THE UNIVERSITY OF BRITISH COLUMBIA
UBC Health

Health Data Research Network Canada Webinar

June 24, 2021

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

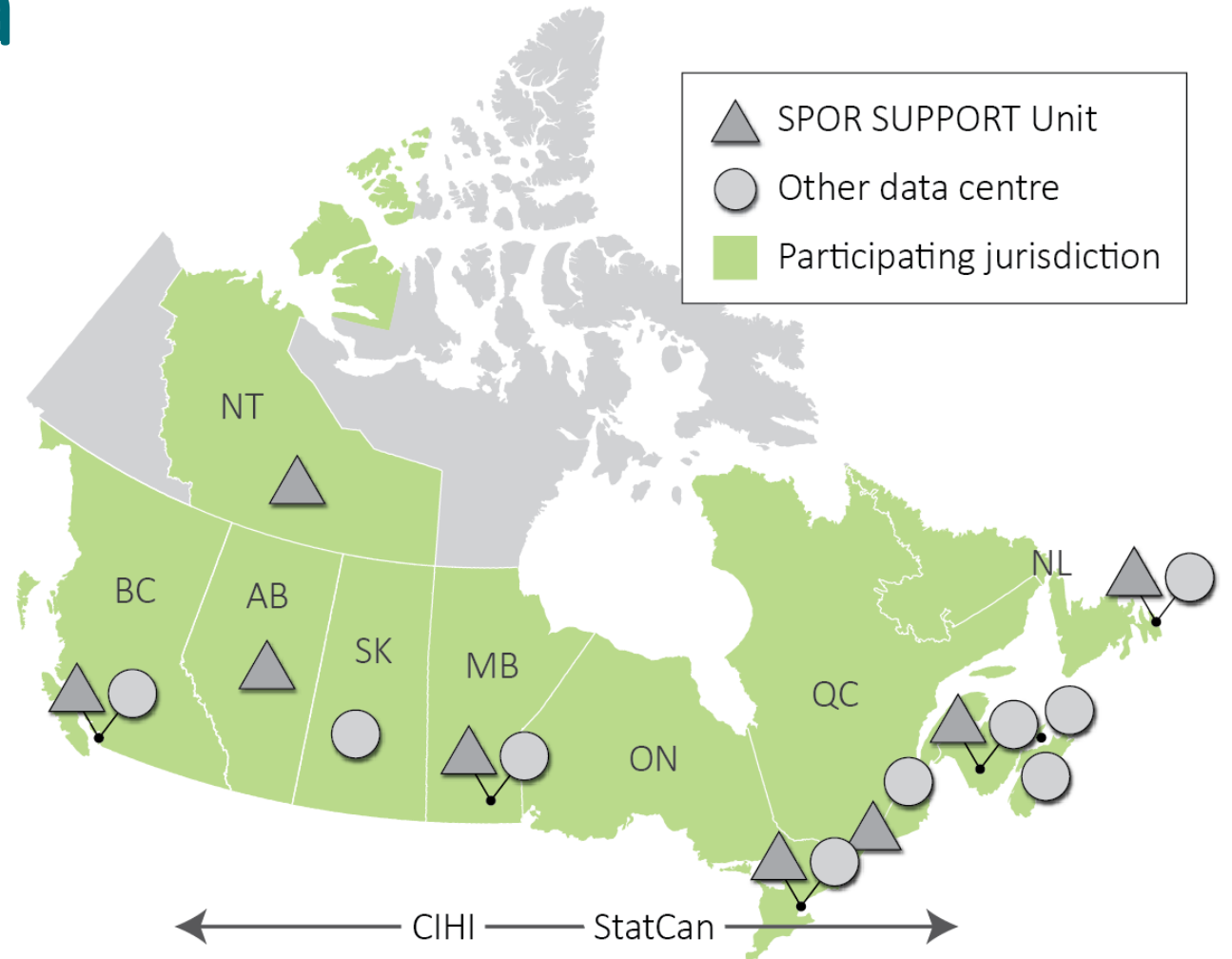Kimberlyn McGrail

University of British Columbia
24 June 2021

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.
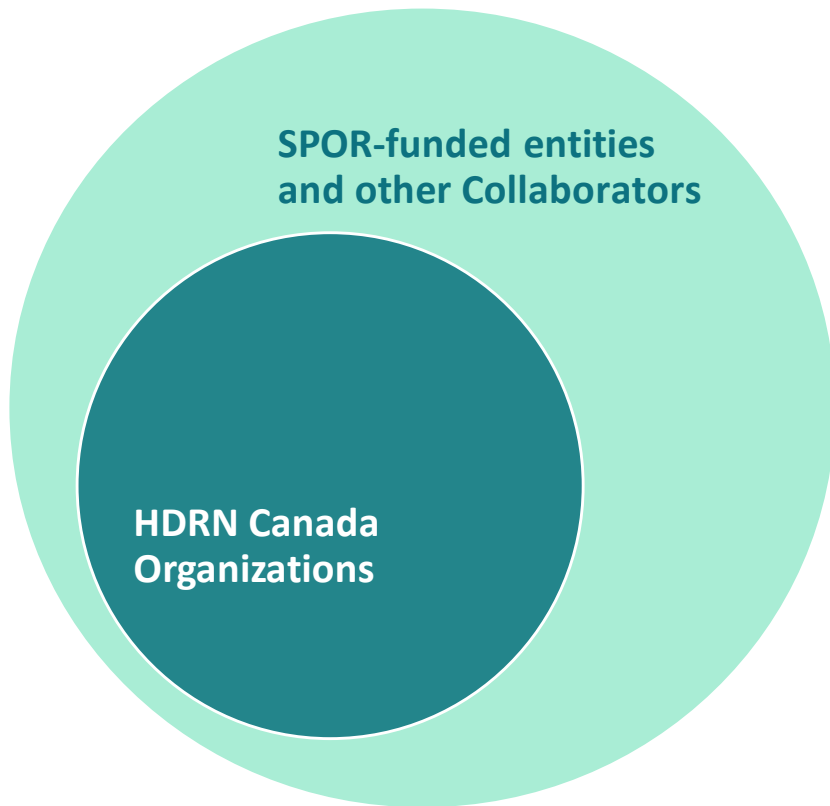
By working together, we can:

- Share expertise
- Identify opportunities for collaboration
- Foster innovation

HDRN Canada Organizations

HDRN Canada is comprised of provincial, territorial, and pan-Canadian organizations with decades of experience managing health data.

SPOR-funded entities and other Collaborators

HDRN Canada Organizations

Canadian Institute for Health Information
Better data. Better decisions. Healthier Canadians.

UNB | NB-IRDT
UNIVERSITY OF NEW BRUNSWICK | New Brunswick Institute for Research, Data and Training

Alberta SPOR SUPPORT Unit

Statistics Canada · Statistique Canada

