HDRN Canada

Leads Terms of Reference

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# 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:

1. Provide input to the HDRN Canada Executive Committee (the “Executive”) on development and planning priorities; and
2. Serve as a community of practice through which HDRN Canada Organization representatives come together to:
3. Receive updates and information on HDRN Canada operations to be shared with each member’s respective entity/organization, and
4. Collaborate and problem-solve regarding opportunities and risks, including strategic alignment of objectives and research activities between HDRN Canada and the data centres
5. 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

**Newfoundland and Labrador**

* Newfoundland and Labrador Centre for Health Information
* Newfoundland and Labrador SPOR SUPPORT Unit

**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

**Prince Edward Island**

* Centre for Health and Community Research, University of PEI

**Northwest Territories**

* Hotıì ts’eeda: Northwest Territories SPOR SUPPORT Unit
* Northwest Territories Bureau of Statistics

**Yukon**

* Yukon SPOR SUPPORT Unit
* Yukon University

**Pan-Canadian**

* Statistics Canada
* Canadian Institute for Health Information

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

* Algorithms and Harmonized Data Working Group
* Cybersecurity Team
* Data Access Support Hub Working Group
* Inclusivity, Diversity, Equity and Accessibility Team
* Indigenous Data Team
* Public Advisory Council
* Patient Engagement Working Group
* Privacy Team
* Modeling and Informatics Group
* Stakeholder Partnerships

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 the HDRN Canada website.

# 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 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: Fall 2020. Updated May 2021

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **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](https://wiki.hdrn.ca/display/CDPPC/Mary-Ann%2BMacSwain) 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](https://wiki.hdrn.ca/display/CDPPC/Sam%2BStewart) | NS | 9. |
|  | Hotıì ts’eeda: Northwest  Territories SPOR SUPPORT Unit | [Stephanie Irlbacher-](https://wiki.hdrn.ca/display/CDPPC/Stephanie%2BIrlbacher-Fox) [Fox](https://wiki.hdrn.ca/display/CDPPC/Stephanie%2BIrlbacher-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 | Nathan Nickel | MB | 14. |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **HDRN Canada Organization/Group**  **Represented** | **Member** | **Jurisdiction** |  |
|  | MCHP | Alan Katz | 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. |
|  | Northwest Territories Bureau of Statistics | Vishni Peeris | NWT | 19. |
|  | Population Data BC,  University of British Columbia | Gitta Oldendorff | BC | 20. |
|  | Quebec SPOR SUPPORT Unit | Jean-François Ethier | QC | 21. |
|  | Saskatchewan Health  Authority | Brandy Winquist | SK | 22. |
|  | Saskatchewan Health Quality Council / Saskatchewan Centre for Patient-Oriented Research | Tanya Verrall | SK | 23. |
|  | Statistics Canada | Claudia Sanmartin | Pan-Canadian | 24. |
|  | Yukon SPOR SUPPORT Unit | Michelle Leach | YK | 25. |
|  | Government of Yukon | Heather Grant | YK | 26. |
| **Working Group & Team Chairs** | Chair of HDRN Canada Public Advisory Council | Frank Gavin (also listed above) | ON |  |
|  | Indigenous Data Team Navigator | Meghan Valvasori (on leave) | ON | 27. |
|  | Indigenous Data Team Research Assistant | Letebrhan Ferrow | ON | 28 |
|  | Chair of the Privacy Team | Donna Curtis Maillet | NB | 29. |
|  | Chair of the DASH Working  Group | Jordan Hunt | Pan-Canadian | 30. |
|  | Chair of the Algorithms and Harmonized Data Working  Group | Lisa Lix (also listed above) | MB |  |
|  | Chair of the Public  Engagement Working Group | Catherine Street (also listed above) | NL |  |
|  | Chair of the IDEA Team | Amy Freier | MB | 31. |
|  | Chair of the MIG | JF Ethier (also listed above) | QC |  |
|  | Chair of the Pragmatic Trials Training Grant Working Group | Amit Garg | ON | 32. |
|  | Strategic Partnerships | Anne Hayes | ON | 33. |

## Leads Team Observers

|  |  |  |
| --- | --- | --- |
| **Role** | **Member** |  |
| **Director of Operations** | David Parker | 1 |
| **Platform Administration, meeting secretariat** | Sarah Kesselring | 2 |
| **Project Coordinator** | David Yang | 3 |
| **Strategic Communications Manager** | Kate Milberry | 4 |
| **Communications Coordinator** | Tasha Rennie | 5 |
| **Patient Engagement Fellow** | Julia Burt | 6 |
| **Pragmatic Trials Training Grant Lead** | Taylor McLinden | 7 |
| **MIG Lead** | Mark McGilchrist | 8 |
| **Maelstrom Research** | Isabel Fortier | 9 |
| **Alternate Rep AB** | Jeff Bakal | 10 |
| **Alternate Rep AB** | Finlay McAlister | 11 |
| **Alternate Rep MCHP** | Charles Burchill | 12 |
| **Alternate Rep ISQ** | Mike Benigeri | 13 |
| **Alternate Rep StatCan** | Julie Stratton | 14 |
| **Alternate Rep StatCan** | Lynn Barr-Telford | 15 |
| **Alternate Rep StatCan** | Scott McLeish | 16 |
| **Alternate Rep StatCan** | TD Nguyen | 17 |
| **Alternate Rep NLCHI** | Kendra Lester | 18 |
| **Alternate Rep NB-IRDT** | Lindsey Gilbert | 19 |
| **Alternate Rep PEI** | Robyn Kydd | 20 |
| **Alternate Rep Yukon** | Jay Tilley | 21 |
| **Alternate Rep NWT** | Knox Makumbe | 22 |