New possibilities for research and innovation: An introduction to Health Data Research Network Canada

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About HDRN Canada

Health Data Research Network Canada (HDRN Canada) is made up of provincial, territorial and pan-Canadian organizations that hold and manage data.

By working together, we can:
• Share expertise
• Identify opportunities for collaboration
• Foster innovation
Each HDRN Canada Organization brings its established relationships, including with their ministries of health and local data providers.
Our Mission

A distributed network that facilitates and accelerates multi-jurisdictional research
Principles / Commitments

We have a strong starting point – and need to close the gap

- Distributed network with distributed funding
- Respect for local context and policy environment
- Leverage and share wherever possible
- Openness to ideas, input and opportunities
HDRN Canada Governance

Board of Directors
- Guy Bujold (Chair)
- Anne Martin-Matthews
- Chris Power
- Christine Weise
- Mahadeo Sukhai
- Rebecca Fuhrer
- Robert Bell

Executive
- Kim McGrail - BC
- Alan Katz - MB
- Alison Paprica - ON
- Brent Diverty - CIHI
- Frank Gavin - ON
- Jennifer Walker - ON
- Jean-Francois Ethier - QC
- Michael Schull - ON
- Ted McDonald - NB
- Charles Victor - ON
**HDRN Canada Management**

**Leads Team includes**
- Alain Vanasse - QC
- Catherine Street - NL
- Denis Roy - QC
- Don Macdonald - NL
- Donna Curtis-Maillet - NB
- Hude Quan - AB
- Isabel Fortier - QC
- Claudia Sanmartin - STC
- Juliana Wu - CIHI
- Lisa Lix - MB
- Mary-Ann MacSwain - PEI
- Nicole Yada - ON
- Sam Stewart - NS
- Stephanie Irlbacher-Fox - NWT
- Tanya Verrall - SK
Engagement in action

Public Advisory Council

Chair: Frank Gavin, also member of HDRN Canada Public Engagement Working Group and Executive

Membership: Currently, 13 individuals across diversity of geographic locations within Canada, age, ethnicity, occupation, socio-economic status, language and gender.

Purpose: To provide guidance, from essentially public perspectives, to HDRN Canada about its priorities, development, and operations.
Partnerships in action

**SPOR CDP Advisory Committee**

**Chair:** Member of HDRN Canada Executive (Michael Schull)

**Membership:** Representatives from 11 different SPOR-funded entities from across Canada

**Purpose:** Established as a formal mechanism to receive strategic advice from SPOR entities on SPOR CDP activities and their alignment with individual and collective needs and priorities.
Objectives for the SPOR Canadian Data Platform

1. Create data access support system
2. Harmonize definitions/ algorithms for key chronic diseases
3. Continue to expand sources and types of data
4. Develop technology infrastructure to support efficiency and scaling
5. Create supports for advanced analytics
6. Build Partnerships: patients, public, Indigenous communities
7. Build strong governance and enable national coordination
Data starting points

LEGEND AND NOTES:
- Population-wide coverage
- Less than population-wide coverage
- Linkage and integration planned not yet implemented

Continue to expand sources and types of data

COVID-19 TEST RESULTS DATA
HEALTH ADMINISTRATIVE DATA
- Acute care hospitalizations
- Ambulatory clinic visits
- ED visits
- Physician claims
- Prescribed medications
- Home care
- Continuing care

OTHER HEALTH DATA
- Vital statistics
- Primary care EMR
- Cancer registry
- PREMs and PROMs
- Genomics
- Lab and imaging

SOCIAL DATA
- Education
- Immigration
- Workers compensation
- Early childhood development

BC AB SK MB ON QC NB NS NL CIHI STC

_RESET_
Focus on scalability and sustainability

Develop technology infrastructure to support efficiency and scaling

Support metadata collection and management all in support of longer-term automation of services; review distributed data analysis needs; plan distributed analysis supports
Priorities for the coming year

- **Indigenous engagement**: Supporting COVID-19 research with First Nations, Inuit and Métis communities; increasing our Network’s information and training around Indigenous engagement and principles of data sovereignty

- **Public engagement**: Implementing advice received from the Public Advisory Council; gathering public feedback through public deliberations and other engagement mechanisms
• Launched in February 2020, DASH is a single-stop online portal through which researchers can request access to data from multiple provincial, territorial and pan-Canadian sources.

• Services led by the Canadian Institute for Health Information (CIHI), with distributed staff across HDRN Canada partner data centres

• Over 40 multi-jurisdictional data access requests and inquiries received since launch
Objectives:

• Make local processes transparent
• Provide coordinated support to researchers navigating data sharing issues and analytic design options
• Harmonize data access processes across HDRN partner data centres
• Streamline and progressively automate the DASH central request process
**DASH Website**

**Resources available through DASH:**

- 380+ datasets available for request
- 140+ multi-jurisdiction algorithms from 34 existing validation or feasibility studies
- Inventory of data access requirements and procedures at HDRN Canada data centres
- Online request intake form
COVID-19 Support and Resources

• Regularly updated webpage (hdrn.ca/en/covid) providing a central repository for:
  • Information about linkable COVID-19 test results data and metadata
  • Links and resources from HDRN Canada organizations

• DASH has helped facilitate multi-jurisdictional COVID-19 related research requests on topics including emergency medicine, surgery, paediatric diabetes, neonatal care and virtual care
Algorithms and Harmonized Data Working Group

**Purpose:** To oversee:

(a) development of data resources and their metadata and  
(b) development of measures of population health, health service use and determinants of health that can be used for research in all provinces and territories.

