



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

Public Advisory Council of Health Data Research Network Canada (HDRN Canada)

Annual Report for 2021-2022

September 2022



In its second year the Public Advisory Council (PAC) offered HDRN Canada specific advice about topics ranging from how the kinds of data held by Network organizations should best be made clear to the public to how public trust in the ways health data are collected and used can be earned and maintained. The PAC was equally focused on finding ways it can carry its work forward from meeting to meeting and have more impact in two key areas: communicating with the public about health data and advancing inclusion, diversity, equity, and accessibility within the Council, the Network, and the work the Network does.

Membership

The PAC's Terms of Reference call for between twelve and fifteen members, including at least two Indigenous individuals, at least two Francophones from Quebec, and one Francophone from outside Quebec. More generally, Council members are, as intended, quite diverse in terms of age, location, occupation, cultural or ethnic background, and kinds of experience with the healthcare system.

For half the year membership stood at thirteen; one member then resigned in the winter. Four members who completed their terms in June chose not to seek second terms. A recruitment campaign, conducted largely via social media, resulted in the submission of two dozen applications, nearly all of which were quite strong. A team of five people (including the Public Engagement Working Group chair, the Public Engagement Fellow, the Chair of the PAC, and two other members of the Working Group) created a short list of applicants, interviewed ten, checked references, and offered membership to six at the end of August. One position, to be filled by a francophone from outside Quebec, remains open. Suggestions from existing members in the spring helped make the process less onerous and more flexible—for instance, application could be made by video—for applicants.

Communication a Priority

Members completed a review of the PAC's Terms of Reference begun in the first year and decided to make advising HDRN Canada about how best to communicate with the public about various aspects of health data the PAC's primary role or responsibility. They put this into practice by providing detailed advice about a data grid the Network is developing to show what kind of data each of its member organizations holds. They recommended that users, by employing their cursors' "hover function," be able to find out more about certain terms and categories (such as "EMR Data"). and they advised addressing some questions raised by the data grid in the "frequently asked questions" section of the website. In addition, several PAC members remain involved in HDRN's Plain Language about Data project.

Members also decided that a "Communications Interest Group" be formed so that a group of particularly interested PAC members could provide ongoing recommendations



to HDRN Canada about a range of issues related to communications. Five members of the Interest Group met for the first time late in the spring.

Inclusion, Diversity, Equity, and Accessibility (IDEA)

Amy Freier, Chair of HDRN Canada's IDEA team, joined the PAC at one of its meetings and led a discussion of IDEA in the Network and, more particularly, within the PAC itself. One result was the formation of an IDEA Interest Group. So far one member has joined and is now preparing a blog post about the importance, in his view, of IDEA in research using health data. We expect more members to join the group.

Informing Health Data Projects

Some PAC members have been participants or peer reviewers in the development of a Health Data Social Licence White Paper project being led by HDRN Canada for the Public Health Agency of Canada (PHAC). And at the PAC's final meeting of the year Eric Sutherland from PHAC (who is leading the team developing a Pan-Canadian Health Data Strategy) and Alies Maybee (who is a patient partner on the team) provided an overview of their project and addressed a number of observations and suggestions from PAC members. Eric and Alies reported finding what they heard helpfully different from most of what they had already heard from other groups.

New Partners

In June Alison Paprica, who had been instrumental in the formation and development of the PAC, completed her term as the Chair of HDRN Canada's Public Engagement Working Group—which included deep involvement in planning, participating in, and following up on every PAC meeting. She somehow managed always to be simultaneously practical and inspiring. Catherine Street, Alison's successor as Chair of the Working Group, began attending PAC meetings even before her term began and has already shown herself similarly committed to the PAC and public engagement. Meanwhile, Julia Burt, HDRN Canada's Public Engagement Fellow has immersed herself in many of the projects and initiatives named above, often in a leadership role and always with diligence.

Members' Evaluation

This year five members responded to the invitation to submit written confidential comments about what they thought was working well, what wasn't working so well, and what suggestions they had for the PAC in the future.

Some members said they liked the diversity of members, the consistent and effective bilingualism in which the PAC functions, the opportunities to go to "breakout rooms" for smaller group discussions during meetings, and the fact that meetings are well-prepared.



Réseau de recherche sur les données de santé du Canada

Health Data Research Network Canada

The same members said there should be more “back and forth discussion” rather than individual members simply taking their turn in asking questions or making suggestions, more input from members about HDRN Canada’s priorities and a mechanism (an online notice board?) for identifying HDRN Canada projects that require and / or welcome the involvement of PAC members, more time for members to get to know one another better, and—though there’s been some progress in this area—more time before meetings for members to review the agenda and meeting materials.

A few commented—as others have at several times—that not being able to meet in person over the two years of the PAC’s existence has made many things harder. There is much anticipation that an in-person meeting in the fall will fortify the PAC in both tangible and intangible ways over the course of the whole of its third year. The PAC will add at least one more meeting a year, something that should help it gain and sustain momentum.

Frank Gavin
PAC Chair
September 2022