HDRN Canada

Public Engagement Plan

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# Introduction

Health Data Research Network Canada (HDRN Canada) is committed to increasing public influence on data systems through purposeful involvement of the *public*±, communities and various organizations. As outlined in its strategic plan, the development and delivery of a Public Engagement Plan for HDRN Canada is key to ensuring strategic coordination of projects that require the involvement, sometimes the deep involvement, of members of the public and the meaningful engagement of the public in HDRN Canada’s overall work and goals.

Supported by the Canadian Institutes of Health Research (CIHR) [Strategy for Patient-Oriented Research (SPOR)](https://cihr-irsc.gc.ca/e/41204.html)**,** HDRN Canada will undertake public engagement that is *continuous, substantial and meaningful.* This means it must begin early, be sustained and adapt to changing circumstances and needs, and be carefully and regularly reviewed and evaluated. HDRN Canada’s engagement efforts will embrace the principles of [SPOR’s Patient Engagement Framework:](https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf) inclusiveness, adequate support and flexibility, mutual respect, and co-building/co-design. Public engagement will also align with the [Consensus Statement on Public Involvement and Engagement with Data-Intensive Health Research](https://ijpds.org/article/view/586/2829)**,** which emphasizes that “the public should not be characterized as a problem to overcome but a key part of the solution to establish socially beneficial data-intensive health research for all."

Central to HDRN Canada’s public and patient engagement is the work of the Public Advisory Council (PAC)**;** however, engagement also involves patients associated with other SPOR entities and with non-SPOR groups, as well as members of various publics across Canada.

The PE Working Group commits to review (and revise, if necessary) the Public Engagement Plan at a minimum when the HDRN Canada Strategic Plan is reviewed, in addition to when advice from members of the PAC and other stakeholders is received.

±*HDRN Canada chooses to use the term ‘public’ instead of patients 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.*

# 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. With support from the PE Working Group, the PAC and IDEA/Indigenous Data Teams will work collaboratively on key projects and activities in a way that reflects the PAC’s role within HDRN Canada.

The process for establishing a formal Public Engagement (PE) Plan for HDRN Canada was led by the HDRN Canada Public Engagement Working Group, which first conducted a survey of HDRN Canada member organizations and SPOR entities in Spring 2021 to gather input on public and patient engagement practices. Based on the responses to the survey as well as on discussions with HDRN Canada’s Public Advisory Council, Executive Committee and Strategy for Patient-Oriented Research (SPOR) collaborators, a scope for the HDRN Canada PE Plan was articulated. This scope has since been further expanded to include:

* Deliverables focused on seven key workstreams (see Figure A - *Work breakdown structure*)
* Resources, budget and key roles involved in the implementation of the PE Plan (see Appendix A – *HDRN Canada public engagement roles and resources*; and Appendix B – *High-level budget for 2023*)
* Timeline (see Appendix C – *Gantt chart 2023-2027*)
* Plan for communications and stakeholder involvement, which is captured throughout multiple workstreams (including the Public Advisory Council and public-oriented communications). Communications plans for individual projects and activities will be developed in consultation and with guidance from HDRN Canada’s communications team.

