Enhancing the CLSA research platform: Updates on new initiatives, data availability and data access

Dr. Parminder Raina
McMaster University

Dr. Matilda Saliba
Research Institute of the McGill University Health Centre

on behalf of the CLSA Research Team

October 31, 2022

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Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

Overview

- CLSA Research Platform

- Platform enhancements

- Data Availability

- Data Access

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CLSA Leads

Christina Wolfson
Principal Investigator
McGill University

Parminder Raina
Lead Principal
Investigator
McMaster University

Susan Kirkland
Principal Investigator
Dalhousie University

CLSA Leads

Lauren Griffith
Co-principal
Investigator
McMaster University

Cynthia Balion
Co-principal
Investigator
McMaster University

What is the 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.

CLSA Network of Collaborating Institutions

Terminology

- **Tracking Cohort**
  - Target - 20,000 participants from all 10 provinces, followed through Computer-Assisted Telephone Interviews (60 minutes at baseline)
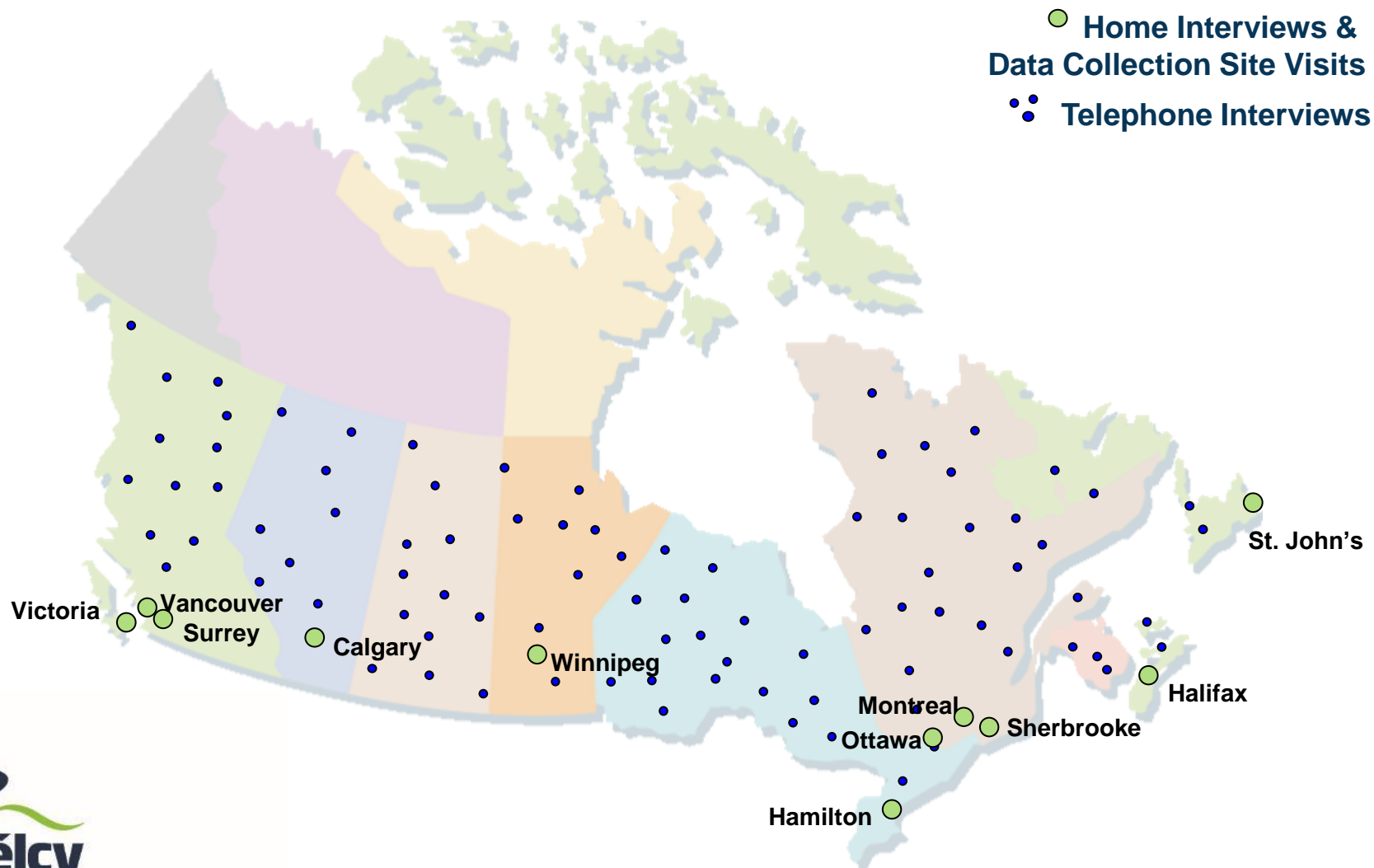 - **21,241 recruited**

- **Comprehensive Cohort**
  - Target - 30,000 participants living within 25 km (or 50 km) of a CLSA Data Collection Site (DCS)
  - Followed through in-home interviews (60 minutes) and physical assessments (2-3 hours) at a DCS
  - **30,097 recruited**

