



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

Health Data Research Network Canada Public Advisory Council

Terms of Reference



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:

- A. 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
- B. To advise HDRN Canada about its short-term, medium-term, and long-term priorities
- C. 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
- D. 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 Team (Executive) and, through the Executive, to the HDRN Canada Board (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:

12-15 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 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% 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 member 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 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:

Half of the initial members should have two-year terms; the other half should have three-year terms. After the initial terms expire, all terms will be three years. No member will serve more than a total of six years.

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 will be nominated from among existing PAC members and confirmed by the Executive.

Preferred Method of Decision-Making:

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



Quorum:

At least 50% of the members.

Meetings:

The PAC will meet at least five times 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 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 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 also be expected to take part in at least 50% 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 the HDRN Canada.



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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.