CLSA WEBINAR SERIES

# Accessing linked CLSA data at HDRN Canada data centres

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Health Data Research Network Canada

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# Meeting Agenda

1. Overview of CLSA's national dataset
2. Overview of HDRN Canada/DASH
3. Linked data availability and timeline
4. DASH process for accessing linked data
5. Single site experience with HDRN-CLSA data sharing project

# 1) Overview of CLSA's national dataset

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# 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.

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# CLSA: Key facts

- Major strategic initiative of CIHR; on Canadian research agenda since 2001
- More than 160 researchers and collaborators – 26 institutions
- Multidisciplinary – biology, genetics, medicine, psychology, sociology, demography, economics, epidemiology, nutrition, health services
- Largest research platform of its kind in Canada for breadth & depth
- Following 50,000+ Canadians aged 45-85 at baseline for 20 years

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# Terminology

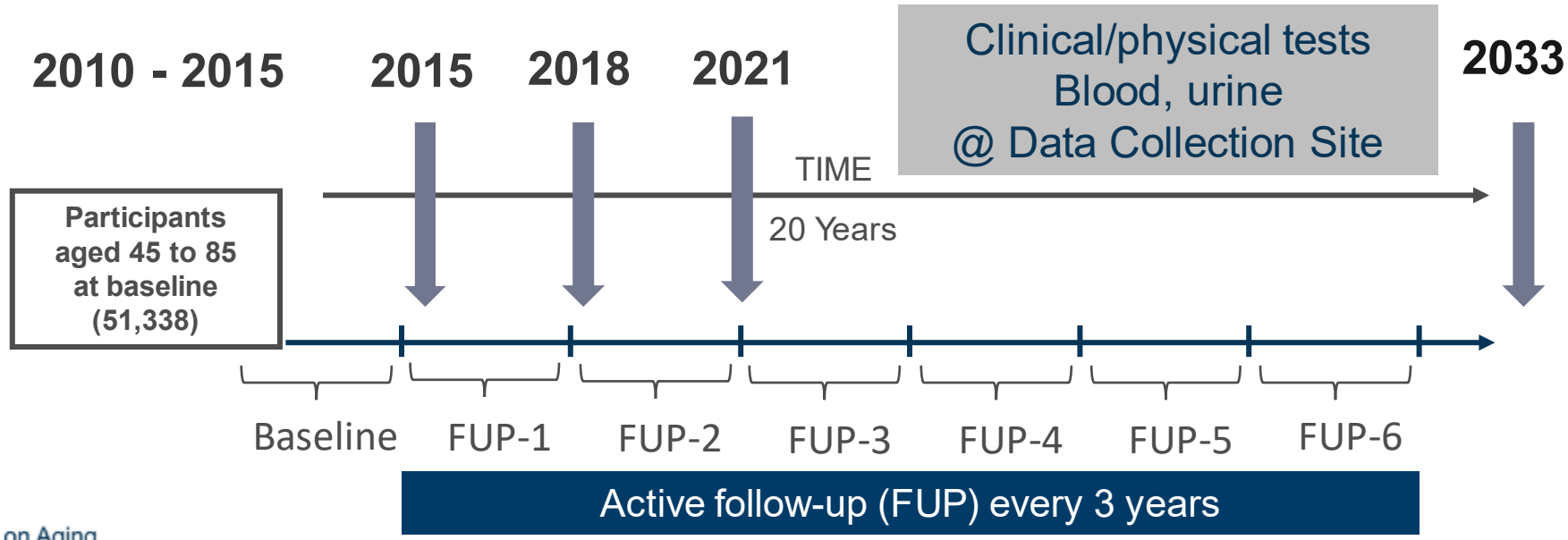
- **Tracking Cohort**
  - Target - 20,000 participants from all 10 provinces, followed through Computer-Assisted Telephone Interviews (60 minutes at baseline)
  - **21,241 recruited**
- **Comprehensive Cohort**
  - Target - 30,000 participants living within 25 km (or 50 km) of a CLSA Data Collection Site (DCS)
  - Followed through in-home interviews (60 minutes) and physical assessments (2-3 hours) at a DCS
  - **30,097 recruited**

# CLSA Research Platform

50,000 participants aged 45 - 85 at baseline

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

| Questionnaire<br>By telephone (CATI) | Questionnaire<br>In person, in home (CAPI) |
|---|---|