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Exclusion Criteria

- Residents in the three territories
- Persons living on federal First Nations reserves
- Full-time members of the Canadian Armed Forces
- Individuals living in institutions
- Individuals unable to respond in English or French
- Individuals with cognitive impairment

National Scope

Home Interviews & Data Collection Site Visits

Telephone Interviews

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

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CLSA Research Platform

50,000 participants aged 45 - 85 at baseline

| Target: 20,000 Actual: 21,241 Randomly selected within provinces | Target: 30,000 Actual: 30,097 Randomly selected within 25-50 km of 11 sites |

Questionnaire By telephone (CATI)

Questionnaire In person, in home (CAPI)

Clinical/physical tests Blood, urine @ Data Collection Site

2010 - 2015   **2015**   **2018**   **2021**   **2033**

TIME
20 Years

Participants aged 45 to 85 at baseline (51,338)

Baseline   FUP-1   FUP-2   FUP-3   FUP-4   FUP-5   FUP-6

Active follow-up (FUP) every 3 years

Questionnaire-based & passive data collection in CLSA

HEALTH INFORMATION

- Chronic disease symptoms (disease algorithm), Pain and General Health
- Medication and supplements intake
- Women's health
- Self-reported health service use
- Oral health
- Preventative health (Baseline)
- Mood, psychological distress
- PTSD (Baseline)
- Injuries and consumer products
- Mobility-lifespace

LIFESTYLE

- Smoking
- Alcohol consumption
- Physical activity (PASE)
- Nutrition (nutritional risk and food frequency)

SOCIODEMOGRAPHIC & PSYCHOSOCIAL

- Birth location
- Ethnicity/race/gender
- Marital status
- Education
- Social participation
- Social networks and support
- Caregiving and care receiving
- Coping, adaptation
- Work-to-retirement transitions
- Retirement planning
- Social inequalities
- Elder Abuse (FUP1)
- Adverse Childhood Experiences (FUP1)
- Intimate Partner Violence (FUP2)
- Built environments
- Income, Wealth and Assets

- Administrative data linkage health services & drugs & other administrative databases (Planned)

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Linkage with Contextual and Environmental Data: Collaboration with The Canadian Urban Environment Health Research Consortium (CANUE)

Social & Material Deprivation Indices

Can-ALE Data

Weather & Climate

Air Quality

Nighttime Light

Greenness

Biomarkers and Omics in the CLSA

HEMATOLOGY	CHEMISTRY	GENETICS	METABOLOMICS	PROTEOMICS
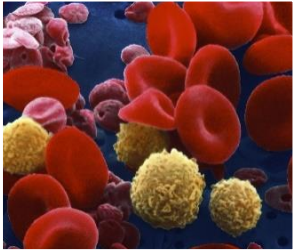
13 Parameters
Beckman AcT

Baseline = 24,425
FUP1 = 22,144

15^1 Analytes
Roche Cobas

Baseline = $27,170^2$
FUP1 = 23,156
Including hs Troponin, NT-prBNP, IL6, TN Alpha*

Genotyping
820K UK Biobank Axiom Array
Affymetrix
N1 = 26,884

Whole Exome Sequencing
Baseline = 30,000 (In Progress)

Epigenetics
850K Infinium MethylationEPIC BeadChip
Illumina
N1 = 1,500

1000^3 Metabolites
UHPLC/MS/MS
Metabolon

Baseline = 10,000
In progress remaining 20,000 from the baseline, FUP1, FUP2 and FUP3
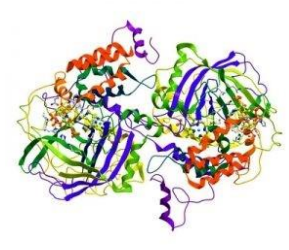
92 Proteins
Neurology Panel
Immunoassay
Olink

Baseline = 3,000*

[1] Varies with follow-up
[2] HbA1c, n = 26,961
[3] Approximate number
* In discussions

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CLSA Data Collection
Data Collection Site Assessments

Physical Assessments

- Height, Weight, BMI
- Bone Density, Body Composition, Aortic Calcification
- Blood Pressure
- ECG
- Carotid Intima-Media Thickness
- Pulmonary Function
- Vision & Hearing
- Performance testing

