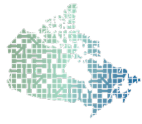


Réseau de recherche sur les données de santé du Canada
Health Data Research Network Canada

SPOR CDP Advisory Committee

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-jurisdictional 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-jurisdictional research.

Purpose

Ongoing coordination and collaboration are necessary to ensure both sustainability of SPOR investments and the relevance of the SPOR CDP to SPOR entities¹ and to the broader research community and policy-makers. The SPOR CDP is one of several SPOR entities, and the Canadian Institutes of Health Research (CIHR) expects that all entities, including the SPOR CDP, will work together to enable knowledge generation that supports learning across and between jurisdictions.

HDRN Canada has established the SPOR CDP Advisory Committee 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.

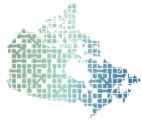
Role

The role of the SPOR CDP Advisory Committee is to:

1. Advise HDRN Canada on data and analytic infrastructure development and priorities for the SPOR CDP, such as identifying priority algorithms/measures that would benefit from development, review and endorse recommendations about the Data Assets Inventory and Algorithms Inventory and provide advice to the Algorithms and Harmonized Data Working Group and other SPOR CDP working groups as appropriate; and
2. Serve as a mechanism through which multiple SPOR entities:
 - a. Bring forward data and information needs from their respective entities, advise on strategic opportunities and risks for the SPOR CDP to consider, including strategic alignment of objectives and research activities between entities and the SPOR CDP, and identify opportunities for collaboration in support of mutual goals; and
 - b. Receive updates and information on SPOR CDP development and operations to be shared back with each member’s respective entity/organization of which they are representing.

The SPOR CDP Advisory Committee is just one mechanism through which the SPOR CDP will elicit feedback and input from other SPOR entities. Other channels to ensure all SPOR entities have the opportunity to provide feedback on SPOR CDP development priorities will be communicated and made readily available (such as webinars, presentations, and direct communications).

¹ “SPOR entities” refers to Strategy for Patient-Oriented Research (SPOR) SUPPORT Units, SPOR Networks and Innovative Clinical Trial (iCT) grantees, chairholders and the SPOR CDP unless otherwise specified



Membership

Members will be selected, in consultation with the Chair, based on their skills and perspectives, with individual leads from SPOR entities nominated through existing SPOR governance channels. Special effort will be made to involve perspectives that are representative of the wide range of geography, languages, cultures and ethnicities that reflect the pan-Canadian spirit of HDRN Canada. The SPOR CDP Advisory Committee will be made up of no fewer than 10 and no more than 12 members. Membership terms are staggered and will include up to two renewable three- year terms. Members and their terms are listed in the Appendix.

The Chair of the SPOR CPD Advisory Committee is a member of the HDRN Canada Executive (also represented on the Leads Team²) and will serve for a term of 3 years. The incoming Chair will join the Committee as a non-voting member one year prior to assuming the role of Chair so that there is one year of overlap between the incoming and outgoing Committee Chairs.

The Scientific Director (and/or delegate) will attend meetings as an observer.

Accountability

The SPOR CDP Advisory Committee is a Committee of the HDRN Canada Leads Team, and through the Leads, will also provide advice to the Scientific Director and Executive. Through this reporting relationship and with representation from the Executive Team in serving as Chair, the SPOR CDP Advisory Committee will be provided regular, timely updates on current SPOR CDP development timelines and operational reporting.

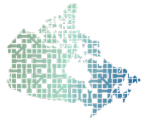
Quorum

Quorum for the SPOR CDP Advisory Committee 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 SPOR CPD Advisory Committee is advisory in nature, and thus will not be expected to present formal direction or make decisions. However, should the Committee decide to vote, the SPOR CDP Advisory Committee will strive to make decisions by consensus. In cases where consensus cannot be reached, a summary of the views presented will be provided to the HDRN Canada Executive for consideration.

² The Leads Team consists of leads of SPOR SUPPORT Unit Data Platforms in addition to other representatives from provincial, territorial and pan-Canadian data-holding organizations; all members of the HDRN Canada Executive are also members of the Leads Team. The Leads Team meets on a monthly basis and is chaired by the HDRN Canada Scientific Director



Expectations and Obligations of Committee Members

- Foster and contribute to open, collaborative and respectful discussions
- Read and review all meeting materials which, combined with active participation time, is expected to require an average commitment of up to 20 hours per year of membership
- Actively participate in all meetings, drawing on knowledge, expertise and experience to provide constructive advice to HDRN Canada
- Attend SPOR CDP Advisory Committee meetings and participate in teleconferences; 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 with the member his/her continued membership on the Committee.
- At the beginning of each meeting, the Chair will ask members to disclose any potential conflicts of interest. Should a real or perceived conflict of interest arise, the member must disclose this conflict to the Chair whose responsibility it is to ensure conflicts are appropriately managed.

Meeting Frequency and Agenda

The SPOR CDP Advisory Committee will meet virtually at least twice in its first year of operations, with likelihood of increased frequency after 18 months. Opportunities to meet in person, such as at existing SPOR meetings, will be sought.

The meetings shall be planned by the Chair with support from the Scientific Director (or delegate) of HDRN Canada. The Committee will receive status reports on the operational work of the HDRN Canada/the SPOR CDP in advance of its meetings. Ad hoc meetings of individual Committee members and HDRN Canada staff may occur throughout the year on specific issues or projects to complement existing meetings.

Administration and Review Frequency

Secretariat support for the SPOR CDP Advisory Committee will be provided by HDRN Canada staff. Action items and decisions made (if any) will be captured; detailed meeting minutes will not be kept. The Chair and members shall serve without remuneration.

Membership of the SPOR CDP Advisory Committee and this Terms of Reference will be reviewed on an annual basis.



Appendix: List of Members

SPOR Entity	Jurisdiction	Name	Term (Start date and end date)
CANHEART SPOR ICT grantholder: Using Big Data to Conduct Innovative Cardiovascular Clinical Trials	Ontario	Jacob Udell	
Can-SOLVE Chronic Kidney Disease Network	Pan-Canadian	David Collister, Adeera Levin	
Chronic Pain Network	Pan-Canadian	Kimberly Begley	
Diabetes Action Canada	Pan-Canadian	Cathy Whiteside	
iCT Multi-Year grantee: BedMed initiative	Multi-jurisdictional, based in Alberta	Scott Garrison	
iCT multi-year grantholder: Innovative Pragmatic Cluster-Randomized Registry Trials to Improve Hemodialysis Care	Multi-jurisdictional, based in Ontario	Amit Garg, Stephanie Dixon	
Primary and Integrated Health Care Innovations Network (PIHCIN) National Coordinating Office	Pan-Canadian	Sabrina Wong, Onil Bhattacharyya	
SPOR Evidence Alliance	Pan-Canadian	Andrea Tricco	
SPOR Mentorship Chair in Innovative Clinical Trials	Multi-jurisdictional, based in Quebec	Bertrand LeBouche	
SPOR SUPPORT Unit Council	Pan-Canadian	Ontario SSU: Vasanthi Srinivasan Alberta SSU: Tim Murphy	