SASKATCHEWAN HEALTH QUALITY COUNCIL — Connecting people. Igniting ideas. Accelerating improvement.

GRIIS

GEORGE & FAY YEE Centre for Healthcare Innovation

mælstrom

IC/ES Data Discovery Better Health

Institut national d'excellence en santé et en services sociaux Québec

UNITÉ DE SOUTIEN SRAP | QUÉBEC

Hotıı ts'eeda NORTHWEST TERRITORIES SPOR SUPPORT UNIT

DALHOUSIE UNIVERSITY Health Data Nova Scotia

NEWFOUNDLAND AND LABRADOR SUPPORT Support for People and Patient Oriented Research and Trials

populationdata BC

UNIVERSITY OF MANITOBA | Manitoba Centre for Health Policy

UNIVERSITY of Prince Edward ISLAND Centre for HEALTH and COMMUNITY RESEARCH

Newfoundland & Labrador Centre for Health Information

Each HDRN Canada Organization brings its established relationships, including with their ministries of health and local data providers.
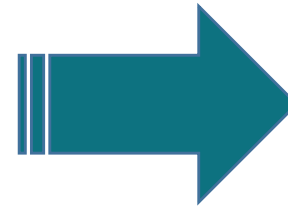
Our Mission

A distributed network that facilitates and accelerates multi-jurisdictional research