Biospecimen Collection

- Blood
- Urine

Cognitive Assessments

- Memory
- Executive function
- Reaction time

New FUP3 Measures

Physical Assessments

- Wearables (PA Chronotype)
- Vision contrast sensitivity
- Optoelectronic motion capture
- Olfactory function
- Body Temperature *(Comprehensive)*
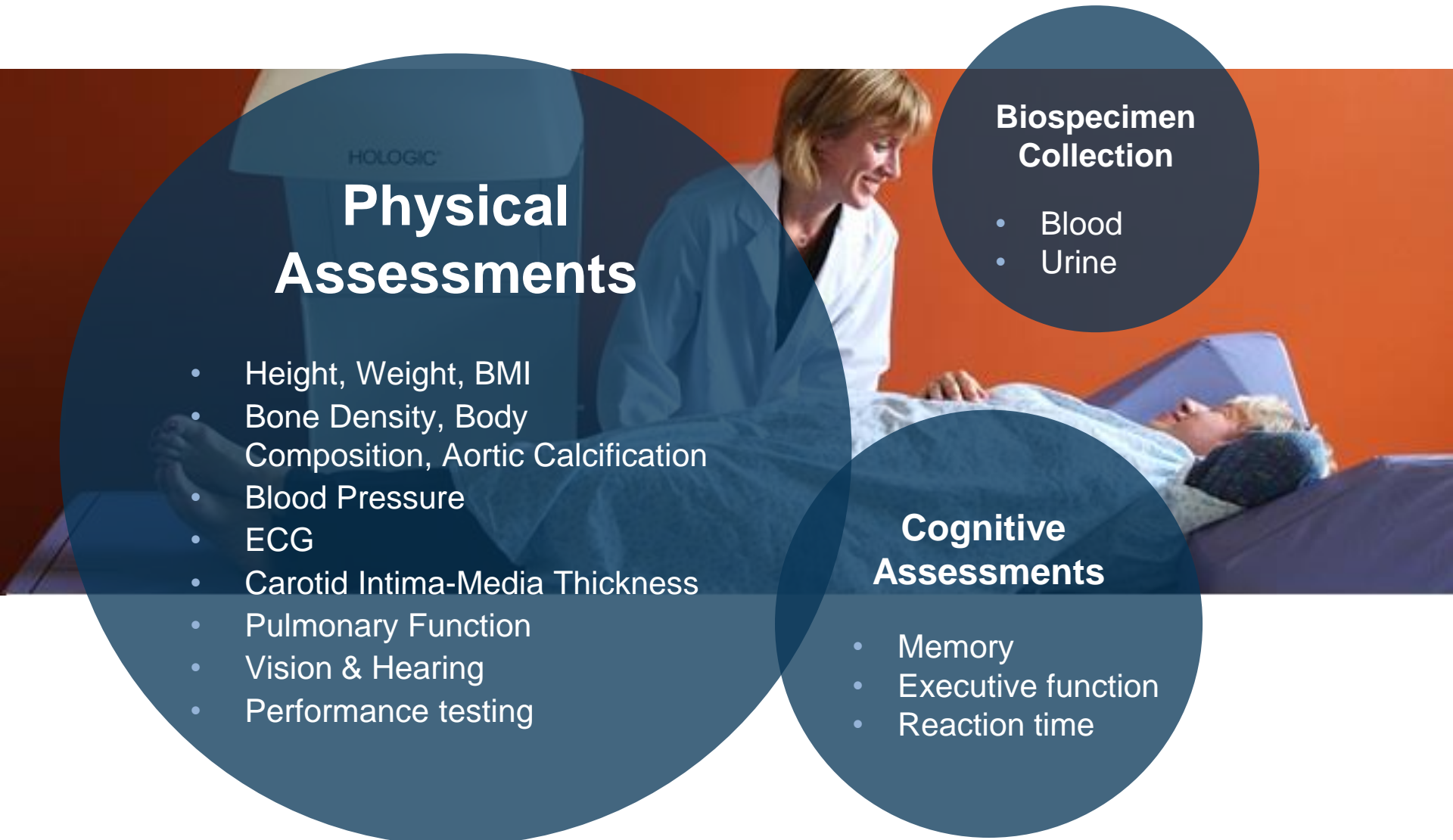
Questionnaires

- Quality of life
- Sleep chronotype
- Nutrition chronotype
- Healthcare utilization
- Sexual health*
- Family history of disease*

Biomarkers

- Proteomics
- Repeat metabolomics
- Repeat core biochemistry
- Urine biomarkers (Clinitek)

Reintroduction of Measures

- Elder Abuse
- Preventative Health Behaviors

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*through web questionnaire

Platform Enhancements

CLSA Data Collection
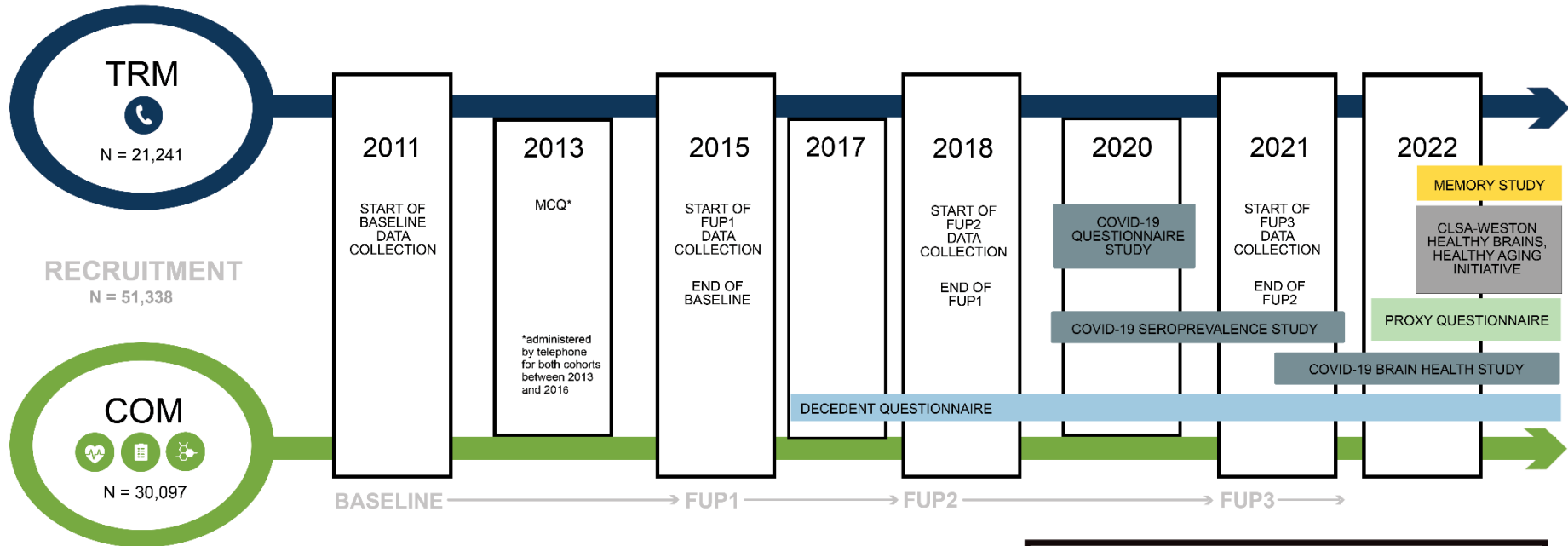
CLSA Research Platform

