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 what new kinds of data can be collected and
* 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.

# Reporting Relationship

The PAC will report to the HDRN Canada Executive Committee (Executive) and, through the Executive, to the HDRN Canada Board of Directors (Board). The Chair of the PAC will also interact directly with the Board. 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. Members of the Executive and Board will be welcome to attend PAC meetings and address the members.

# Membership

Twelve to 15 individuals are 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 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 & Accessibility (IDEA)

The work of the PAC will be conducted in an inclusive manner with regards to language and technology. This includes but is not limited to live simultaneous French-English interpretation during PAC meetings and PAC materials that include English and French text with large fonts, accessible formats, and colour palettes. When communicating with each other outside of meetings, PAC members are encouraged to take the identified needs of other members into account.

# Membership Terms

All members have an initial three-year term. After this term expires, members are able to renew their term for an additional year, up to three consecutive years. No member will serve more than a total of six years.

Members who remain inactive (no participation in PAC activities – meetings, email correspondence, etc.) for a period of four months will be contacted to review their membership on the council. No response to this contact will be considered confirmation of a desire to relinquish membership.

# Method of Selecting Members

The PE WG will select members of the PAC and its initial Chair. After the term of the initial Chair ends, the new Chair may be nominated from among existing PAC members or through external recruitment. The selection committee (composed of the current Chair, a current PAC member and HDRN Canada public engagement staff) will review and shortlist nominations, conduct interviews and recommend a successful candidate. The HDRN Canada Executive will consider the recommendation and make a final determination.

# Preferred Method of Decision-Making

Consensus, though if consensus cannot be achieved members may vote on a question.

# Quorum

At least 50 percent of the members.

# Meetings

The PAC will meet at least five times a year, with the possibility of an in-person sixth meeting.

## Expenses & Reimbursement

All expenses incurred by members in performance of their responsibilities will be reimbursed as promptly as possible, in accordance with the policies of the 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 each 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 who reports to – and may be a member of – the HDRN Canada Executive, will be higher than that of other members and set by the HDRN Canada Executive.

# Reimbursements & 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 are required to sign a confidentiality agreement. Members will also be expected to take part in at least 50 percent of meetings within each year of membership.

# 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 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 HDRN Canada Executive.