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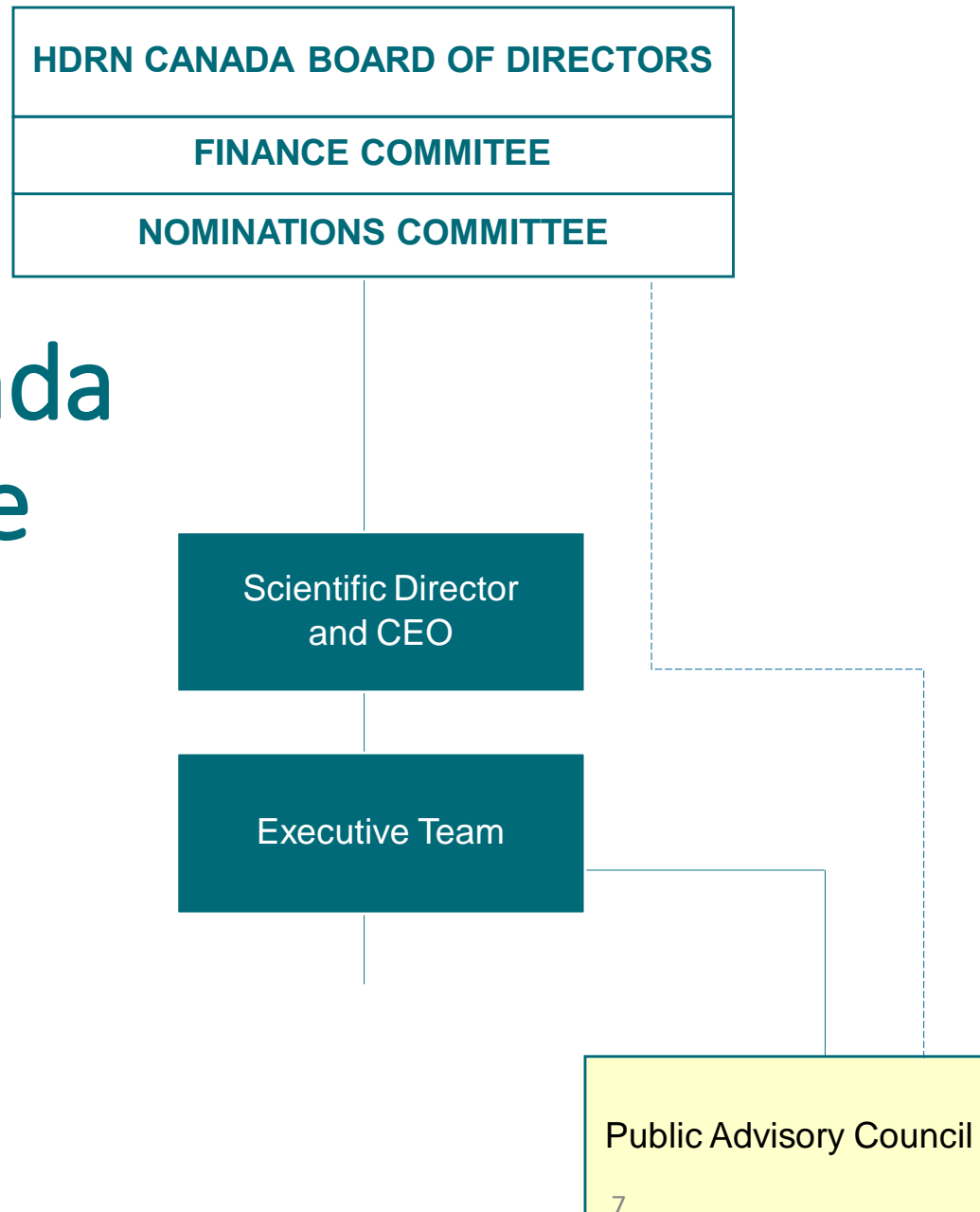
Principles / Commitments