2010-2015 Baseline

2015-2018 Follow-up 1

2018-2021 Follow-up 2

2021-2024 Follow-up 3

COVID-19 Questionnaire Study

- April 2020 – Dec 2020
- Web and telephone surveys
- Weekly, biweekly, monthly
- 28,565 participants
- COVID-19 Data Dashboard: **clsa-elcv.ca/covid-study-results**

COVID-19 Seroprevalence Study

- October 2020 – July 2021
- 19,334 participants:
    - Dried blood spots samples (self-collection)
    - Venous blood sample collection (Data Collection Sites)

COVID-19 Brain Health Study

- Launched Summer 2021
- Impact of COVID-19 on cognition & brain health
- MRI, phone assessment

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

- $12M brain health initiative funded by the Weston Family Foundation

- Comprehensive participants

- HBHA Cohort (N=6,000)

- To advance our understanding of the impact of lifestyle behaviours on successful cognitive aging:

  - Physical activity

  - Sedentary behaviour

  - Sleep

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Healthy Brains, Healthy Aging
Neuro Cohort

- HBHA Neuro (N=2,630)
  - Brain MRI
  - Gut microbiome (fecal sample)
  - Cognitive assessment – Cambridge Neuropsychological Test Automated Battery (CANTAB)
    - Match to Sample Visual Search (MTS)
    - Paired Associates Learning (PAL)
    - Rapid Visual Information Processing (RVP)
  - Mobility trackers
  - Sleep trackers

Healthy Brains, Healthy Aging
Microbiome Cohort

- HBHA Microbiome
  - N=6,000 (3,370 + 2,630 HBHA Neuro)
  - Stool sample collection kit
  - At home, returned to Data Collection Site
  - Metagenomics and metabolomics analyses
  - Mobility trackers

Sleep Trackers

- Sleep quality (e.g., duration, fragmentation, efficiency)

- EEG for sleep architecture

- Muse

- ActiGraph (wrist)

- HBHA Neuro (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

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Decedent Questionnaire

- Launched in April 2017

- Occurs three months after the participant's death, or after learning the participant is deceased if the exact date is unknown

- A letter is sent to the alternate contact on file

- Decedent interview takes approximately 20 minutes, by phone or web

Decedent Questionnaire
Interview Questions

- Details surrounding death (e.g., primary and secondary causes of death)
- Living arrangements prior to death
- Cognitive and physical function at one month before death
- Information about the main caregiver
- Participant's health care preferences and decisions
- Quality of the participant's death and how they died

Proxy Questionnaire

- Launched in January 2022

- Participants over 70 years of age are asked to designate a proxy decision maker and a proxy information provider

- Proxy decision maker acts on participant's behalf if they are no longer able to make decisions for themselves about their participation (e.g., power of attorney)

- Proxy information provider answers interview questions on a participant's behalf (e.g., a family member, friend or caregiver)

- Participants may change proxy decision maker or proxy information provider

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Proxy Questionnaire

- Proxy information provider answers questions through telephone interviews

- Interviews take place every three years, on the same schedule as the main data collection event (e.g., Follow-up 3, Follow-up 4, etc.)

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CLSA Dementia Ascertainment (Memory) Study

- $1M study funded through PHAC's Enhanced Dementia Surveillance Program

- Estimate of undiagnosed dementia in Canada by:
  - Developing an algorithm to identify dementia cases using CLSA data
  - Validate CLSA algorithm with clinical diagnosis
  - Linking CLSA data with provincial health-care databases

- Conduct an analysis of known and emerging risk factors associated with dementia

- Determine the feasibility of adding additional measures to enhance the CLSA as a dementia platform

CLSA Dementia Ascertainment (Memory) Study

How will the algorithm be developed?