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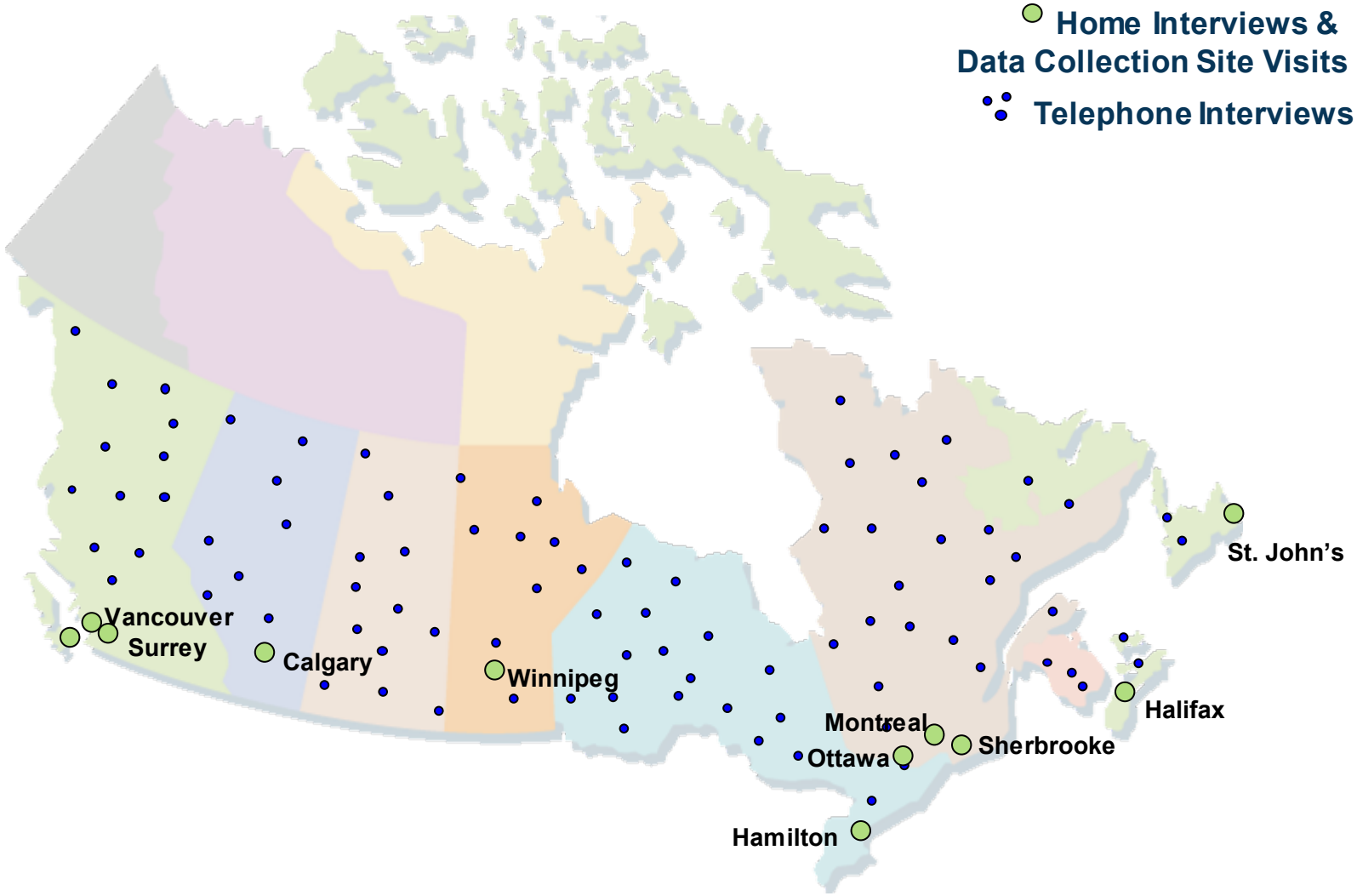
# National Scope

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# What data are available?

- Information on the changing biological, medical, psychological, social, lifestyle and economic aspects of people's lives.
- These factors may be studied to understand the impact in both maintaining health and in the development of disease and disability as people age.
- Data collection is conducted through telephone and in-home interviews, as well as during visits to Data Collection Sites (DCS).