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

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

HDRN Canada Governance

HDRN CANADA BOARD OF DIRECTORS

FINANCE COMMITEE

NOMINATIONS COMMITTEE

Scientific Director and CEO

Executive Team

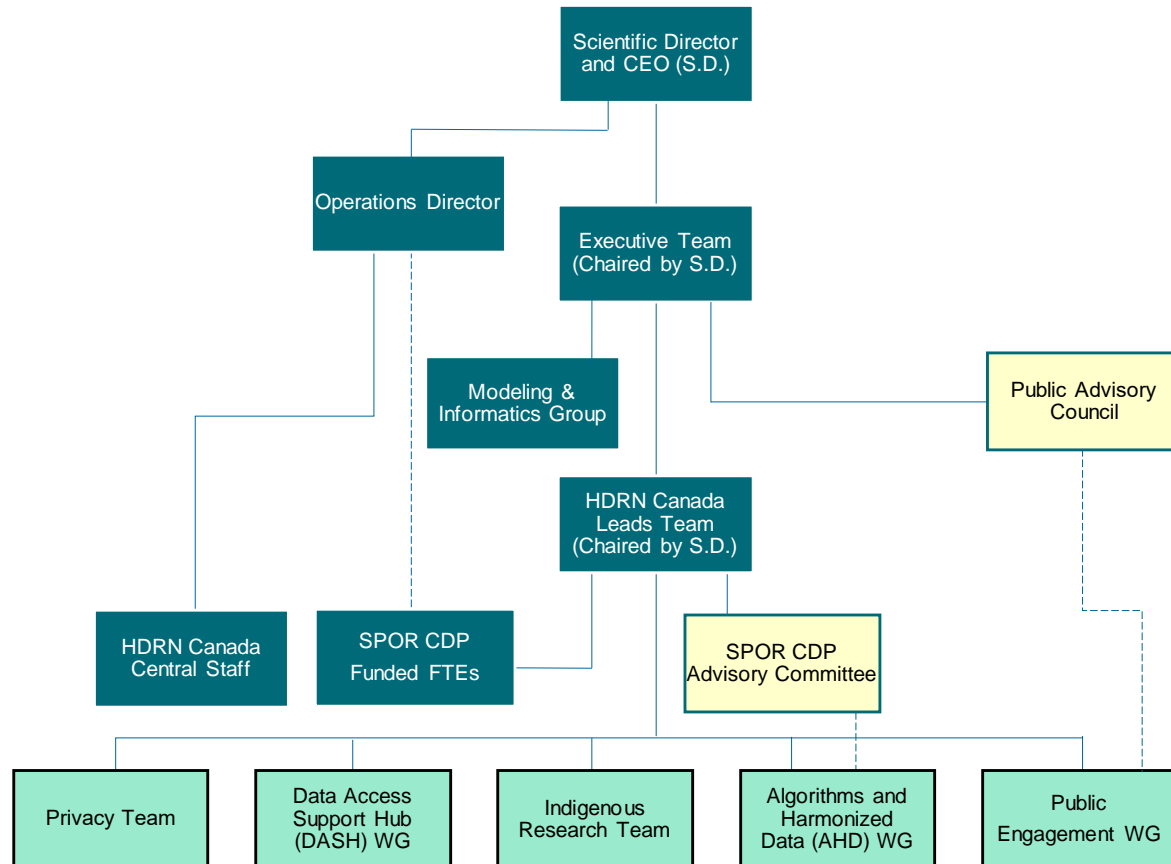Public Advisory Council

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

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Health Data Research Network Canada

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
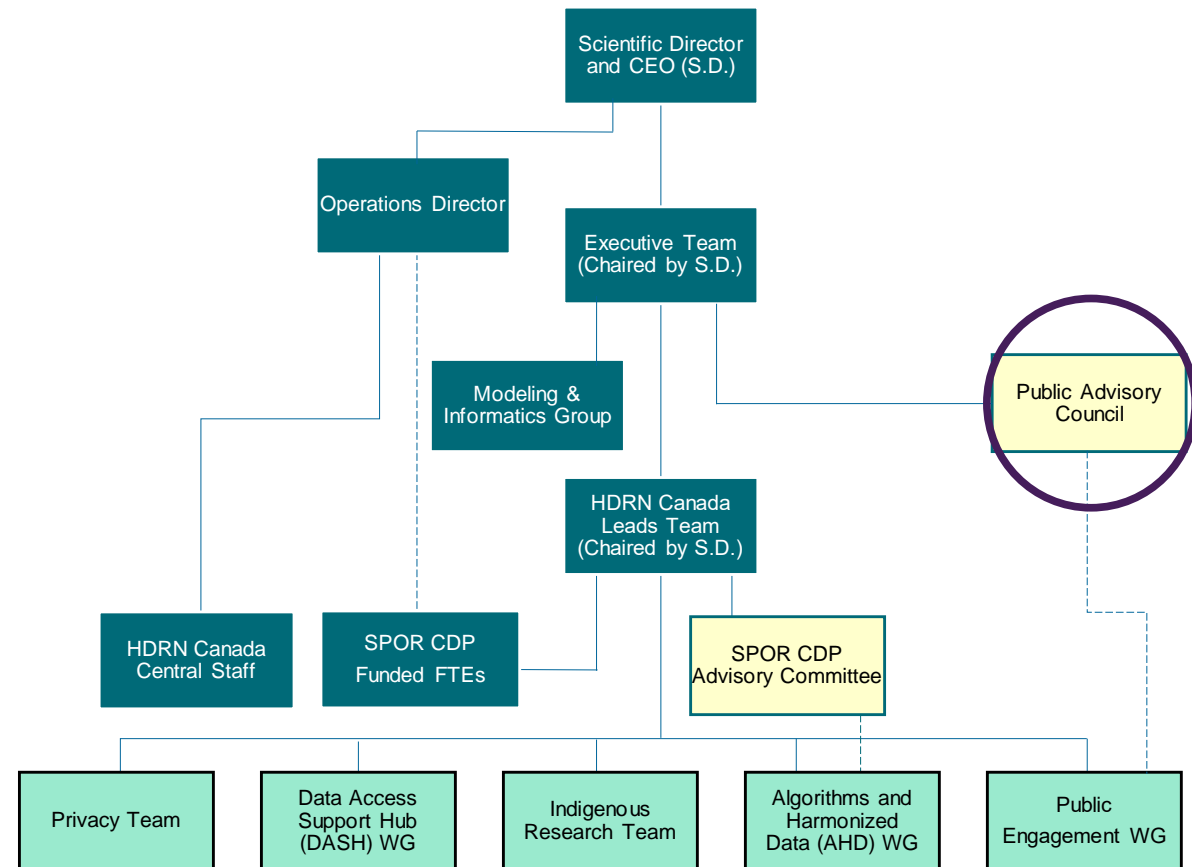
Stephanie Irlbacher-Fox - NWT