- 600 participants with a range of cognitive ability
- Complete a one-hour medical assessment with a study clinician
  - Medical history and brief cognitive test
  - A neurocognitive examination
- Identify a family member or friend for a 20-minute telephone interview

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CLSA Research Team

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

UVic: Scott Hoffer, Theone Paterson, Olave Krigolson
UBC: Teresa Liu-Ambrose, Michael Kobor
SFU: Andrew Wister, Theodore Cosco
UCalgary: David Hogan, Jacqueline McMillan, Eric Smith
USask: Megan O'Connell
UManitoba: Verena Menec, Philip St. John
McMaster: Parminder Raina, Cynthia Balion, Lauren Griffith, Andrew Costa, Guillaume Paré, Laura Anderson, Marla Beauchamp
UofT: Andrew Lim
UWaterloo: Mary Thompson, Changbao Wu, Mark Oremus, Bill McIlroy, Karen van Ooteghem
UOttawa/Bruyere: Vanessa Taler, Patrick Davidson
McGill: Christina Wolfson, Brent Richards, Mark Lathrop, Nicole Basta
USherbrooke: Benoît Cossette, Isabelle Dionne, Mélanie Levasseur, Karina Lebel
Dalhousie: Susan Kirkland
Memorial: Gerry Mugford, Zhiwei Gao
Eindhoven University of Technology: Edwin van den Heuvel

+ Scientific working group members and co-investigators

Data Availability

Core CLSA Data

	Baseline	FUP1	FUP2
Questionnaire Data	✓	✓	✓
Physical Assessments	✓	✓	Expected Summer 2023
Blood Biomarkers			
Hematology	✓	✓	To be determined
Chemistry	✓	✓	
Genomics	✓	-	-
Epigenetics	✓	-	-
Metabolomics	✓	-	-

Core CLSA Data – Questionnaire Data

	Baseline	FUP1	FUP2
Questionnaire Data			
Socio-demographics	✓	✓	✓
Lifestyle & Behaviour	✓	✓	✓
Labour Force	✓	✓	✓
Physical Health	✓	✓	✓
Psychological Health	✓	✓	✓
Social Health	✓	✓	✓
Medications	✓	March 2023	To be determined
Cognition	✓	✓	Expected summer 2023

NEW at FUP2

- **Weight perception**
- **Resiliency scale**
- **Aortic Valve Stenosis**

- **Generalized Anxiety Disorder**
- **Positive Mental Health**
- **Intimate Partner Violence**

Questionnaire Data
Cognition

Cognition Measures

- Full Cognitive Battery*:
  - Miami Prospective Memory Test (event- & time-based)
  - Stroop – Victoria Version
  - Controlled Oral Word Association Test
  - Choice Reaction Time
  - Meta Memory
  - Subjective Cognitive Decline
- Cognitive Norms

○ Baseline & FUP1

● Baseline only

● FUP1 only

*Includes Rey, Mental Alternation, Animal Fluency Tests, Meta Memory

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www.clsa-elcv.ca/data-availability

Physical Assessments
Baseline & Follow-up 1

- Contraindications
- 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
- Visual Acuity
- Tonometry
- Electrocardiogram
- Carotid Intima Media Thickness
- Bone Density by DEXA:
  - Dual Hip
  - Forearm
  - Whole Body

Physical assessment data from Follow-up 2 are not yet available

www.clsa-elcv.ca/data-availability

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Core Biomarkers: Baseline & FUP1

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

*N represents Baseline only. Biomarkers from Follow-up 2 are not yet available.

Linked Data

	Baseline	FUP1	FUP2
Environmental Indicators (CANUE & Health Canada datasets)	✓	✓	To be determined

Social & Material Deprivation Indices

Greenness

Can-ALE Data

Weather & Climate

Air Quality

Noise

Nighttime Light

Access to Employment

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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: you need to provide detailed justification explaining how these data will help to achieve proposed objectives and describe how they will be analyzed

- You need to have the experience 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

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COVID-19 Data

**COVID-19
Questionnaire Study**

Collected longitudinal data from April 2020 to December 2020.
(N = 28,565)

**COVID-19
Seroprevalence Study**

Collected blood samples and questionnaire data from October 2020 to July 2021
(N = 19,334)

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www.clsa-elcv.ca/access

Mortality Data
Information collected by March 2022

- **Participant status** (Vital and withdrawal status)

- **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)