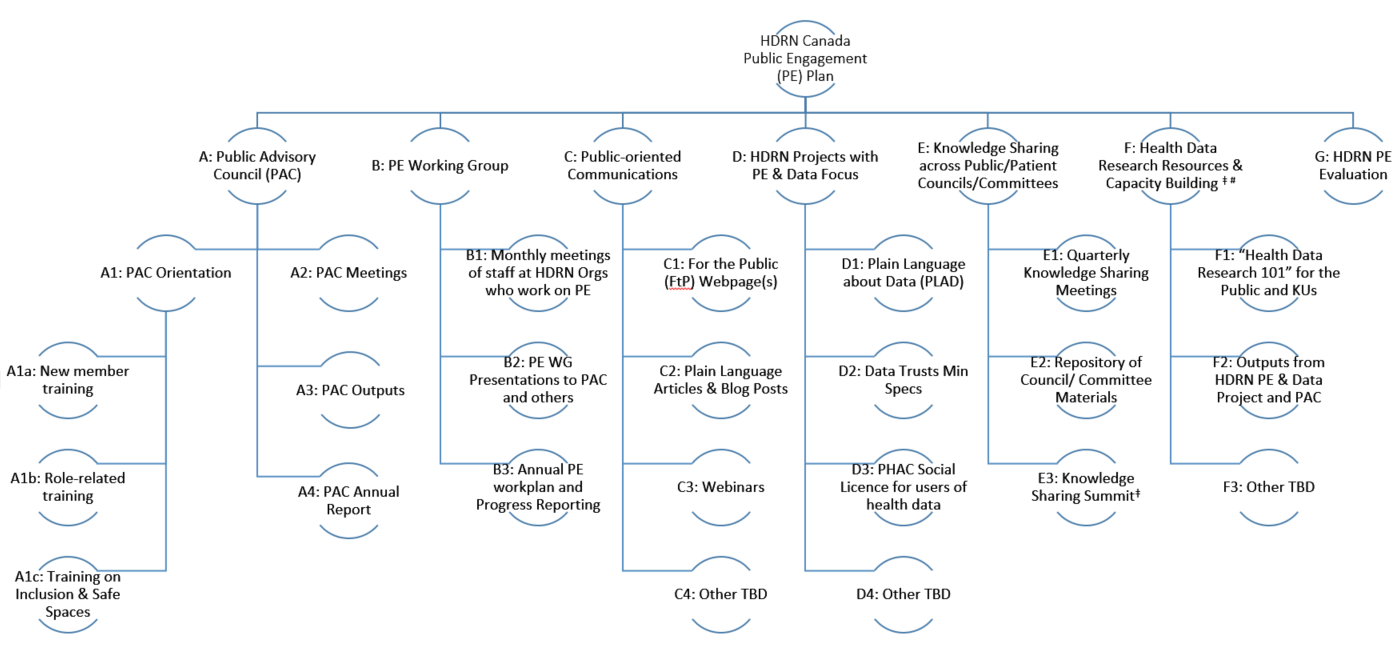
Questions or comments about HDRN Canada’s public engagement can be directed to:

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# Public Engagement Plan – Workstreams and deliverables

HDRN Canada’s PE plan is organized into seven workstreams and corresponding deliverables based on input and advice from HDRN Canada member organizations, SPOR entities, and the HDRN Canada Public Advisory Council. A text-only version of the work breakdown structure, including workstreams and corresponding deliverables, is available in Appendix D.



*Figure A: Work breakdown structure*

# Public Advisory Council

HDRN Canada’s Public Advisory Council (PAC) was established in 2020 and comprises 12-15 members who are diverse in terms of geography, age, gender, occupation, language, culture, ethnicity and other characteristics.

The purpose of the PAC is to:

* Advise HDRN Canada about how best to communicate with the public and, where appropriate, with particular communities
* Advise HDRN Canada about its short-term, medium-term, and long-term priorities
* Provide responses and feedback on materials that HDRN Canada brings to PAC members for discussion and comment and inform or advise HDRN Canada about issues members identify as important to the public or particular publics
* Identify and discuss new kinds of data, especially “patient-generated data”, that some or all data collectors and holders within HDRN Canada might consider collecting and/or prioritizing

## Recruitment

As per the PAC’s Terms of Reference, each PAC member serves a three-year term, with no member serving a total of more than six years. New PAC members will be recruited prior to the end of current members’’three-year terms (if they choose not to continue) and/or as necessary to maintain a diverse group of 12-15 members. Appendix E outlines the PAC recruitment strategy, which has been streamlined to simplify the application process for prospective applicants and includes a fillable MS word application form (see Appendix F).

## Retention and engagement

The PAC Chair and PE Working Group are committed to ensuring that PAC members are meaningfully engaged in the council’s activities and that the level of engagement aligns with individual members’ interests and expectations, for example:

* The PAC Chair and PE Fellow will check in with each new member on a quarterly basis (in the first year) and then annually to discuss their experience on the council and any concerns or feedback they may have
* The PAC Chair will send an annual survey to gather feedback and improve processes based on responses
* Members will be informed on a consistent basis of public and patient partner opportunities in health data-focused research *(mechanism TBD)*

In line with its commitment to IDEA, the HDRN Canada PE Working Group will continue to ensure inclusivity, diversity, equity and accessibility in all PAC-related activities. The PE Working Group is committed to:

* Maintaining a diverse PAC membership to ensure that the recommendations made and input provided by the members represent a broad range of lived experiences (see the PAC’s Terms of Reference for details on membership criteria, e.g. Francophone and Indigenous representation)
* Ensuring that the work of the PAC is conducted in an inclusive manner with regards to language and technology (e.g., the use of live-simultaneous French-English interpretation and materials circulated in accessible formats)
* Working with current PAC members to identify and remove barriers to participation in meetings and in other PAC-related activities (e.g., time of meetings, costs, technology issues)
* Regularly providing learning opportunities and training in IDEA for all PAC members
* Supporting the work of a PAC IDEA Interest Group, composed of a subset of PAC members interested in providing recommendations and advice to HDRN Canada on the topics of equity, diversity, inclusion and accessibility

Committing to the above deliverables will also ensure the successful retention and engagement of current PAC members.

