HDRN Canada

Public Engagement Working Group Terms of Reference

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# Background

Based on principles articulated in Canada’s national Strategy for Patient-Oriented Research (SPOR) and the Consensus Statement on Public Involvement and Engagement with Data Intensive Health Research, Health Data Research Network Canada (HDRN Canada) will have public engagement that is continuous, substantial, and meaningful.

The term “public engagement” (vs. patient engagement) is used for HDRN Canada/the SPOR Canadian Data Platform to emphasize that HDRN Canada data extends beyond that of patients interacting with the health system.  There are many publics who are stakeholders of HDRN Canada, including communities, populations with particular health differences or needs, patients, family members, parents and guardians, care partners and health services recipients, many of whom will be “well” and may not identify as having a disease. HDRN Canada’s public engagement efforts will embrace the principles of SPOR’s Patient Engagement Framework: inclusiveness, adequate support and flexibility, mutual respect, and co-building/co-design. Our approach to engagement will also support the Consensus Statement on Public Involvement and Engagement with Data-Intensive Health Research that “the public should not be characterized as a problem to be overcome but a key part of the solution to establish socially beneficial data-intensive health research for all”.
The HDRN Canada Public Engagement Working Group (“the PE Working Group”) has been established to develop and deliver HDRN Canada’s [Public Engagement Strategy](https://docs.google.com/document/d/19Hct0ih6knHhfnKCsS3Lfcog5ww3Dm50/edit?usp=sharing&ouid=107026173103889438582&rtpof=true&sd=true), working closely with the HDRN Canada Public Advisory Council (PAC).

Issues that the PE Working Group may seek the PAC’s advice on include but are not limited to:

* Values-related issues around data linkage, access to and uses of data,
* Network priorities and
* Opportunities for communicating HDRN Canada’s activities to the public so that, at a minimum, informational transparency about HDRN Canada’s activities is achieved and there are also opportunities for deeper involvement of members of the public in HDRN Canada.

The PE Working Group will work closely with other HDRN Canada Working Groups and Teams to ensure complementary (not duplicative) activities. It will also proactively identify ways for the PAC to interact with other groups and individuals within HDRN Canada, including governance bodies.

# Inclusion, Diversity, Equity and Accessibility (IDEA) and Indigenous Data Sovereignty

HDRN Canada’s work is informed by best practices in inclusion, diversity, equity and accessibility (IDEA) and by principles and practices of Indigenous-led data sovereignty. We recognize that inclusion and diversity are integral to ethical and effective public engagement, and we aim to be inclusive of the perspectives of Indigenous Peoples and other systemically marginalized populations. In collaboration with, and seeking advice from, HDRN Canada’s IDEA and Indigenous Data teams, the PE Working Group is committed to ensuring that these best practices are reflected in all public engagement activities undertaken by HDRN Canada. Ways in which IDEA principles guide the operations of the PE Working Group include, but are not limited to:

* Maintaining a diverse membership
* Ensuring accessible meetings and removing barriers for participation (e.g., timing of meetings, appropriate and accessible technology, asynchronous work and options for both virtual and in-person meetings when possible)
* Sharing learning opportunities in IDEA

# Objectives

The PE Working Group has three overarching functions:

* Lead and coordinate HDRN Canada’s public engagement work,
* Respond to requests for support from National organisations, in the field of Public Engagement in health data intensive research and
* Work closely with PAC in two ways:
* The PE Working Group will work with the HDRN Canada PAC, Leads Team, Working Groups, Executive Committee and Board of Directors to identify topics for PAC meeting agendas, e.g., risks and opportunities related to PE, support the PAC in priority-setting, and prepare relevant materials to support PAC discussion of the topics
* The PE Working Group is the primary group responsible for receiving, considering and, where appropriate and feasible, acting upon advice from the PAC

# Membership

Members should include the Chair of the PAC and individuals from HDRN Canada member organizations or affiliated partners who have expertise or responsibilities related to public engagement.  The PE Working Group is open to the addition of new members affiliated with HDRN Canada Organizations at any time.