Tanya Verrall - SK

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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.
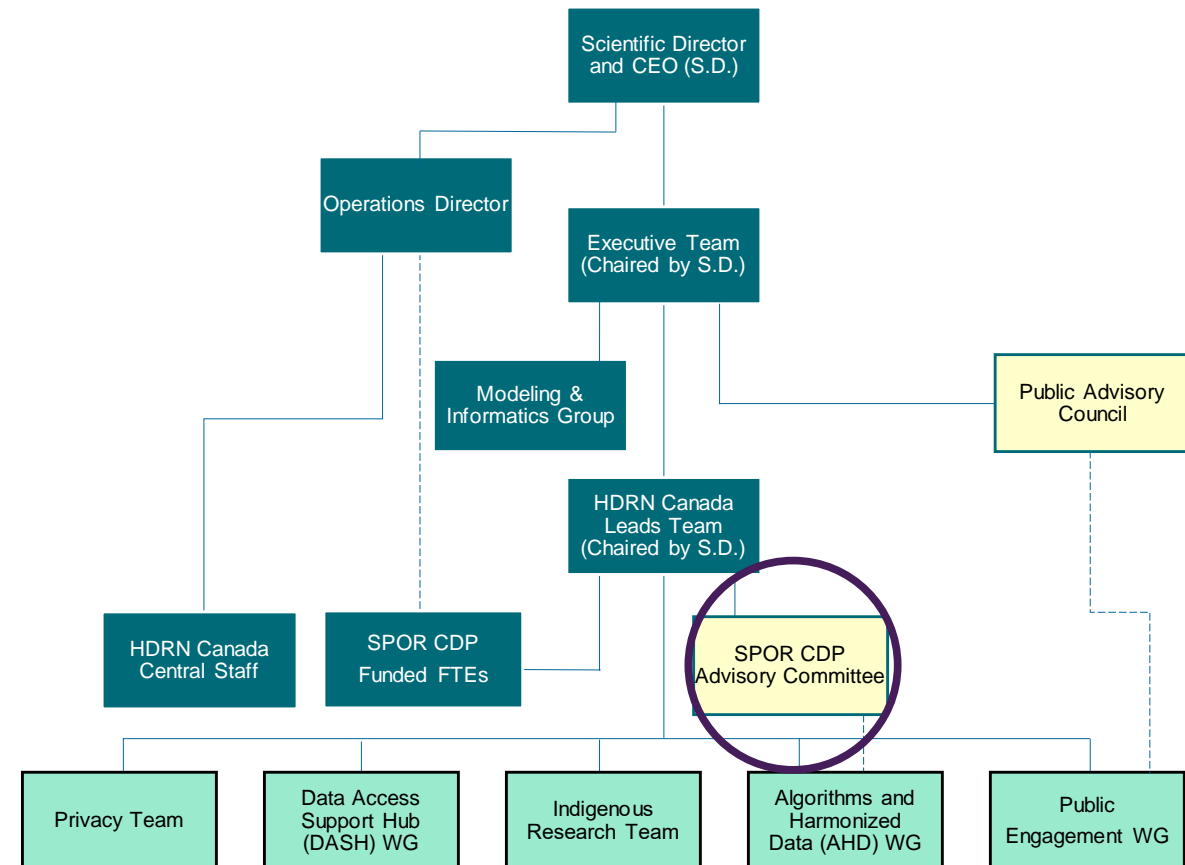

Scientific Director and CEO (S.D.)

Operations Director

Executive Team (Chaired by S.D.)

Modeling & Informatics Group

Public Advisory Council

HDRN Canada Leads Team (Chaired by S.D.)