## Orientation

An orientation package will be provided to all new members at the beginning of their term. Members will have an opportunity to meet with the PAC Chair and/or Public Engagement Fellow prior to their first meeting to discuss any questions or issues they have. Orientation for new members is composed of the following three main components:

1. **New member training***:* Materials focused on basic information members need to know to contribute meaningfully to the council
2. **Role related training:** Health data and data-intensive health research-focused training materials need to be developed and adapted for plain language
3. **Training on inclusion, diversity, accessibility and equity (IDEA) and safe spaces**: The PE Working Group will collaborate with the HDRN Canada IDEA team to provide ongoing IDEA and safe space training to all PAC members

Example training material to use and/or adapt for PAC orientation can be found in Appendix G.

## Meetings

PAC meetings will be held a minimum of five times per year, one of which will be in-person. PAC meetings will give members the opportunity to provide advice on the various initiatives and projects undertaken by HDRN Canada, for example:

* How HDRN Canada can best communicate with the public about its role and the use of health data in research
* What new kinds of data (especially patient-generated data) could or should be collected
* What changes, if any, should be made to key materials such as the HDRN Canada PAC Terms of Reference, Public Engagement Plan, etc.
* What items should be on the agendas for upcoming PAC meetings

PAC meetings will also provide a forum for HDRN Canada and its affiliated organizations to present on current projects, activities and training opportunities that may be of interest to the PAC and to receive feedback on those projects. Asynchronous work may occur between meetings, and subgroups of PAC members may also meet outside of regular meetings to work on specific projects/activities of interest to them.

To ensure maximum attendance at PAC meetings, the PE Working Group and PAC Chair commit to:

* Providing flexible meeting times with multiple options based on feedback from PAC members
* Sending meeting materials four days in advance and at least one reminder prior to each meeting
* Obtaining ongoing feedback from PAC members on agenda items and topics of interest
* Including standing items on agendas to provide continuity between meetings

## Outputs

All PAC materials (including meeting summary documents, documentation of PAC-generated priorities, action items, surveys and materials that have been refined and improved based on PAC advice) will be shared with PAC members on an ongoing basis and kept in a central location (e.g., on HDRN Canada’s Confluence page or alternative file sharing platform used by HDRN Canada).

## Annual report

An Annual Report will be submitted by the PAC Chair to the HDRN Executive Committee and shared with the HDRN Board of Directors, Leads Teams and others. The report will highlight the PAC’s key achievements, including recruitment efforts, advice provided to HDRN Canada from public partners and results of the council’s yearly evaluation.

# Public Engagement Working Group

**Overview**

The HDRN Public Engagement (PE) Working Group consists of staff and researchers from HDRN organizations who meet monthly to lead, coordinate and strengthen HDRN Canada’s PE work and projects, each of which include patient/public contributors.

The PE Working Group has two overarching functions – to lead and coordinate HDRN Canada’s public engagement work and to work closely with the PAC in the following ways:

1. Identifying topics for PAC meeting agendas in collaboration with the PAC, Leads Team, other HDRN Canada Working Groups the Executive Committee and Board of Directors;
2. Receiving, considering and, where appropriate and feasible, acting upon advice from the PAC;
3. Presenting on HDRN Canada’s public engagement work at PAC meetings.

The PE Working Group’s Terms of Reference (see Appendix H), workplan and progress reporting are reviewed on an annual basis.

**Membership**

Members include the Chair of the PAC (who is the one member of the working group not eligible to chair it) and individuals who have expertise related to public engagement and who are affiliated with HDRN Canada Organizations. The PE Working Group is open to the addition of new members affiliated with HDRN Canada organizations at any time. They will be chosen based on their interest, skills and experience to provide the PE Working Group with the necessary perspectives to enable ongoing and effective public engagement. If a member needs to withdraw, the member will notify the Chair in writing, and where possible, suggest a replacement member. HDRN Canada central support staff and members of other working groups may attend PE Working Group meetings as guests. See Appendix I for a current membership list as of July 2022.

# Public-oriented Communications

A key role of the PE Working Group and the PAC is to provide advice about and sometimes help create public-oriented communications on behalf of HDRN Canada. The overarching goal of HDRN Canada’s public-facing material is to communicate with the public about the role of HDRN Canada and the importance of data-intensive health research.

**PAC Communications Interest Group**

On the PAC’s advice, an Interest Group focused on public-oriented communications has been established with a subset of PAC members. Its goal is to provide recommendations to HDRN Canada on how to meaningfully engage with various publics about the work of the network and the health data holdings of network organizations. Members of the PE Working Group are responsible for facilitating the group’s work and for sharing its recommendations with the wider network.