Data Access

Approved Applications
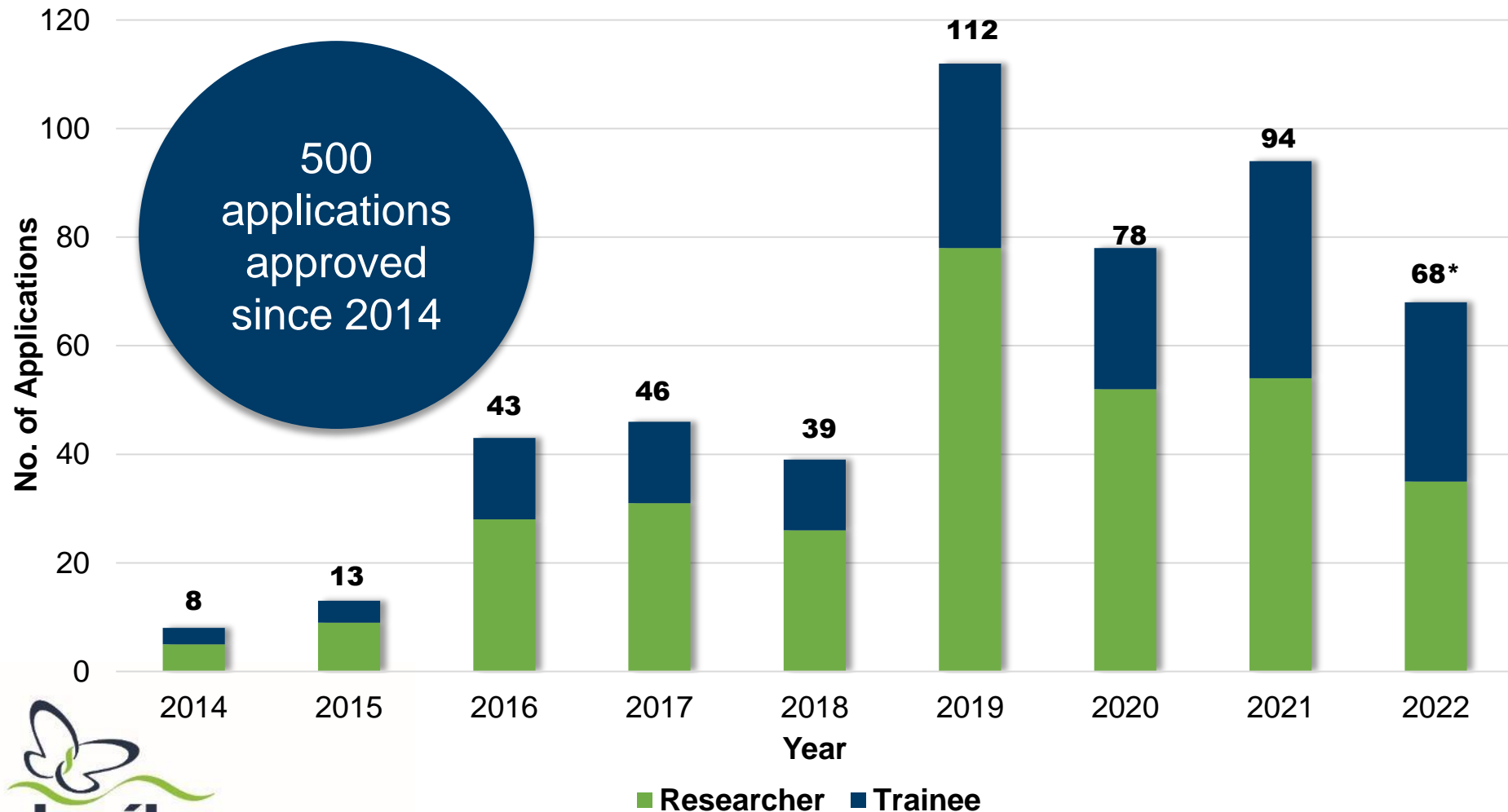
Approved Applications Summary

Year	Researcher	Trainee	Total
2014	5	3	8
2015	9	4	13
2016	28	15	43
2017	31	15	46
2018	26	13	39
2019	78	34	112
2020	52	26	78
2021	54	40	94
2022	35	33	68
Total	318	183	501

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Applying for data access

Step 1: Request an account

Step 2: Log-in and start an application

Step 3: Complete the form

Step 4: Submit your application

Step 1: Request an account

- The Primary Applicant should email access@clsa-elcv.ca to request a Magnolia* user account. Provide your full name, institutional email, position title and institution

- 2-3 working days to receive login information

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* CLSA's online data access application system

Step 1: Request an account - Trainee

- The **supervisor** (Primary Applicant) on behalf of the trainee must email access@clsa-elcv.ca to request a Magnolia* user account.
Please include the trainee name, institutional email and program.

* CLSA's online data access application system

Step 2: Log-in and start an application

For trainee application: Trainee should sign in

Step 2: Log-in and start an application

Trainees must initiate the project in Magnolia. If the supervisor initiates the application, the trainee cannot be added.

Trainee must click add and start the application
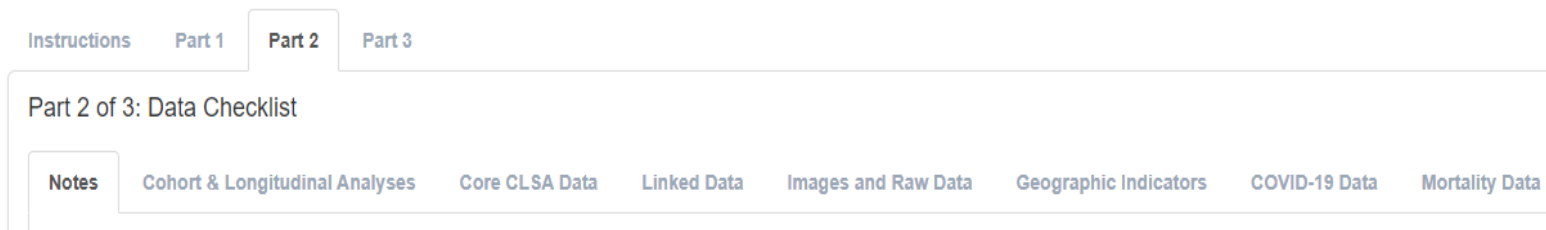
Step 3: Complete the form