HDRN Canada Central Staff

SPOR CDP Funded FTEs

SPOR CDP Advisory Committee

Privacy Team

Data Access Support Hub (DASH) WG

Indigenous Research Team

Algorithms and Harmonized Data (AHD) WG

Public Engagement WG

Réseau de recherche sur les données de santé du Canada
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Partnerships in action
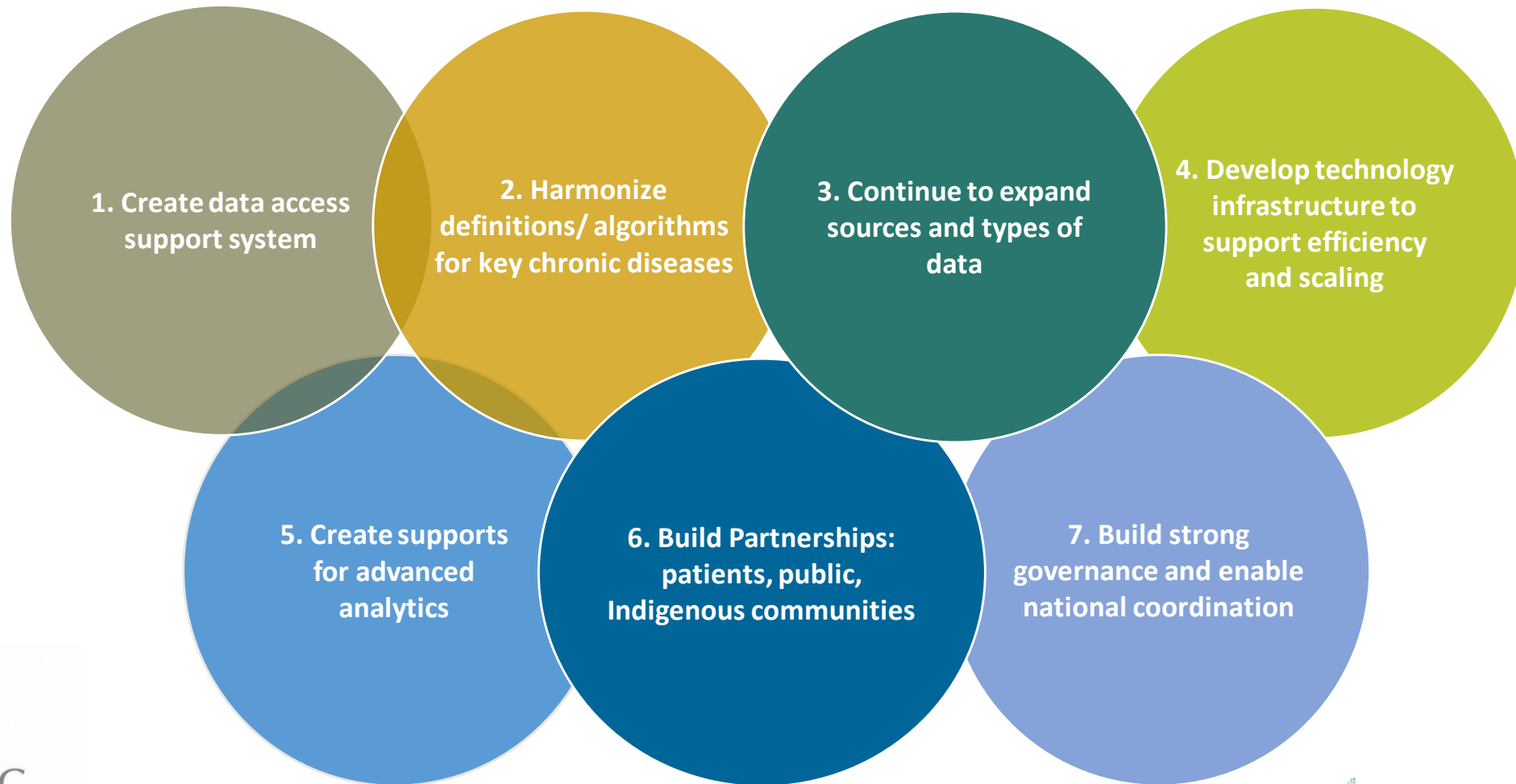# SPOR CDP Advisory Committee

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.

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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

Continue to expand sources and types of data

	BC	AB	SK	MB	ON	QC	NB	NS	NL	CIHI	STC
COVID-19 TEST RESULTS DATA	██	██		██					██		
HEALTH ADMINISTRATIVE DATA											
Acute care hospitalizations	██	██	██	██	██	██	██	██	██	██	██
Ambulatory clinic visits		██	██	██	██	██	██	██	██	░░	
ED visits	██	██	██	██	██	██	░░	██	██	░░	██
Physician claims	██	██	██	██	██	██	██	██	██	░░	
Prescribed medications	██	██	██	██	░░	░░	██	██	██	░░	
Home care	██	██	██	██	██		plan		plan	░░	
Continuing care	██	██	██	██	██	██			██	░░	
OTHER HEALTH DATA											
Vital statistics	██	██	██	██	██	██	██	██	██		██
Primary care EMR	░░	░░		░░	░░	░░	██	██	██	░░	
Cancer registry	██	██	██	██	██	██	██	██	██		██
PREMs and PROMs	░░	░░								░░	
Genomics	░░					░░	plan		plan		
Lab and imaging	░░	░░	░░	░░	░░	plan	░░	plan	██		
SOCIAL DATA											
Education	██			██		░░	██	░░	░░		██
Immigration	██			██	██		██				██
Workers compensation	██						░░				
Early childhood development	██			██	plan		██				
	BC	AB	SK	MB	ON	QC	NB	NS	NL	CIHI	STC