**For-the-public materials**

Based on advice from the PAC (including the PAC Communications Interest Group), HDRN Canada’s Communications Officer and other SPOR collaborators, the following have been identified as key public-facing materials:

1. For the public webpage – the content on this page of the HDRN Canada website will be reviewed on an ongoing basis by the PAC Communications Interest Group to ensure clear messaging about the role of HDRN Canada and the importance of health data in research.
2. Plain language articles and blog posts, for example:
   1. Material created by the PAC Communications and IDEA Interest Groups
   2. Links to articles published in [The Conversation](https://theconversation.com/ca)
   3. Other materials as suggested by PAC members
3. Public-facing webinars – projects undertaken by HDRN Canada with a public focus, as well as sessions on relevant health data-related topics from experts outside of HDRN Canada

Potential topics for public-facing material may include:

* What are administrative health data? How are they used?
* Who can access my health data and how?
* How are my health data kept secure?
* What is necessary for there to be social acceptability of health data uses/users and how does the public feel about the use of their data?
* What is the role of HDRN Canada? Does it collect and store data?
* What are some examples of HDRN Canada projects?

# HDRN Canada projects with a focus on public engagement about health data

HDRN Canada has undertaken a number of projects with a focus on public engagement about health data and will continue to work in collaboration with the PE Working Group and the PAC to identify new projects that would benefit from public perspectives. Summaries of projects undertaken by HDRN Canada (some in collaboration with external partners) with a focus on public engagement and data are highlighted in Appendix J and will be updated annually.

# Knowledge sharing across public and patient councils and committees

Multiple SPOR entities currently exist with councils or committees consisting of members of the public and patient partners. The PE Working Group commits to enabling knowledge sharing and learning between these existing councils and committees through the following mechanisms:

1. Facilitating quarterly knowledge sharing meetings at which researchers, staff and public/patient partners discuss key public engagement activities undertaken by the PE Working Group and the PAC and provide feedback about them
2. Ensuring HDRN Canada representation on the SPOR Patient Engagement Community of Practice (SPENCOP)
3. Managing a repository of bilingual PAC/PE Working Group materials in a central and easily accessible location to be viewed by staff/researchers of HDRN Canada, SPOR colleagues and others
4. Hosting an annual (or frequency TBD) Knowledge Sharing Summit consisting of a mix of presentations and small group activities to promote knowledge sharing and generate dialogue between public members, researchers and other stakeholders

# Health data research resources and capacity-building

The work of the HDRN Canada PE Working Group will be aligned with capacity-building competencies defined by the SPOR National Training Entity and other SPOR entities.. The group will leverage and incorporate materials and outputs from existing work streams (including the work of the PAC, public-facing communications and projects with a PE focus), for example:

**1. Outputs from the Plain Language about Data Project –** As part of this project, a Dialogue Guide and other background material were prepared to educate members of the public on the importance of plain language about data.

**2. Material developed by the PAC (including the PAC Communications Interest Group) and the PE Working Group** – These outputs can be disseminated throughout multiple audiences, primarily targeting researchers, clinicians and policymakers to help them understand public values and preferences related to secondary uses of health data so that these perspectives and values are incorporated into policies and procedures.

**3. Health Data Research 101 for the public/other knowledge users –** Leveraging training material developed for PAC members, this will include documents, videos, webinars and other online resources tailored to members of the public, patients and knowledge users to help them understand how health data are used in research as well as the opportunities, risks and limitations associated with data-intensive health research.

# HDRN Canada public engagement evaluation

To ensure accountability and the effective implementation of the PE plan, HDRN Canada public engagement activities will be evaluated on an ongoing basis, and processes and deliverables will be revised based on feedback gathered from evaluation efforts. The PE Working Group and the PAC will play key roles in the evaluation process and will ensure that evaluation results are also reported to the wider Network and to other relevant stakeholders.

Key components of the public engagement evaluation include:

1. Annual anonymous survey sent to PAC members by the PAC chair to gather feedback on current experiences and suggestions for improvements
2. Exit interview conducted by the PAC Chair and PE Working Group members at the end of each member’s term
3. Evaluation by the PE Working Group – annual survey (TBC)
4. Project-specific evaluation to be included in all HDRN Canada projects with a PE focus

# List of appendices

A. Roles and resources

B. High-level budget for 2023-2024

C. Gantt chart/timeline for 2023-2027

D. Workstreams and key deliverables

E. PAC recruitment strategy

F. PAC new applicant form

G. Examples of PAC orientation materials

H. PE Working Group Terms of Reference

I. PE Working Group membership

J. Summary of projects with a focus on public engagement about health data