HDRN Canada

Public Advisory Committee Annual Report for 2022-2023

September 2023

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HDRN Canada’s Public Advisory Council (PAC)’s third year was quite different from its first two. After being unable to meet in person because of COVID-19, members gathered for in-person meetings in October 2022 and April 2023, while meeting four more times via Zoom. In addition, the Council was deeply involved in planning and conducting HDRN Canada’s first public forum, *Health Data for All of Us: Sharing Ideas and Priorities*. To many, it felt like moving out of a basement meeting room into a sunlit public square, even if the forum itself was held in a windowless hotel conference room.

# Health Data for All of Us: Sharing Ideas & Priorities

From its conception to its completion, the public forum reflected and advanced HDRN Canada’s commitment to one of its [strategic goals](https://www.hdrn.ca/en/about/strategic-plan/strategic-goals/): to “ensure purposeful and on-going public and community involvement.” PAC members would probably use simpler language to describe what the forum was all about: connecting with a variety of people (most of whom were not “data people”) in person and online about why health data matter to them and what concerns they have about such data.

Through months of close collaboration with HDRN Canada’s Public Engagement Working Group (PEWG) and the Network Coordination & Operations Team, PAC members had a hand in everything from choosing the title of the forum—even deciding to call it a “forum” rather than a “summit”—to deciding when and how technology would (and wouldn’t) be used to engage the participants. On the day itself, some members served as facilitators, presenters and questioners. There were technical glitches and some last-minute complications caused by factors relating to the pandemic, and an epic fog, but the forum was by all accounts a success, a real success that HDRN Canada and the PAC can build upon. (A detailed summary of the forum can be found [here](https://www.hdrn.ca/en/public/public-engagement-working-group/public-forum/) and videos of most of the presentations can be found [here](https://www.youtube.com/playlist?list=PL6iM14R_AMRXpxPBOmB1thc5JgkeqKwLG).)

# Other Activities & Accomplishments

While the public forum was the focus of much of the Public Advisory Council’s attention and work for several months, PAC members also:

* reviewed and suggested changes to the draft [Public Engagement Plan](https://www.hdrn.ca/wp-content/uploads/Public-Engagement-Plan-.docx), such as making the language plainer and moving some material to appendices;
* reviewed and recommended additions, such as more information about what the Network does and doesn’t do, to the draft of the orientation guide for new PAC members;
* continued to review versions of the data grid (eventually to be posted on [hdrn.ca](https://www.hdrn.ca/en/)) that shows what kind of health data are held by which jurisdictions or pan-Canadian organizations;
* continued to participate in the *Social Licence for Uses of Health Data* project that produced a report (renamed at the suggestion of a PAC member) with several PAC members as co-authors and Julia Burt, Public Engagement Operational Lead, as lead author. Some PAC members are also co-authors of a follow-up manuscript (which will be submitted to a peer-reviewed journal for publication) focused on the process taken to engage with members of the public in this project; and
* reviewed and suggested changes to the *Health Data for All of Us* detailed summary, such as simplifying language and defining terms.

# The Communications & IDEA (Inclusion, Diversity, Equity, & Accessibility) Interest Groups

The PAC established the Communications Interest Group and the IDEA Interest Group early in 2022 to offer focused recommendations that other HDRN Canada members, especially the PEWG, could act upon. Since then, each interest group of three to seven members has met only a few times, and neither has yet to gain much momentum. In their end-of-the-year survey responses, some members expressed a wish for the groups to meet more often and to focus on specific areas or topics, such as an IDEA infographic or a frequently-asked-questions section on the new website.

# Public Advisory Council Meetings: Breadth, Depth & Continuity

Public Advisory Council members heard about and discussed a wide range of issues related to health data, as the list below of presenters and their topics at the six PAC meetings indicates. The number and variety of these issues point to a challenge identified by several members in their survey responses: the difficulty of choosing—but the need to choose—which issues the PAC should focus upon. There is a recognition that rather than jump from issue to issue in successive meetings, the PAC should decide which handful of issues it will return to over the course of several meetings so as to make measurable differences.

# Presentations at PAC Meetings

Below is a list of presenters and their topics. In all cases, there were questions and discussions following each presentation.