LEGEND AND NOTES:

██ = Population-wide coverage

░░ = Less than population-wide coverage

plan = Linkage and integration planned not yet implemented

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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

6. Build Partnerships: patients, public, Indigenous communities

- **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

Data Access Support Hub (DASH)

1. Create data access support system

- 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

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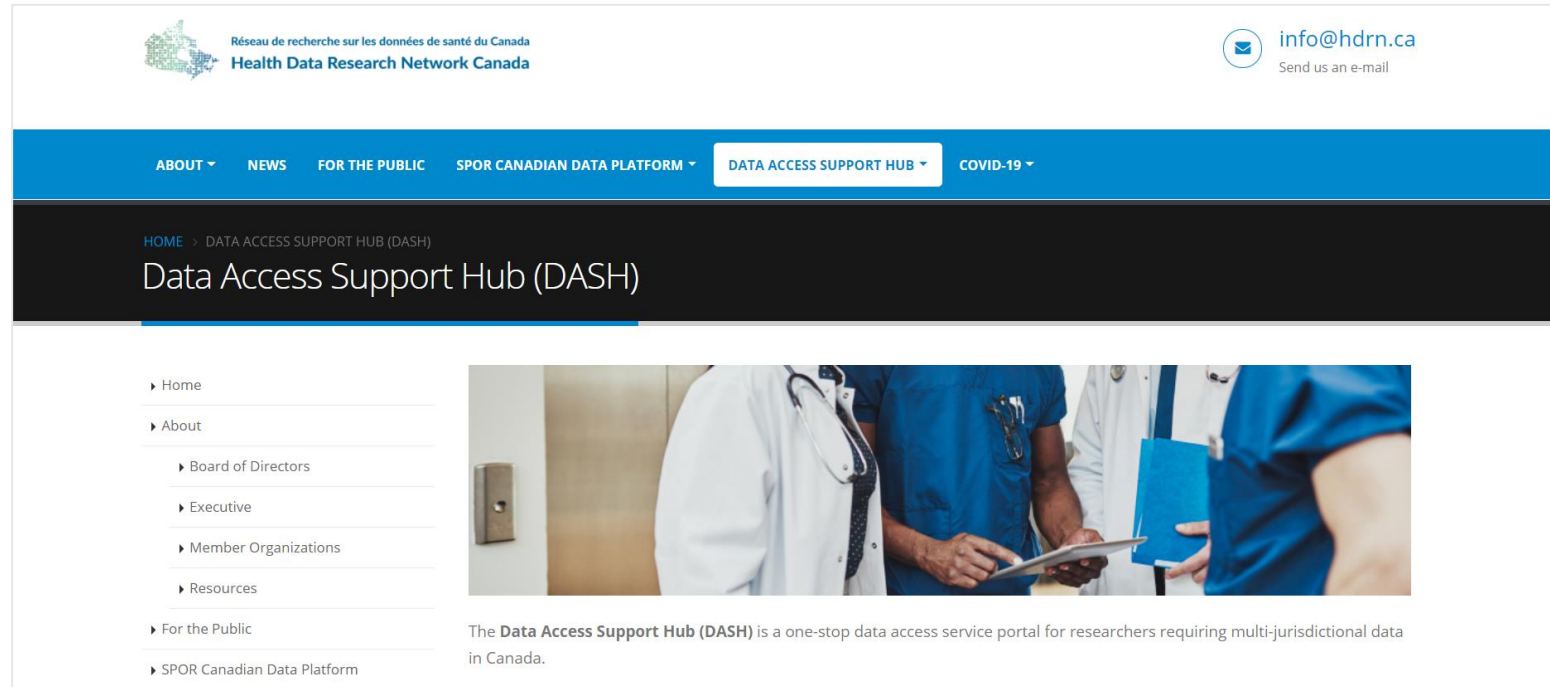# Data Access Support Hub (DASH)

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

Coordination, Support

for study design & data sharing options

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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