- Read carefully the instructions included in Magnolia
- Fill out part 1

| Instructions | Part 1 | Part 2 | Part 3 |

Part 1 of 3: General Project Information

| Applicant | Project Team | Timeline | Description | Scientific Review | Ethics |

- Fill out part 2

| Instructions | Part 1 | Part 2 | Part 3 |

Part 2 of 3: Data Checklist

| Notes | Cohort & Longitudinal Analyses | Core CLSA Data | Linked Data | Images and Raw Data | Geographic Indicators | COVID-19 Data | Mortality Data |

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Step 3: Complete the form – Part 1

Trainee projects:
- **Supervisor is the main applicant**

- **specify the fee waiver**

Step 3: Complete the form – Part 1

Delete   Download ▾   Submit

Instructions   **Part 1**   Part 2   Part 3   Total fees: $3000

Part 1 of 3: General Project Information

Applicant   **Project Team**   Timeline   Description   Scientific Review   Ethics

All Co-Applicants and Other Personnel must be listed below. You must inform your collaborators that you have included them on this application. Please note that changes to the project team, including change of Primary Applicant and addition or removal of Co-Applicants and Support Personnel **require an amendment**. To submit an Amendment request, please click on "Create Amendment" in the upper-right corner of your screen and follow the instructions.

No co-applicants have been added.

Name	
Position	
Institution	
ⓘ E-mail	
Role	
Requires Access to Data	Yes

Include all project team members

Add Co-Applicant

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Step 3: Complete the form – Part 1

Part 1 of 3: General Project Information

Applicant   Project Team   Timeline   **Description**   Scientific Review   Ethics

Provide the level of detail you would normally provide in a grant application. Failure to provide adequate detail to assess feasibility will result in rejection of the application. Please adhere to character count

Project Title

ⓘ **Keywords**

Please provide a lay language summary of your project (**maximum 1000 characters**) suitable for posting on the CLSA website if your application is approved.

ⓘ **Lay Summary**
(0 characters)

Please provide a description of the proposed project. The proposal should be informative and specific and **no more than 4500 characters per section. Non-compliant applications will be returned.**

Background and Study Relevance
(0 characters)

Study Objectives and/or Hypotheses
(0 characters)

ⓘ **Study Design and Methodology**
(0 characters)

ⓘ **Data Analysis**
(0 characters)

Please include a list of the most relevant references (maximum 20)

- Lay summary written in lay language

- Objectives are clear and concise

- Use of requested CLSA data is described

- Enough information to assess feasibility

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Step 3: Complete the form – Part 2

Ensure application is for data that are available at the time of submission:
www.clsa-elcv.ca/data-availability

Step 3: Complete the form – Part 2

No physical assessments, medications, and biomarker data

Delete

Instructions   Part 1   **Part 2**   Part 3

Part 2 of 3: Data Checklist

Notes   **Cohort & Longitudinal Analyses**   Core CLSA Data   Linked Data   Images and Raw Data   Geographic Indicators   COVID-19 Data   Mortality Data

Please select the cohort (Tracking and/or Comprehensive - YOU MUST SELECT "YES" FOR AT LEAST ONE COHORT) for which you are requesting data:

ⓘ Tracking Cohort (Telephone Interview)

(choose)

ⓘ Comprehensive Cohort (In-home Interview & DCS visit)

(choose)

You will be able to make your selection of the wave of data collection (Baseline and/or Follow-up 1) within the Data Checklist.

Is this project part of longitudinal or integrative analyses involving previously approved project using CLSA data?

(choose)

← Return to the previous section   Proc

Describe in the proposal what are you adding to the previous approved project

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Step 3: Complete the form – Part 2

- **Select only the modules needed for your project**

- **Make sure they are described in your proposal**

Note: cognition and medications data are included in the Questionnaire module

Step 3: Complete the form – Part 2

Please note that images output data are included in the Physical Assessments module

- **Select only if images are needed**

- **Describe how they can help to achieve proposed objectives and how they will be analyzed**

Additional costs $$$

Step 4: Submit your application

The primary applicant is responsible for the content of the application.

