HDRN Canada

Public Advisory Council Terms of Reference

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# Name

Public Advisory Council (PAC) to Health Data Research Network Canada (HDRN Canada).

# Purpose

To provide guidance, from public perspectives, to HDRN Canada about its priorities, development and operations.

# Responsibilities / Roles

1. To advise HDRN Canada about how best to communicate with the public and, where appropriate, with particular publics:

* About the health data held by its member organizations;
* About how such data are used in research;
* About how privacy and confidentiality are protected;
* About how members of the public can influence and/or participate in the work of HDRN Canada and its member organizations.

1. To advise HDRN Canada about its short-term, medium-term and long-term priorities.
2. To provide responses and feedback on materials that HDRN Canada brings to PAC members for discussion and comment and to inform or advise HDRN Canada about issues members identify as important to the public or particular publics.
3. To 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.

**Relationship with Public Engagement Working Group**

The Chair of the PAC will be a member of the Public Engagement Working Group (PE WG), in part to ensure close and regular communication and collaboration between the PAC and the PE WG. The Chair will also be a member of the HDRN Canada Executive Committee.

**Reporting Relationship**

The PAC will report to the HDRN Canada Executive Team (Executive) and, through the Executive, to the HDRN Canada Board (Board). The Chair of the PAC will also interact directly with the Board in an agreed upon format. Once a year the PAC will produce and present a written report to the Executive, which will then be shared with the Board and made available to the public on the HDRN Canada website and other public avenues as deemed appropriate. Members of the Executive and Board will be welcome to attend PAC meetings and address the members.

**Membership**

Twelve to 15 individuals broadly reflective of the Canadian adult population in terms of geography, sex and gender, age, ethnicity, occupation and socio-economic status. At least three members will have French as their first language, and at least one of the French speaking members will reside outside of the province of Quebec. The PE WG, in collaboration with the HDRN Canada Indigenous Data Team, will seek to ensure there are at least two members of the PAC who are Indigenous (Inuit, Metis, and/or First Nations).

To make it easier for the PAC to approach and perform its work primarily on behalf of the public at large, at least 50 percent of the members should be individuals whose experiences do not include being a patient-partner (e.g., in an initiative funded by Canada’s Strategy for Patient Oriented Research [SPOR]) or being a member of a patient group.

While some members may belong or have belonged to one or more organizations—whether a cultural organization, a patient group, a political or social advocacy organization, etc.,—they will not represent those organizations in their role or work as PAC members. Individuals who work mainly in the area of health data or data privacy are not eligible to be PAC members since other members might be inclined, consciously or not, to defer to them in some discussions.

**Inclusivity, Diversity, Equity and Accessibility (IDEA)**

The work of the PAC will be conducted in accordance with the IDEA Strategy for HDRN Canada, including: maintaining a diverse PAC membership; ensuring that the work of the PAC is conducted in an inclusive manner with regards to language and technology (including use of live simultaneous French-English interpretation); working with PAC members to identify and remove barriers to participation in meetings and other PAC-related activities; and regularly providing learning opportunities and training in IDEA for all PAC members.

**Membership Terms**

Members will serve one three-year term with the option to renew for an additional three years in increments of one year. No member will serve more than a total of six years.

**Method of Selecting Members**

Members will be recruited on a yearly basis to align with current members’ expiring terms and to ensure diversity in membership. The Chair will be recruited by the PE WG and may come from within the existing PAC or outside. The appointment will be approved by the Executive.

**Preferred Method of Decision-Making**

Consensus.

**Quorum**

At least 50 percent of the members.

**Meetings**

The PAC will meet at least five times a year online, including one hybrid (in-person and online) meeting once a year.

**Expenses and Reimbursement**

All expenses incurred by members in performance of their responsibilities will be reimbursed as promptly as possible, in accordance with the policies of HDRN Canada. HDRN Canada will endeavor to pay larger expenses, e.g., airfare and hotel charges, directly.

**Compensation**

Each member (excluding the Chair) will receive an honorarium of $750 per year for participating in and preparing for at least five meetings per year, for responding to requests between meetings, for reviewing materials intended for the public, and for facilitating two-way communication between HDRN Canada and various communities and organizations. Individual members (or all members) may receive up to an additional $250 in a particular year for undertaking additional work. The exact amount of additional honorarium will be agreed upon before the work commences and will not be based on an hourly rate. The maximum yearly honorarium for each member (other than the Chair) will be $1,000. The honorarium will be taxable.

The compensation for the Chair, who is also a member of the PE WG, the HDRN Canada Leads Team and the HDRN Canada Executive, will be higher than that of other members and set by the HDRN Canada Executive.

**Requirements and Expectations of Members**

All members will be made aware of conflict-of-interest principles and procedures and will be asked to declare any conflicts at each meeting. Members will also be made aware of confidentiality requirements and required to sign a confidentiality agreement. Members will be expected to take part in at least 50 percent of meetings within each year of membership. Members will be expected to review all meeting materials prior to each meeting.

**Leaves of Absence and Termination of Membership**

Members may request a leave of absence for periods of up to six months. Members who are unable to be active for a period of more than six months will be expected to resign. They may reapply when able to resume active membership.

**Evaluation**

The PAC will be evaluated once a year in a process that includes an evaluation of itself in which all members will be invited to participate. The PAC will also participate in the evaluation of HDRN Canada.

**Changes to the Terms of Reference**

The PAC will review its Terms of Reference at least every two years and may recommend particular changes to the Terms to the HDRN Canada Executive.