



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

Leads Team

Terms of Reference



Introduction

Health Data Research Network Canada (HDRN Canada) is a pan-Canadian initiative to connect researchers, policymakers and decision-makers from across the country to use data and expertise effectively in multi-regional studies and initiatives, and to support international collaborations.

HDRN Canada Organizations are working together to build and operate the SPOR Canadian Data Platform (“SPOR CDP”). The vision of the SPOR CDP is to develop a distributed network that facilitates and accelerates multi-regional research.

Objective

The Leads Team has been established to enable discussions and gather feedback from the HDRN Canada partner sites on topics relevant the development of the SPOR CDP and other HDRN Canada initiatives.

The role of the Leads Team is to:

- Provide input to the HDRN Canada Executive Committee (the “Executive”) on development and planning priorities; and
- Serve as a community of practice through which HDRN Canada Organization representatives come together to:
- Receive updates and information on HDRN Canada operations to be shared with each member’s respective entity/organization, and
- Collaborate and problem-solve regarding opportunities and risks, including strategic alignment of objectives and research activities between HDRN Canada and the data centres
- Identify and pursue new funding and/or strategic opportunities that are aligned with HDRN Canada’s mission and vision

Membership

Membership consists of:

- Provincial, territorial and pan-Canadian organizations that are responsible for research access to and supports for health and health-related data. In some cases, this will mean multiple representatives from the same region;
- Chairs of HDRN Canada’s Working Group and Teams who oversee pan-Canadian funded FTEs
- A member of the public, an Indigenous researcher, and a knowledge user / policy maker, all of whom are also a SPOR-CDP co-PIs or co-investigators

The Leads Team includes representatives from the following organizations:

- British Columbia
 - Population Data BC



- Alberta
 - Alberta SPOR SUPPORT Unit
- Saskatchewan
 - Saskatchewan Health Quality Council
 - Saskatchewan Centre for Patient-Oriented Research (SCPOR)
 - Saskatchewan Health Authority
- Manitoba
 - Manitoba Centre for Health Policy
 - George & Fay Yee Centre for Healthcare Innovation, University of Manitoba (MB SPOR SUPPORT Unit)
- Ontario
 - ICES
- Quebec
 - Quebec SPOR SUPPORT Unit
 - Institut national d'excellence en santé et en services sociaux (INESSS)
 - Institut de la statistique du Québec (ISQ)
- New Brunswick
 - New Brunswick Institute for Research, Data and Training
- Nova Scotia
 - Health Data Nova Scotia
- Newfoundland and Labrador
 - Newfoundland and Labrador Centre for Health Information
 - Newfoundland and Labrador SPOR SUPPORT Unit
- Prince Edward Island
 - Centre for Health and Community Research, University of PEI
- Northwest Territories
 - Hotil ts'eeda: Northwest Territories SPOR SUPPORT Unit
- Yukon
 - Yukon SPOR SUPPORT Unit
- Pan-Canadian
 - Statistics Canada
 - Canadian Institute for Health Information

The Leads Team includes the chairs of these working groups with Pan-Canadian membership

- Indigenous Data Team
- Data Access Support Hub
- Algorithms and Harmonized Data
- Public Advisory Council
- Patient Engagement Working Group
- Privacy Team
- Modeling and Informatics Group



Other membership principles:

- The Chair of the Leads Team is HDRN Canada's Scientific Director and CEO.
- Individual membership on the Leads Team will be reviewed on an annual basis, and upon request of HDRN Canada Organizations at times of leadership change.
- Observers
 - The Director of Operations and one other HDRN Canada staff participate as observers and to produce minutes.
 - Where appropriate, and decided in conjunction with the Chair, HDRN Canada-funded staff or select members of Working Groups and other invited guests may attend Leads Team meetings, for all or part of the agenda, as observers.

As local practices evolve, a member or HDRN Canada Organization may wish to nominate a representative to join the Leads Team. In this circumstance, the requesting individual/organization shall submit the name of the nominated individual along with rationale for membership in writing to the Chair for review and approval by the Executive.

Members and their organizations are listed in the Appendix and on Confluence at the link [here](#).

Accountability

The Leads Team provides input to the Executive. All HDRN Canada Working Groups and Teams report through the Leads Team to the Executive.

Quorum

Quorum for the Leads Team is half its membership plus one. In the absence of quorum, it is at the Chair's discretion if the meeting should continue, with items for discussion and review circulated to members who were unable to attend.

Decision Making

The Leads Team is advisory in nature, and thus will not be expected to present formal direction or make decisions. However, should the Leads Team members make a decision, they will aim to do by consensus.

In cases where consensus cannot be achieved, a summary of the views presented will be provided to the Executive for consideration.

Member Responsibilities

- Foster and contribute to open, collaborative and respectful discussions
- Read and review all meeting materials and actively participate in all meetings, drawing on knowledge, expertise and experience to provide constructive advice to HDRN Canada; this includes submission of agenda items and materials that



would benefit from the collective input and expertise of the Leads Team members

- Members unable to attend a meeting will be provided action items and any documented decisions and will be encouraged to provide written feedback. If a member is absent for two or more meetings, the Chair will review their continued membership on the Leads Team. If a member cannot attend, a delegate may be sent following notification of the designate to the Chair, and their attendance as a delegate will be noted in the minutes

Meeting Frequency and Agenda

The Leads Team meets on a monthly basis by teleconference or web meeting. Meetings will be planned by the Scientific Director and CEO in consultation with the Operations Director. Agenda and materials will be distributed to members at least two business days in advance of the meeting. Requests for agenda items can be provided to the Operations Director at any time, but are unlikely to be able to be accommodated when presented less than a week in advance of a Leads meeting.