Only the primary applicant will be able to submit the application – this also applies to trainee applications.
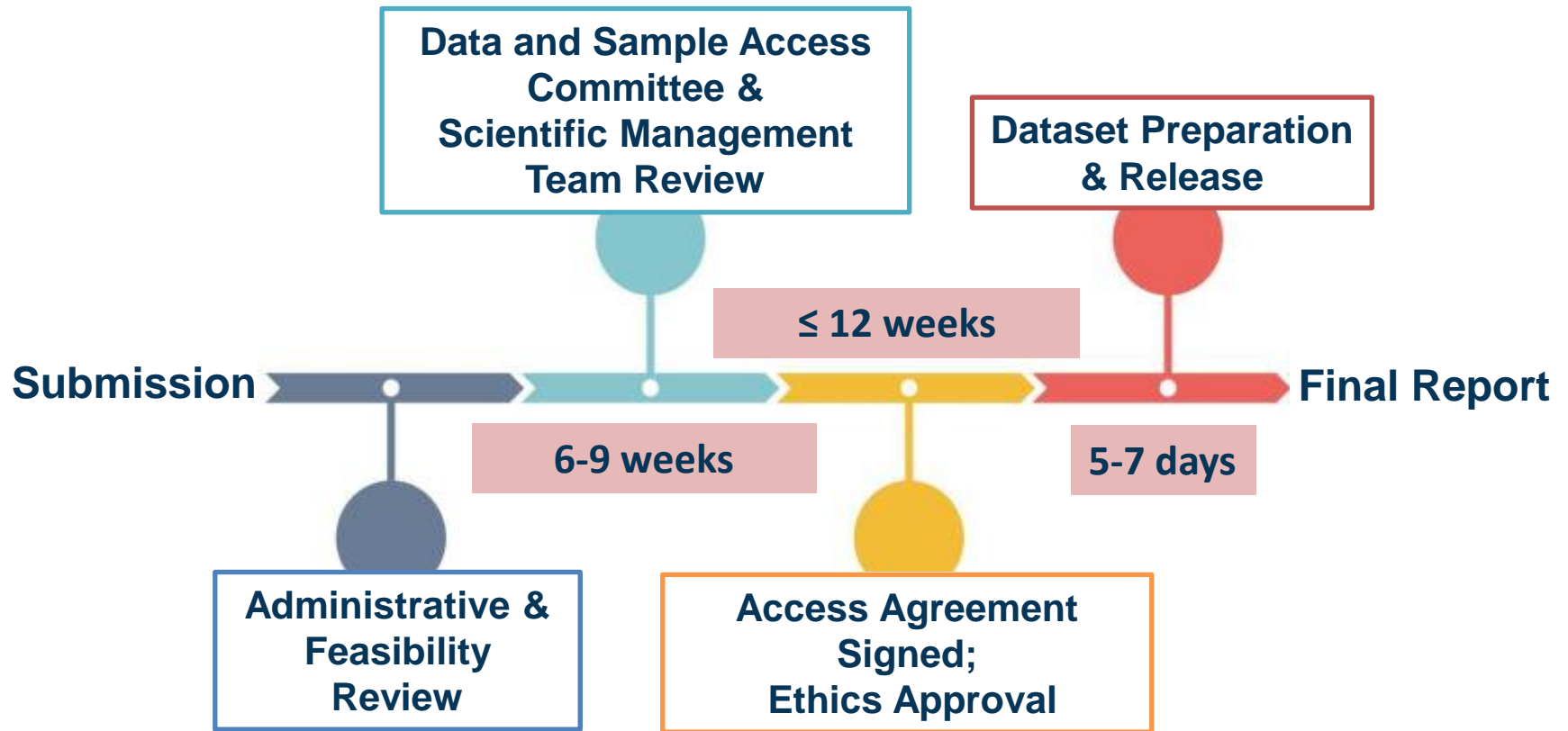

- Applications must be received by 5 p.m. ET on the submission deadline

2023 Application Deadlines

- January 18, 2023
- April 12, 2023
- July 12, 2023
- October 4, 2023

Data Access Timeline

Review Process

1. Administrative review

2. Feasibility review

3. Data and Sample Access Committee (DSAC) review

4. CLSA Executive Committee review

Review outcomes:

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

Canadian Longitudinal Study on Aging
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Data and Sample Access Committee

- **Chair:** Mark Oremus (University of Waterloo)

- **Members:**
  - Truls Ostbye (Duke University)
  - Robert Tate (UManitoba)
  - Andrea Gruneir (UAlberta)
  - Megan O'Connell (USask)
  - Danielle Bouchard (UNB)
  - Danilo Bzdok (McGill)
  - Theodore Cosco (SFU)
  - Zhiwei Gao (Memorial)
  - Marie Pigeyre (McMaster)

- Despoina Manousaki (UMontreal)
- Mark Keezer (UMontreal)
- Plinio Morita (UWaterloo)
- Theone Paterson (UVic)
- Olga Theo (Dalhousie University)
- Suzanne Tyas (Waterloo)
- Parminder Raina (CLSA Representative, McMaster)
- Matilda Saliba (CLSA Data Access Officer, RI-MUHC)

- *Ex-officio*
  - Advisor (CIHR)

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Main reasons for minor revisions

- Writing the lay summary in a language that is not suitable for the general public.

- Selecting a cohort that does not include the data needed for the proposed project

- Selecting data modules that are not described in the proposal

- Requesting images although only images output data are needed (included in Physical assessment module).

Main reasons for major revisions

- Research objectives are not clear and concise enough

- The use of requested data is not adequately described

- Proposed methods are not clearly described

Main reasons for rejection

- Requested data are not available at the time of submission

- Failure to provide the level of detail sufficient to assess the study feasibility

- Not applying requested revisions

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Data Access Fees

- **Partial Cost Recovery Model**
  - **Alphanumeric data**
    - CAD $3,000 for researchers based in Canada
    - CAD $5,000 for researchers based at institutions outside of Canada
    - **Graduate students** using data solely for thesis research & **postdoctoral and clinical research fellows** using data solely for the fellowship project are eligible for a **fee waiver** (once as a fellow)
    - **Fee waivers** only apply to trainees enrolled at a Canadian institution or supported by Canadian funds if working outside Canada
  - **Images & Complex data**
    - Additional fees apply for access to image files, raw data and datasets that require more complex customization

www.clsa-elcv.ca/fees

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Questions?