navigate to the tab labelled “Manuscripts” (to the right of Part 3 of the application) and add the document



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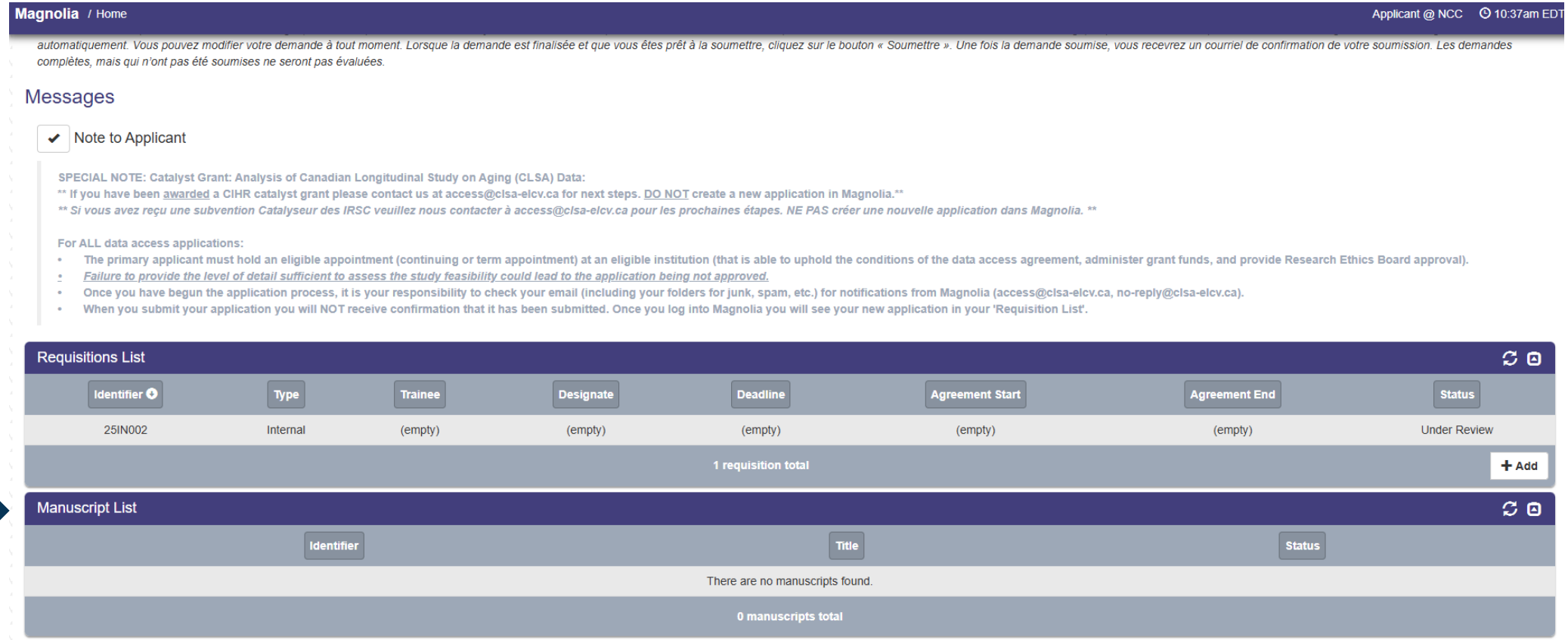
How do I submit a manuscript in Magnolia?

- The submitted document will then appear in your Manuscript List when logging in.



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Amendments in Magnolia

- Approved users must keep the CLSA updated on any changes that affect your data access agreements:
  - Have you moved institutions?
  - Has the research team changed?
  - Has a trainee graduated or moved to a new position?
- Request an amendment through Magnolia
- Having trouble submitting an amendment request or if you have any questions concerning amendments? Reach out to **access@clsa-elcv.ca**