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

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

Annual Report for 2020-2021

November 2021

The Public Advisory Council (PAC) of the Health Data Research Network Canada (HDRN Canada) is a committee of diverse volunteers (each of whom receives a small yearly honorarium) established to provide guidance, from essentially public perspectives, to HDRN Canada about its priorities, development, and operations.

The PAC met for the first time in September 2020 and has met five times since, always via Zoom.
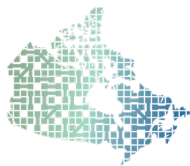
Recruitment of PAC Members

In 2019 and 2020, an Interim PAC was established to draft a terms of reference for the PAC and to help plan the process for recruiting 12-15 members of the first full PAC. Over 40 people from across Canada applied for PAC membership in the summer of 2020. Four members of HDRN Canada's Public Engagement Working Group interviewed those selected for interviews in English and two other PEWG members interviewed those selected for interviews in French.

The twelve members (including the chair) selected are, as intended, diverse in terms of age, location, race or ethnicity, occupation, and degree of personal involvement with the health system. Six are men; seven are women. In accord with our terms of reference, two of our members are Francophones from Quebec and another is a Francophone from outside Quebec. There is simultaneous English-French and French-English interpretation during each meeting, and documents such as agendas and meeting summaries are in both official languages. There were challenges identifying First Nations, Métis, and Inuit Peoples people who were interested in joining the PAC, so the goal of having two Indigenous PAC members was not achieved until March 2021. Biographies of PAC members are included on HDRN Canada's website.

Presentations to PAC Members

There have been presentations at all PAC meetings but one. Here is a list of the presenters, all of whom took questions and engaged in discussions with PAC members:

- Kim McGrail (Scientific Director of HDRN Canada who regularly attends PAC meetings) provided an introduction to health data and to HDRN Canada
- Jennifer Walker (Leader of HDRN Canada's Indigenous Team) outlined some of the history, concerns, and potential in Indigenous peoples' relationship with health data and described what is meant by Indigenous data sovereignty.
- Donna Curtis Maillet (Leader of HDRN Canada's Privacy Working Group) described some of the work of the privacy working group and asked for feedback (in French or English) to the draft she is preparing to help patients make an

informed choice about whether to give consent for the use of their data by research projects beyond the projects in which they are participants.

- Marie-Chantal Ethier (Member of the Data Access Support Hub Working Group) presented a grid that identified the kinds of data held by HDRN Canada member organizations.
- Isabel Fortier (Leader of the Maelstrom Research Platform) explained how and why different research projects use quite different variables in capturing race and ethnicity data from participants.
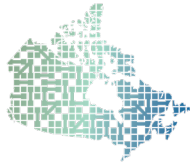
Advice Provided by PAC Members

In addition to the comments and suggestions by PAC members to the above-named presenters during PAC meetings, many members provided detailed written advice about:

- many aspects (content, accessibility, and clarity) of the draft HDRN Canada strategic plan. Several of the suggestions (e.g., defining "Indigenous Data Sovereignty," providing more detail about the goal related to public engagement, adding more detail about HDRN Canada's commitment to privacy, and using more accessible language) were adopted.
- the content and clarity of both the French and English texts of the document about patients consenting to the secondary use of data about them
- changes to the PAC's terms of reference
- the draft work plan of the HDRN Canada Public Engagement Working Group

Alison Paprica, Leader of HDRN Canada's Public Engagement Working Group who attends and helps organize all PAC meetings, facilitated a short interactive session on plain language about data and invited PAC members to join a project she is leading on plain language and data (PLAD). A few PAC members joined. She also elicited preferences and comments about what data holdings and data-holding organizations should be called (data trusts? data repositories? databanks? etc.).

Participation of PAC Members in Events about HDRN Canada

Denis Boutin and Frank Gavin participated in, respectively, French and English webinars about HDRN Canada intended for both researchers and the general public. Mpho Begin, Krysta Nesbitt, and Frank Gavin participated as panelists in a session about the experience of public advisors either to HDRN Canada or IC/ES (the Ontario health data organization) at the annual--and virtual--conference of The Canadian Association for Health Services and Policy Research (CAHSPR).

Members' Evaluation of First Year

PAC members were asked after the June 2021 meeting to respond, anonymously, to a survey in which they were asked to identify what they thought went well in the PAC's first year and what didn't go well and to share any ideas or suggestions they had for the next year. Most members responded, indicating they liked the diversity of members, the receptiveness of HDRN Canada to their suggestions, and the responsiveness of presenters to their questions. Many lamented the inability, because of COVID, to have at least one in-person meeting, and some thought there was insufficient continuity from meeting to meeting and a lack of clarity about the PAC's role and objectives. Some also suggested the PAC identify specific objectives and develop a plan for the year or so ahead.

Response to Members' Evaluation

A small working group was formed in early October 2021 to review the PAC's terms of reference, especially in relation to its roles and responsibilities, and to help identify objectives for the next 12 to 18 months.

Frank Gavin
PAC Chair
November 2021