**Key deliverables:**

- **Data Assets Inventory**
- **Algorithms Inventory**
Background

Supporting standardized approaches to common data-related tasks is essential to produce reliable and accurate multi-jurisdiction research evidence

**Standardized and Validated Algorithms:**

- Standardization: common approach(es) to measure; To avoid “apples and oranges” comparisons
- Validation: checking the accuracy of a measure

**Harmonized Data:** processes to integrate data from different sources and provide users with comparable views of the data
Algorithms Inventory

An on-line tool populated with published measures that have been validated or assessed for feasibility of implementation across multiple provinces or territories.

Quality control of content is a key goal.
Algorithms Inventory: Content

• **Initial focus:** algorithms for **chronic and acute health conditions**

• **In progress:** algorithms for the **determinants of health**
  • We are compiling a list of social determinants measures that can be implemented across Canada; most are based on Statistics Canada Census data
    • income quintile
    • social and material deprivation
    • rural/urban residence location
    • race & ethnicity

• **After that:** algorithms for **healthcare measures**
  • high cost users
  • Comorbidity indices
  • procedures & interventions
Expanding Algorithms Inventory

A Call for Proposals was issued in May 2020 to expand the Algorithms Inventory via collaborations with experienced teams of Canadian researchers. Proposals focus on describing new validation studies or feasibility studies using administrative data from multiple provinces / territories.

Four projects are currently underway:

- **External validation of the Passive Surveillance Stroke SeVerity (PaSSV) score** (PI: Amy Yu, University of Toronto, Sunnybrook Hospital)
- **Validation of algorithm to identify Juvenile Idiopathic Arthritis (JIA) across the provinces of Alberta, Manitoba, Ontario, Nova Scotia, PEI and New Brunswick** (PI: Deborah Marshall, University of Calgary)
- **Predicting hospital admissions for ambulatory care sensitive conditions using primary care electronic medical record data: a multi-jurisdictional feasibility and validation study** (PI: Andrew Ponto, University of Toronto)
- **Development of a validated, patient-level definition of chronic pain for use in administrative health data** (PI: Morgan Slater, Queen’s University)
No one organization has “all the data”

• HDRN Canada mandate to expand available data – with our member organizations holding foundational population-based data

• Data environment is complex and complementary

• HDRN Canada is developing the Canada HDR Alliance to enable research access to data that accommodates this complexity without necessarily having to hold the data ourselves

• First pilot members of the HDR Alliance are the Canadian Partnership for Tomorrow’s Health (CanPath) and the Canadian Longitudinal Study on Aging (CLSA)
Canada HDR Alliance in action

• The Canadian Partnership for Tomorrow’s Health (CanPath) was the first member of the Canada HDR Alliance
  • CanPath’s current dataset includes >330,000 participants
• Collaborative activities with CanPath:
  • CanPath pilot projects coordinated through DASH
  • Facilitating linkage with regional cohorts and HDRN Canada data centres where not currently existing
  • Identifying and documenting joint DASH/CanPath intake workflow, feasibility review activities and timing
Canada HDR Alliance in action, continued

• The Canadian Longitudinal Study on Aging (CLSA) recently joined the Alliance. CLSA is a large, national, longitudinal research study of adult development and aging.

• Collaborative activities with CLSA:
  • Facilitating the linkage between the CLSA data sets and HDRN data centres, and streamlining requests to access linked data through DASH
  • Co-developing data access and methodological resources that are consistent across provincial and territorial data centres
  • Exploring a number of scientific opportunities to demonstrate impact of data linkage
Other collaborations underway

- **Canadian Network for Observations Drug Effectiveness Studies (CNODES):** Ensuring alignment of efforts and leveraging expertise with multi-jurisdictional research

- **IBM:** Collaborate on innovative infrastructure and supports for researchers to leverage in-kind commitments made in our 2018 CIHR CDP grant proposal

- **Canadian Primary Care Sentinel Surveillance Network (CPCSSN):** Promoting use of EMR data to enhance understanding and management of COVID-19 beyond and before cases are acute

- **Canadian Research Data Centre Network (CRDCN):** Joint funding application to advance conversations about social data linkage

- **Health Data Research UK:** Ongoing international collaboration, including on the International COVID-19 Data Research Alliance

And many more!
Data may not all be available in one location

• Researchers would like data from multiple jurisdictions to be pooled in one location – but this is not always feasible

• Legislative review underway to understand what is possible in current state

• Statistical review underway to determine what analyses are feasible in a distributed data environment

• Secure environment review underway to assess best practices and potential for environments to be connected for distributed analysis
We want to hear from you

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