Ad hoc meetings of individual Leads Team members may occur throughout the year on specific issues or projects to complement existing meetings. The Leads Team will strive to meet in-person on an annual basis, extenuating circumstances notwithstanding.

Conflict of Interest

Annually, Leads Team members must disclose to the Chair, in writing, any situation in which their personal interests or the interests of their host organization(s) are not compatible or aligned with the interests of HDRN Canada. Conflicts of interest will also be a standing agenda item at all Leads Team Meetings. Every declaration of a conflict of interest arising at a meeting of the Leads Team will be recorded in the minutes of the meeting, along with the nature of the conflict.

It is understood that the host organization(s) of Leads Team members will have a direct interest in, and expect to benefit from, HDRN Canada operations; therefore, it is not necessary for Leads Team members to declare any real or perceived benefit that their host organization(s) may realize from advice provided unless the real or perceived benefit to their host organization(s) results in a risk or harm for HDRN Canada. Please refer to HDRN Canada's Conflict of Interest Policy for further details.

Confidentiality

Except in cases where materials are clearly marked or identified as being for public distribution, Leads Team members should treat materials they receive for Leads Team meetings as confidential, and request permission from the Scientific Director and CEO before sharing materials.

Administration and Review Frequency

Secretariat support for the Leads Team will be provided by HDRN Canada staff. Attendance, action items and decisions made (if any) will be captured and shared with



Réseau de recherche sur les données de santé du Canada

Health Data Research Network Canada

the Leads Team for review; detailed meeting minutes will not be kept. The Chair and members shall serve without remuneration.

This Terms of Reference will be reviewed on an annual basis.



Appendix

List of Leads Team Members

Date of last membership confirmation: Updated April 2022

Role	HDRN Canada Organization/Group Represented	Member	Jurisdiction	
Leads Team Chair and HDRN Canada SD/CEO		Kim McGrail	BC	1.
Public Member		Frank Gavin	ON	2.
Indigenous Data Member		Jennifer Walker	ON	3.
Principal Knowledge User for SPOR CDP		Victoria Schuckel	BC	4.
Site Reps	Alberta SPOR SUPPORT Unit	Hude Quan	AB	5.
	Canadian Institute for Health Information (CIHI)	Brent Diverty	Pan-Canadian	6.
	Centre for Health and Community Research, University of PEI	Mary-Ann Standing	PEI	7.
	George & Fay Yee Centre for Healthcare Innovation, University of Manitoba (MB SPOR SUPPORT Unit)	Lisa Lix	MB	8.
	Health Data Nova Scotia (HDNS), Dalhousie University	Sam Stewart	NS	9.



	Hoti ts'eeda: Northwest Territories SPOR SUPPORT Unit	Stephanie Irlbacher-Fox	NWT	10.
	ICES	Michael Schull	ON	11.
	ICES-operated SUPPORT Unit data platform	Charles Victor		12.
	Institut national d'excellence en santé et en services sociaux (INESSS)	Patricia Caris	QC	13.
	Manitoba Centre for Health Policy (MCHP), University of Manitoba	Alan Katz	MB	14.
	Manitoba Centre for Health Policy (MCHP), University of Manitoba	Nathan Nickel	MB	15.
	New Brunswick Institute for Research, Data and Training (NB-IRDT)	Ted McDonald	NB	16.
	Newfoundland and Labrador SPOR SUPPORT Unit	Catherine Street	NL	17.
	Newfoundland & Labrador Centre for Health Information (NLCHI)	Don MacDonald	NL	18.
	Population Data BC, University of British Columbia	Gitta Oldendorff	BC	19.
	Quebec SPOR SUPPORT Unit	Jean-François Ethier	QC	20.
	Saskatchewan Health Authority	Brandy Winqvist	SK	21.
	Saskatchewan Health Quality Council (HQC)/ Saskatchewan Centre for	Tanya Verrall	SK	22.



	Patient-Oriented Research (SCPOR)			
	Statistics Canada	Claudia Sanmartin	Pan-Canadian	23.
	Yukon SPOR SUPPORT Unit	Michelle Leach	YK	24.
	Government of Yukon, Population and Public Health, Evidence and Evaluation Branch	Heather Grant	YK	25.
Working Group and Team Chairs	Chair of HDRN Canada Public Advisory Council	Frank Gavin (also listed above)	ON	26.
	Chair of the Indigenous Data Team	Robyn Rowe	ON	27.
	Chair of the Privacy Team	Donna Curtis Maillet	NB	28.
	Chair of the DASH Working Group	Juliana Wu	Pan-Canadian	29.
	Chair of the Algorithms and Harmonized Data Working Group	Lisa Lix (also listed above)	MB	30.
	Chair of the Public Engagement Working Group	Alison Paprica	ON	31.
	Chair of the IDEA Team	Amy Freier	MB	32.



Leads Team Observers

Role	Member
Director of Operations	David Parker
Platform Administration, meeting secretariat	Sarah Kesselring
Communications Lead	Mary Leong
Strategic Partnerships Manager	Nicole Yada
Alternate Rep AB	Jeff Bakal
Alternate Rep MCHP	Charles Burchill
Alternate Rep NWT	Jullian McLean
Alternate Rep PopData	Megan Ahuja
Alternate Rep ISQ	Mike Benigeri
Alternate Rep ISQ	Denis Roy
Alternate Rep StatCan	Geneviève Jourdain
Alternate Rep StatCan	Thacdung (TD) Nguyen
Maelstrom Research	Isabel Fortier
Alternate Rep NLCHI	Donna Roche