HDRN Canada 

Health Data For All of Us

Sharing Ideas and Perspectives

Summary Report

April 25, 2023 (Winnipeg, Manitoba and Online)



# Table of Contents

[Introduction 2](#_heading=h.ivp6brfahvfc)

[Public Involvement & Engagement in Data-intensive Research: Facilitating Mutually Beneficial Conversations 3](#_heading=h.gjdgxs)

[The Health Data Ecosystem & HDRN Canada 4](#_heading=h.30j0zll)

[A Facilitated Discussion on Patient & Public Priorities for HDRN Canada & Data-intensive Health Research 5](#_heading=h.1fob9te)

[Public Perspectives on Acceptable Uses of Health Data 6](#_heading=h.3znysh7)

[Panel – Making Health Data an Ally for All of Us 7](#_heading=h.2et92p0)

[Reflections & Looking Ahead 9](#_heading=h.tyjcwt)

[Appendix 10](#_heading=h.1t3h5sf)

**Health Data for All of Us: Sharing Ideas and Priorities** was an interactive forum hosted by Health Data Research Network Canada’s (HDRN Canada) Public Engagement Working Group and Public Advisory Council (PAC).

The goals of the Forum were to:

* Share knowledge about HDRN Canada and more generally, the use of health data in research; and
* Generate dialogue among members of the public, researchers and other stakeholders about their priorities for (and the challenges to) data-intensive health research.

Discussion topics focused on the health data ecosystem in Canada, the importance of public input in data-intensive health research, and public perspectives on health data collection, sharing and use, with overarching themes of inclusion, diversity, equity and accessibility (IDEA).

This document summarizes key ideas and themes emerging from the event’s discussions and identifies actions to be taken by HDRN Canada, including ways to broaden and deepen engagement with the public and particular publics or communities.

View the [Forum Agenda](https://www.hdrn.ca/wp-content/uploads/Agenda-Health-Data-for-All-of-Us-PRINT.pdf) and the [Glossary of Health Data Terms](https://www.hdrn.ca/wp-content/uploads/HDRN-Canada_Forum-Glossary_English.pdf) from the event.

# Introduction

The Forum’s Emcee, **Frank Gavin** (HDRN Canada PAC Chair), introduced the event and **Elder Margaret Lavallee** (Elder in Residence, Ongomijzwin, University of Manitoba) then offered an opening prayer.

*“We ask that you have an open mind and open heart so that our people will have a good life for future generations to come…”*

*~* ***Elder Margaret Lavallee*** *on the meaning of “Ongomijzwin”*

We acknowledge that **Health Data for All of Us: Sharing Ideas and Priorities** was hosted in Winnipeg on the ancestral and current day lands and waters of the Anishinaabe, Cree, Ojibway-Cree, Dakota and Denesuline peoples, and on the National Homeland of the Red River Métis. Attendees joined online from across Turtle Island.

# Public Involvement & Engagement in Data-intensive Research: Facilitating Mutually Beneficial Conversations

#### Presenter: **Rachel Plachcinski**, Parent, Patient and Public Involvement Researcher & Consultant

The Forum’s plenary session focused on public involvement and engagement in data-intensive health research, with an emphasis on research and initiatives in the maternity “patient” landscape. Rachel introduced the session by noting the differences between public *engagement* (exemplified by wider conversations with the public and knowledge sharing) and *involvement* (which often includes patients and the public in the prioritization and execution of research, for example as co-primary investigators or part of advisory groups). She described how both public involvement and engagement can improve data-intensive health research, for example by bridging the gap between researchers and the people to whom the data relates. She also noted that while the benefits of public involvement in data-intensive health research have been documented, there is limited public understanding of the possibilities and limitations of data use.[1](https://www.hdruk.org/case-studies/how-the-hdr-uk-public-advisory-board-are-driving-involvement-of-patients-and-the-public-in-data-access-processes/)

Rachel described various public engagement and involvement initiatives related to maternity health, including the [Birth Timing #1 Study](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8121135/)2 and [MuM-PreDICT](https://mumpredict.org/)3 and emphasized the importance of identifying missing data, specifically in the reproductive health landscape (e.g., data on miscarriages). She noted how much population data misses information about how people live their lives, often due to people’s fear and mistrust of the health care system, among other factors, and emphasized the importance of accurate ethnicity coding and the collection of race-based data to drive more meaningful results from research. Rachel also noted the balancing act of involvement and engagement – particularly in the maternity space – when trying to ensure that diverse perspectives are heard while being mindful of people or organizations bringing their “campaigning hat” to (and potentially dominating) conversations.