Membership is listed in Appendix A

HDRN Canada central support staff and members of other working groups may attend PE Working Group meetings as guests.

The PE Working Group is chaired by HDRN Canada’s Public Engagement Executive Lead.

# Accountability

The PE Working Group will report into the HDRN Canada Leads team through its Chair and support the PAC with the PAC Chair as a member. On a monthly basis or as requested, the PE Working Group will provide updates to the HDRN Canada Leads Team on the status of its activities.

# Decision-Making

The PE Working Group will strive to make decisions by consensus. In cases where consensus cannot be reached, a written summary of the views presented will be provided to the HDRN Canada Leads Team or Executive Committee, and others who have an interest in the PE Working Group views on a topic, as appropriate

# Member Responsibilities

All members will be required to sign a participation agreement, which sets out member responsibilities, including:

* Participate in PE Working Group meetings
* Declare conflicts of interest at any time should they arise
* Maintain meeting confidentiality as requested
* Be responsive to emails and requests where active participation outside of regularly scheduled meeting times is required
* Inform the PE Working Group of local activities that may impact the working group or PAC
* Adhere to the guiding principles for communication in all interactions with stakeholders and activities/deliverables on behalf of HDRN Canada.
* Adhere to the [guiding principles for inclusion, diversity, equity and accessibility (IDEA)](https://docs.google.com/document/d/1vkYvcNIA9HjsAV7RLbKgKxWklfGWBpeB8i1aYju--xQ/edit?usp=sharing) as outlined by HDRN Canada’s IDEA Team
* Participate in activities to advance the PE Working Group annual workplan
* Share jurisdictional knowledge and best practices with PE Working Group members to improve collective knowledge and build capacity
* Share information and updates discussed during the meeting with their host entity/organization and network
* Contribute to the development and implementation of the HDRN Canada Public Engagement Strategy and annual workplan including an approach to evaluating the work and processes of the PAC and broader public engagement efforts – by drawing on their own knowledge and experience to leverage and connect HDRN Canada with the science of public engagement
* Support the PAC as a whole, and the PAC Chair, including by participating in the recruitment, selection and onboarding of new PAC members
* If a member cannot attend a meeting, they will notify the Chair and may send a designate
* If a member needs to withdraw from the PE Working Group, the member will notify the Chair in writing, and where possible, suggest a replacement member

# Meeting Frequency and Agenda

The PE Working Group will generally meet bi-monthly, virtually, with the possibility of one in-person meeting annually. Meetings will be planned by the PE Working Group Chair in consultation with HDRN Canada staff as well as with the Chair of the PAC. All members may suggest items to include on the agenda. Opportunities to meet in-person will be sought out when possible, such as at existing HDRN Canada meetings. Members who are unable to attend a meeting will be provided with action items and any documented decisions and will be encouraged to provide written feedback.

# Administration and Review Frequency

Secretariat support for the Public Engagement Working Group will be provided by the Public Engagement Research Assistant. Detailed minutes will not be recorded.  Action items and decisions will be recorded in writing and shared with all members within one week of the completion of a meeting via [Google Drive](https://drive.google.com/drive/folders/1eKxpE27LtVjnyT5AueopJyshZ0-L_IvM?usp=sharing). Members who are unable to attend will be encouraged to provide written feedback.

Membership of the PE Working Group and these Terms of Reference will be reviewed on an annual basis.

The Chair and members shall serve without remuneration.

# Appendix A – Membership as of July 2023

As of July 2023 the PE Working Group includes the Chair of the PAC and individuals affiliated with:

* British Columbia – Population Data BC
* Ontario – ICES
* Québec – GRIIS at the Université de Sherbrooke
* Newfoundland/Labrador – NL SPOR SUPPORT Unit
* Statistics Canada
* HDRN Canada PE opertional lead
* HDRN Canada PE Research Assistant
* University of PEI – Maritime SPOR SUPPORT Unit
* Manitoba - George & Fay Yee Centre for Healthcare Innovation (TBC)