* Dr. Kim McGrail, Scientific Director of HDRN Canada: *HDRN Canada and Public Engagement* (October)
* Dr. Jennifer Walker, Indigenous Lead and Member of the Executive, HDRN Canada: *Indigenous Data Sovereignty* (October)
* Dr. Amy Freier, IDEA Lead, HDRN Canada: *Developing an Inclusion, Diversity, Equity and Accessibility Strategy for HDRN Canada* (October)
* Dr. Kate Milberry, Strategic Communications Manager, HDRN Canada: *Purposeful Communication with the Public and Choosing the Appropriate Channel of Communication* (October)
* Dr. Kim McGrail: *The Work and Recommendations of the Expert Advisory Group to the Pan-Canadian Health Data Strategy* (February)
* Dr. Kim McGrail and Dr. Michael Schull, CEO, Institute of Clinical and Evaluative Studies and Member of the HDRN Executive: *HDRN Canada, HDRN Canada Member Organizations, and Private Sector Entities*—Especially Private Sector Access to Publicly Gathered and Held Health Data (April)
* Holly Etchegary and Kathy Hodgkinson, Memorial University of Newfoundland: *Every Single Use must be Consented to: Public Opinion on Genomic Data Sharing in Newfoundland and Labrador* (April)

# Membership

Seven new members joined the Public Advisory Council in the autumn of 2022, but two had to leave months later: one for health reasons and the other because of academic demands. We noted that the age group from which we were drawing the fewest applications (young adults under 28) was also the only age group where we were having trouble retaining members, so we embarked on a recruiting campaign, mainly using social media and asking for the help of organizations with youth councils, to target young adults. We were happy to receive nearly 20 applications—compared to two or three from younger adults in the first two years—from young people from across Canada with a wide range of experiences and interests. For the first time, two PAC members in addition to the chair were part of the small teams interviewing the short-listed candidates. We look forward to two or three joining the PAC in the autumn.

# Staff Support and Changes

The Public Advisory Council continues to be well supported by Catherine Street, Chair of the Public Engagement Working Group, and Julia Burt, Public Engagement Operational Lead. Both were central to the planning of the public forum. Olivia Canie completed two years as part-time research assistant, during which she very capably looked after many aspects of meeting preparation and follow-up. In May, Jannath Naveed succeeded Olivia in a full-time role and has already carefully and diligently supported the recruiting process and many meeting-related activities. That members feel the PAC is important to HDRN Canada is no doubt due, in large part, to the commitment to the PAC and, more generally, to public engagement that Catherine, Julia, and Jannath have demonstrated.

# Members’ Yearly Evaluation of the PAC

As happened at the end of each of the Public Advisory Council’s first two years, members were invited to respond to a survey about what they thought was working well, what wasn’t working so well, and what changes they would like to see. This year there were a greater number and proportion of members (nine of 13) who responded in writing. Their responses were also more detailed.

Members expressed appreciation for the Council’s safe and respectful environment; for the rich diversity of members’ views, experiences and backgrounds; for the efforts to ensure members can fully participate in English or in French; for the ongoing support and encouragement of HDRN Canada’s leadership and staff; and for the leadership of the chair. The clear consensus is that the PAC is working well and making progress.

Members want to see the two interest groups (Communication and IDEA) meeting more regularly and focusing on specific areas or activities. Some said the PAC’s role, even after three years, is still not well-defined, and several expressed a desire for members to choose a small number of priorities, and objectives linked to those priorities, for the year ahead and some appropriate indicators to measure progress and impact.

There is an evident appetite for the creation or use of case studies that can help the public or particular communities better understand why and how health data are used, especially in research, and what impact their use has on people’s lives. How, for instance, can or does data-intensive research improve primary care and what can people do to support such research? Most members said they enjoyed the opportunities to meet in person and hope such opportunities continue.

# Conclusion

A relatively new member commented during a recent PAC meeting that, compared to her many experiences on other advisory bodies in the health sector, it is harder and takes longer to understand the role and the impact (actual and potential) of both HDRN Canada and its Public Advisory Council. Data can seem abstract, or at least removed from hands-on health care, and HDRN Canada doesn’t itself hold any data or fund any research projects. So maybe it should not be a surprise that we on the PAC are still feeling our way forward and trying to decide where to direct our attention and our efforts.

Nonetheless, there have been many moments in our meetings and at the public forum when the need for various kinds of health data to help us understand and solve problems that are not at all abstract were laid bare. These moments revealed that, in fact, health data are important to individuals and communities—as is the need for public involvement in addressing all the key issues about the collection and use of health data. Attending to these moments and building (even if slowly) on the insights that follow will help the Public Advisory Council and HDRN Canada ensure that public and community involvement in health data research is not only purposeful and ongoing but effective.

Frank Gavin

Chair, Public Advisory Council

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