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# Data Resources

- Website: https://www.clsa-elcv.ca/
- Data Support Documentation: https://www.clsa-elcv.ca/researchers/data-support-documentation
  - Data Collection Tools
  - Data Dictionaries
  - Sampling Weights Documents
  - Derived Variables Documents
  - Other data support materials

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CLSA

HDRN Canada

# 2) Overview of HDRN Canada/DASH

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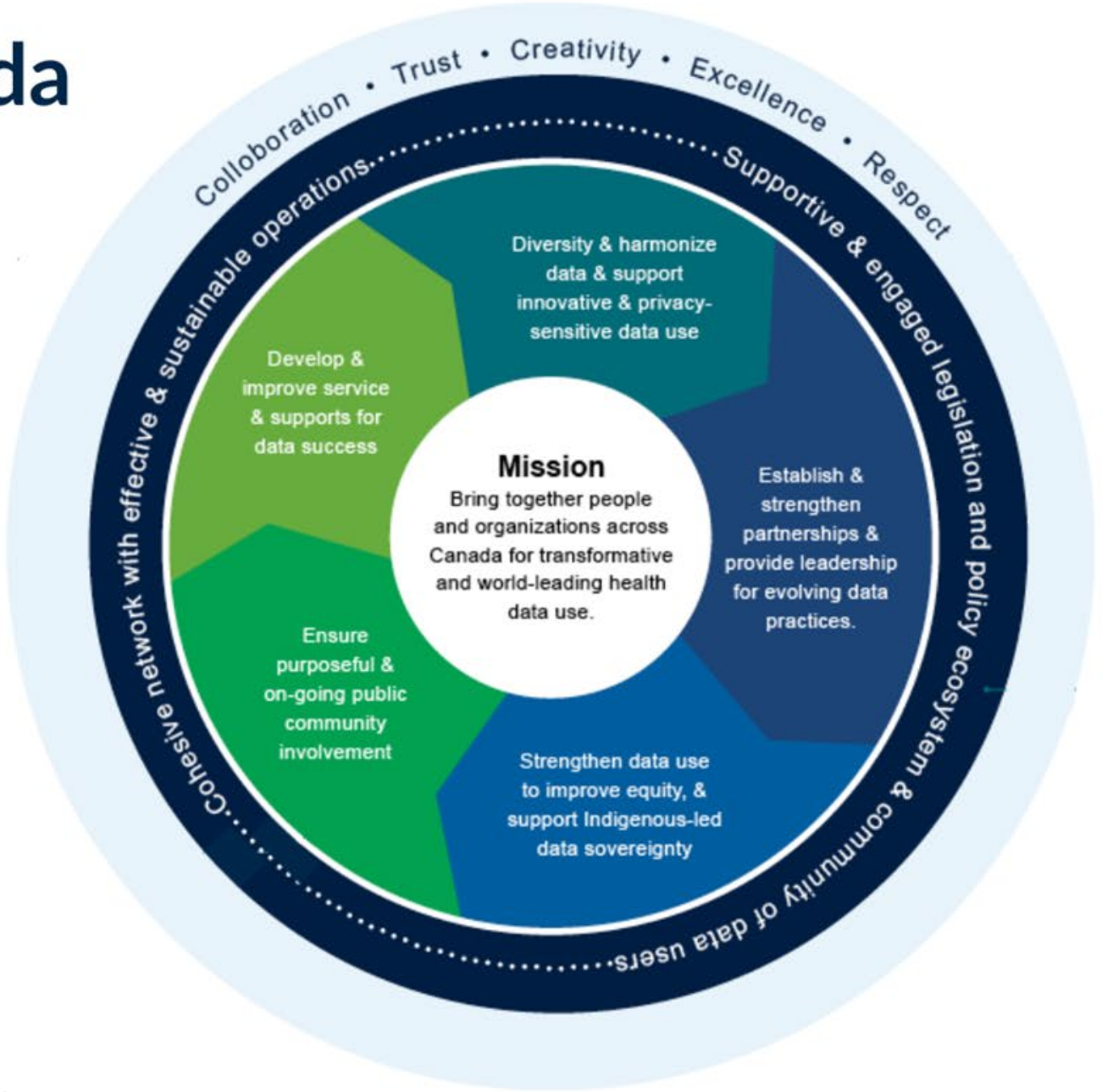
# HDRN Canada Strategic Framework