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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**
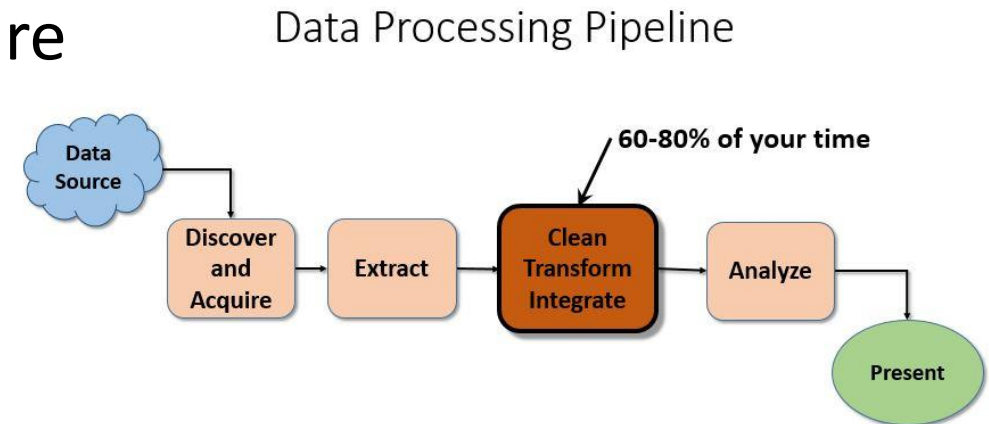- **Algorithms Inventory**

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

Data Processing Pipeline

Martin Magdinier, RefinePro

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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

Systematic Review — Identify algorithms that have been validated or tested for feasibility across two or more Canadian provinces and territories.	→	**Extraction Fields** — Working group identified relevant fields for data extraction from studies.
Review of Data Extraction — Working group reviewed data extraction table and identified any issues/errors/concerns.	←	**Data Extraction** — Two team members extracted data and populated the data extraction table.
Revised Data Extraction — Data extraction fields were revised and data extraction table was re-populated.	→	**Review of Data Extraction** — Working group reviewed data extraction table and identified any issues/errors/concerns.
Data Extraction Table — Data extraction table in Excel completed.	←	**Quality Control Check** — Random sample of studies were selected (n = 12) and assessed for accuracy by two team members. Remaining studies were assessed following the first check
Author Review — Study authors contacted and provided an opportunity to review extracted information.	→	**Online Resource** — Searchable Algorithm Inventory available on website

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

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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.
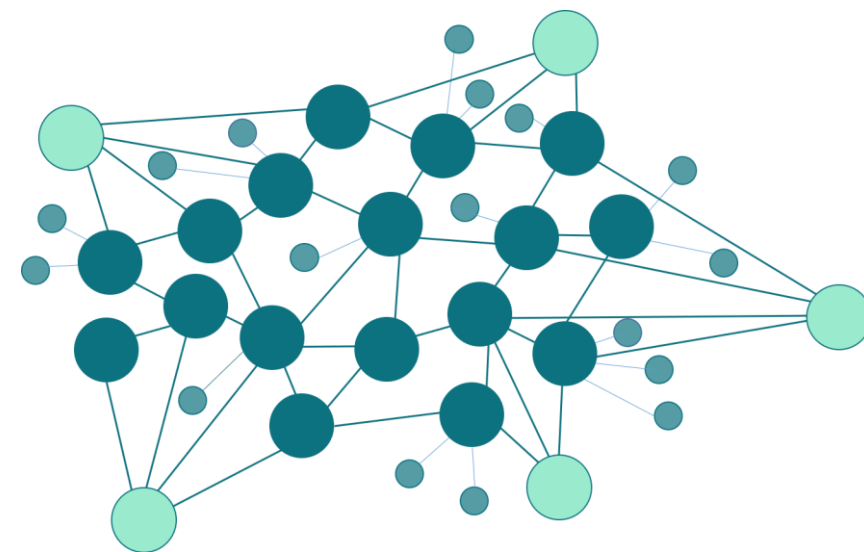
Four projects are currently underway:

- *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 Pinto, 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)

CanPath
Canadian Partnership
for Tomorrow's Health
Partenariat canadien
pour la santé de demain

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clsa élcv
Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

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!

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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

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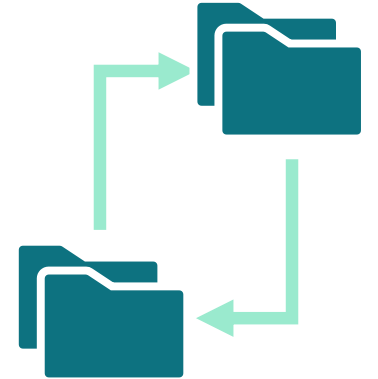
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