HDRN Canada

Public Advisory Council Annual Report for 2023-2024

September 2024

Table of Contents

In its fourth year, HDRN Canada's Public Advisory Council (PAC) continues to build momentum, playing an important role in supporting purposeful public engagement in data-intensive health research. In addition to meeting five times via Zoom, the in-person meeting held in April 2024 renewed the Council's sense of purpose and commitment to their work.

A focus on priority-setting

Starting in September 2023, the PAC spent around six months conducting a priority-setting exercise to help determine potential new initiatives and activities on which the group could focus. Priority areas determined by the PAC, which were refined over a number of meetings, included privacy and consent, private sector involvement, and data equity. In addition, communication and building public trust were determined to be overarching themes that should be reflected in all areas of the PAC's work. Activities related to these priority areas are already underway, and are described elsewhere in this report.

Health Data for All of Us: Earning Trust through Transparency

In April 2024, HDRN Canada hosted its second public forum, *Health Data for All of Us: Earning Trust Through Transparency* in Montreal. Like last year, PAC members helped plan the event, chose speakers and set the agenda. As this year's forum was held in Montreal, input from Francophone members was particularly helpful to ensure that the event met the needs of Francophone attendees. As such, both Maureen Smith and Danièle Remy-Lamarche, Francophone PAC members, participated in the program committee for the event. On the day itself, the event was emceed by Bill Pratt, the PAC Chair, Rob Semeniuk, PAC Member, facilitated a panel discussion on artificial intelligence, and Maureen Smith and Denis Boutin provided French language introductions of sessions. Most other PAC members attended the forum, mostly in-person and some online. *Health Data for All of Us* was considered a great success for the network, and planning is already underway for its third year. Recordings of the presentations can be found here.

Other Activities and Accomplishments

In addition to their involvement in the public forum, PAC members:

- Helped recruit the new PAC chair, including participation in interviews

- Formed a working group to create a plain language glossary of health data-related terms, which is aligned with the group's priority areas and overarching themes of privacy and consent, public trust and communication

- Formed a working group to review and update the PAC's Terms of Reference

- Participated in initiatives related to the network's commitment to inclusion, diversity, equity and accessibility (IDEA), including the development of the IDEA Strategy and the IDEA Community of Practice, aligning with the council's focus on data equity

- Participated in the Strategy for Patient-Oriented Research (SPOR) refresh consultation

At PAC meetings, members heard from other representatives of HDRN Canada, and had the chance to ask questions and provide their perspectives. Presentations included the following:

- Dr. Kim McGrail, Scientific Director of HDRN Canada: *HDRN Canada The Big Picture – Your chance to ask Kim* (April, 2024)

- Dr. Amy Freier, HDRN Canada IDEA Team Lead and Dr. Nathan Nickel, HDRN Canada executive member: *HDRN Canada IDEA Strategy* (April, 2024)

- Joanna Ou, Senior Coordinator, Data Access Support Hub (DASH): *Data Access Support Hub (DASH)* (June, 2024)

Membership

In the Summer of 2023, a recruitment round was launched to invite young adult members to join the council. Three new young adult members with diverse backgrounds and experiences joined in September 2023 and continue to contribute their valuable perspectives to the council.

This year was the final term for four PAC members. We are truly grateful for the contributions of Frank Gavin, Denis Boutin, Jason Leblanc and Danièle Remy-Lamarche, and wish them all the best in their future endeavors! We are now in the process of another recruitment round, this time focused on individuals who are Francophone and those who identify as Indigenous. We were happy to receive a record-breaking number of applications (over 100) and look forward to welcoming three or four new members this Fall. Like last year, two PAC members in addition to the Chair were part of the small teams interviewing the shortlisted applicants.

Staff Support and Changes

The PAC continues to be well supported by Catherine Street, Public Engagement Working Group Chair, Julia Burt, Public Engagement Operational Lead, and Jannath Naveed, Public

Engagement Research Assistant. A transition period occurred at the end of 2023 into the first part of 2024, when the group's first chair, Frank Gavin, stepped down. After a months-long search, Bill Pratt, a current PAC member and experienced charity leader was recruited as the new chair. The transition period lasted from January to April 2024, with Bill chairing his first official meeting in March 2024 and emceeing the public forum in April. We extend our heartful thanks to Frank for his longstanding commitment to the network and his leadership of the PAC. We are looking forward to continued progress under Bill's leadership, building on Frank's successes and maintaining the momentum moving forward.

Members' Yearly Evaluation of the PAC

In an annual year-end survey, PAC members were again given the opportunity to provide their thoughts on what is and is not working well, what changes they would like to see, and their overall satisfaction with their role. Members provided very detailed and thoughtful responses.

The survey told us that most of the members appreciated the valuable discussion and sharing of ideas; the diversity of the group and the presence of different voices (including young adult); and the opportunity to learn about and create connections with the wider HDRN Canada. We are especially pleased that 100% of the respondents indicated overall satisfaction with their role.

There is still some confusion about the role of the PAC within the larger HDRN Canada ecosystem, and the role of the network overall. We hope that by continuing to invite representatives of other working groups, teams and sites to present on their work at PAC meetings, HDRN Canada's mandate, and the PAC's role within it, will become clearer. A lack of momentum between meetings was also highlighted as a concern by more than one member, with some noting a desire for more opportunities to provide input. The need for setting concrete goals was emphasized, as well as evaluating PAC activities as a way to demonstrate the PAC's overall impact within data-intensive health research. We hope that the group's focus on priority-setting and the formation of smaller working groups that focus on specific tasks will help to build momentum and achieve concrete goals.

Conclusion

This year brought many significant changes, including a new chair, new members, and a strong emphasis on priority-setting. As one PAC member noted, our processes are becoming smoother over time and the group is "finding their stride". With a concerted focus on important areas in the health data space, such as communication and public trust, we are excited about our growing impact and supporting the vital role of public involvement in health data and data-intensive health research.