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# Data Access Support Hub (DASH)

## DASH is a service for researchers conducting multi-regional research

- Service provided by a coordination team of representatives from 13 data centres across Canada
- Facilitate data access in provincial/territorial and pan-Canadian data centres and help navigate local requirements
- DASH does not hold data; data resides at the data centres

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# HDRN Canada Members

AbSPORU Alberta SPOR SUPPORT Unit

Canadian Institute for Health Information / Institut canadien d'information sur la santé

GEORGE & FAY YEE Centre for Healthcare Innovation

GRIIS Groupe de recherche interdisciplinaire en informatique de la santé

Health Data Nova Scotia

Hotiì ts'eeda Northwest Territories SPOR Support Unit

IC/ES Data Discovery Better Health

Institut de la statistique Québec

mælstrom

Manitoba Centre for Health Policy

University of Manitoba | Rady Faculty of Health Sciences

NB-IRDT New Brunswick Institute for Research, Data and Training

Newfoundland and Labrador SUPPORT Support for People and Patient-Oriented Research and Trials

NL Health Services

populationdata BC

Saskatchewan Health Authority

Saskatchewan Health Quality Council

SIDR Secure Island Data Repository

Statistics Canada / Statistique Canada

YSPOR Yukon Strategy for Patient-Oriented Research

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# Data Access Support Hub (DASH)

**DASH simplifies the data access process by:**

- Providing **navigational support and coordination** throughout data access request process
- Offering **centralized resources** and **tools**
- **Harmonizing** aspects of **data access processes** across data centres
- **Integrating technological solutions** to streamline and progressively automate the DASH data access request process

# 3) Linked data availability and timeline

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# Data Centre Status

| BC | AB | SK | MB | ON | QC | NB | NS | NL | PEI |
|---|---|---|---|---|---|---|---|---|---|
| ☑ | Loading... | NOT STARTED | Loading... | ☑ | Loading... | ☑ | Loading... | Loading... | Loading... |

☑ CLSA data available for request **by January 2024.**

Loading... CLSA data sharing process **underway.**

NOT STARTED CLSA data sharing process has **not started.**

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# Two routes

**Multi-region linked data through DASH**

**Single-region linked data directly through data centre**

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# 4) DASH process for accessing linked data

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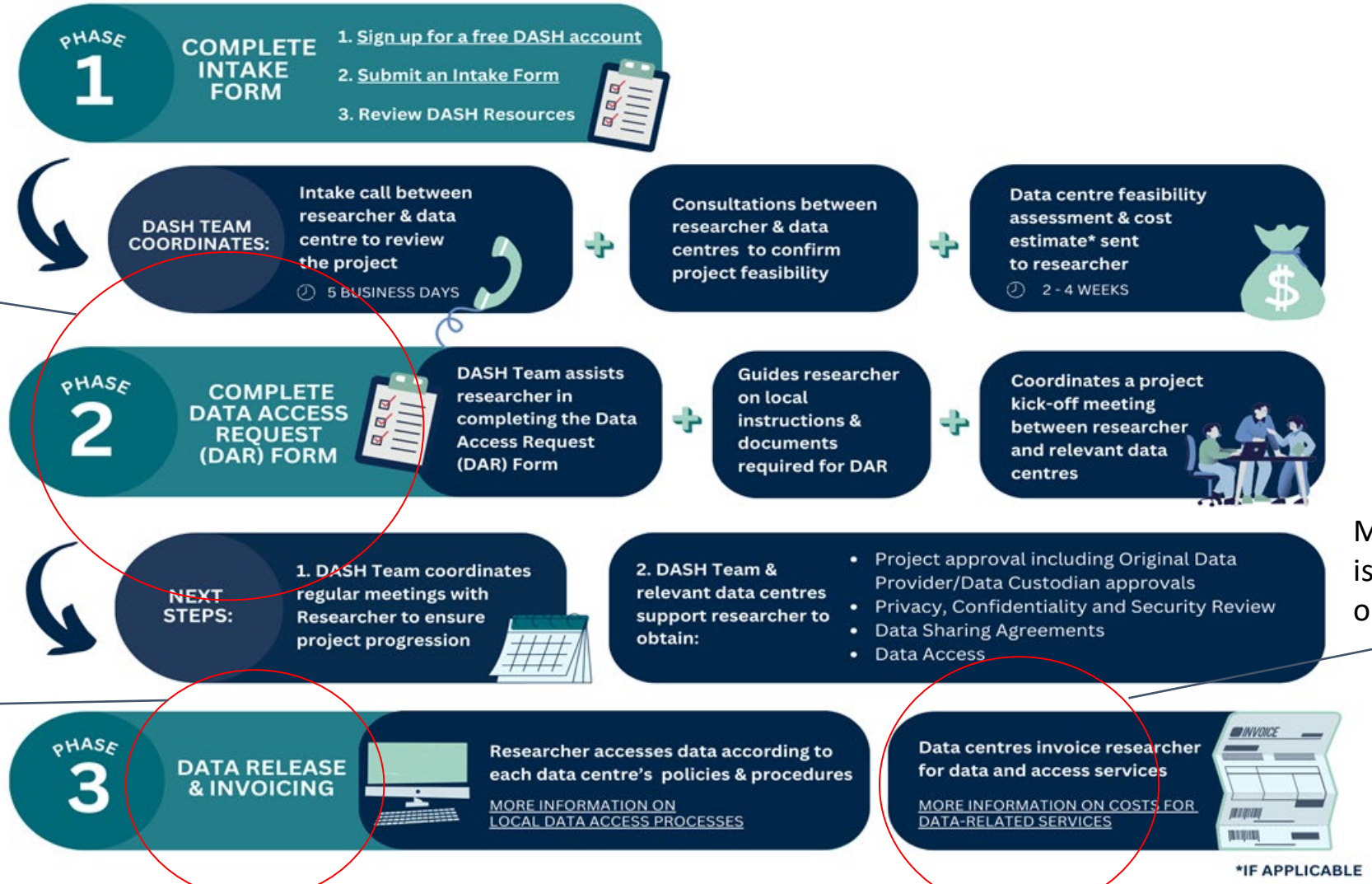
# DASH Process Overview




CLSA has 14 calendar days to reject/rescind approval.

Requestor must review the CLSA Data User Responsibility checklist.

McMaster University will issue invoice to requestor on behalf of CLSA.

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# Innovative Resources

- **Data Assets Inventory** (https://www.hdrn.ca/en/dash/inventory/)
  - **Administrative data** (hospitalization, drug claims, etc.)
  - **Clinical data** (electronic medical records, etc.)
  - **Social data** (education and immigration, etc.)
- **Algorithm Inventory** (https://www.hdrn.ca/en/dash/algorithms/)
- **COVID-19 Data Inventory** (https://www.hdrn.ca/en/dash/covid/)
- **Informed Consent** (https://www.hdrn.ca/en/dash/resources/informed-consent/)
- **Privacy Checklists** (https://www.hdrn.ca/en/dash/resources/privacy/)
- **Web portal for centralized forms & tools**

# Centralized Tools

**DASH web portal integrates forms that are required throughout the data access process**

Project information, services requested, sites of interest

Data requirements, cohort details, data extraction and analysis plan

Project information, ethics, data analysis, access and control

Supporting documents

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# Interested in working with DASH?

**COMPLETE INTAKE FORM**

1. Sign up for a free DASH account
2. Submit an Intake Form
3. Review DASH Resources

**DASH TEAM COORDINATES:**

Intake call between researcher & data centre to review the project

+

Data centre feasibility assessment & cost estimate sent to researcher

2 - 4 WEEKS

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# 5) Single site experience with HDRN-CLSA data sharing project

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# HDRN-CLSA data sharing: NB-IRDT's experience

- Project planning and completion were truly collaborative
- Learned from similarities and differences between organizations
- Consistent standing meetings with a focus on action items kept us moving forward

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# Helpful lessons learned

- Always include plenty of time for legal review in project timelines
- Appoint a key point of contact for each organization
- Map out data flows in advance
- Share key processes
- Check for common understanding of terminology
- Every organization's procedure details do not need to be identical

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

McMaster University | Collaborative for Health & Aging

**Contact:**
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