*“What picture is data building about our lives? What is data missing about how we live our lives? Is data capture, coding and legislation keeping up with social change?”*

***~*** ***Rachel Plachcinski***

During the question and answer period, attendees inquired about and discussed specific strategies to prepare researchers to deal with strong public emotions and noted the importance of approaches to trauma-informed care in public involvement and engagement initiatives. Attendees also discussed ensuring a balance between patient/public privacy and collecting more demographic data (e.g., race-based, ethnicity coding) as a way to delve deeper into health system inequities.

[View the Public Involvement & Engagement in Data-intensive Research session recording](https://www.youtube.com/watch?v=C4AK9AuwMwg)

# The Health Data Ecosystem & HDRN Canada

#### Presenter: **Dr. Kim McGrail,** Scientific Director & CEO, HDRN Canada

Dr. Kim McGrail’s session focused on transforming the health care system by incorporating more equality, equity and justice-based principles. She noted that data can play a crucial role in achieving better and more equitable health outcomes but also reflect our current reality, one that is underpinned by systems of oppression and colonialism. These systems not only bias the ways we collect, distribute and interpret data, but result in the inequitable distribution of health services and outcomes.

*“Raw data is an oxymoron. What we collect is influenced by power decisions and structures…”* ***~ Dr.*** ***Kim McGrail***

To address these issues, Dr. McGrail concluded that instead of focusing on changing individuals and their behaviours, we need to address the systems that serve all of us by acknowledging that:

* Health data in Canada need to be better and more person-centered4 (learn more about how Canada is strengthening its health data foundations through the development of a [Pan-Canadian Health Data Strategy](https://www.canada.ca/en/public-health/programs/pan-canadian-health-data-strategy.html))4
* Principles of Inclusion, Diversity, Equity and Accessibility (IDEA) are fundamental to decisions about data collection, sharing and use
* Supporting Indigenous-led research and Indigenous data sovereignty is part of reconciliation
* The collection, sharing and use of data are normative, values-based decisions and therefore require public input

During the question and answer period, attendees identified challenges in getting the right people at the table to start important discussions on the health data ecosystem and health equity. To address this, a key recommendation from the Pan-Canadian Health Data Strategy’s Expert Advisory Group was to hold public assemblies/deliberations to ensure a diversity of views and opinions on equitable health data practices, not necessarily with the aim of achieving consensus. Attendees also inquired about how to best navigate industry use of routinely collected data considering issues of equity. Dr. McGrail noted that navigating public good, data misuse and innovation is a balancing act, and one that can be addressed in part by putting additional safeguards in place for industry or private sector use of data.

[View the Health Data Ecosystem & HDRN Canada session recording](https://www.youtube.com/watch?v=1OXJ9h2euNA&t=369s)

# A Facilitated Discussion on Patient & Public Priorities for HDRN Canada & Data-intensive Health Research

#### Facilitators:

#### **Dr. Amy Freier**, Inclusion, Diversity, Equity and Accessibility (IDEA) Lead, HDRN Canada,

#### **Denis Boutin,** HDRN Canada Public Advisory Council Member

In this interactive session, Dr. Amy Freier and Denis Boutin facilitated a discussion with virtual and in-person attendees focused on priorities for and barriers to data-intensive health research. Major themes emerging from the discussions, which were guided by three questions posed by the facilitators to the attendees, are summarized below. These themes are also presented visually as word clouds in the appendix.

**Question 1: What are the two most important problems data-intensive health research should focus upon?**

Priorities for data-intensive health research highlighted by attendees included the importance of health equity, access to both health care services and health/social data, data interoperability, Indigenous data sovereignty and the social determinants of health. The significance of race-based data collection was also noted as a key factor in understanding health inequities experienced by systemically marginalized populations. Attendees bringing patient and public perspectives noted and lamented the misalignment often seen between data that are important to researchers and decision-makers, and data that are important to patients.

*“[When collecting and using health data, we must always consider] from whom, on whom, for whom, and with whom.”* ***~ Forum Attendee***

**Question 2: What are the two biggest barriers to gaining strong public support for the collection and use of administrative health data?**

Key barriers to gaining public support for health data collection and use emerging from the discussion included trust, privacy, misinformation and low data literacy, as well as a lack of meaningful engagement with the public.

*“[concerns that] the data will be used against us…”****~ Forum Attendee***

Trust or lack thereof was a common theme highlighted by attendees, not only in the facilitated discussion but throughout the Forum. In particular, attendees emphasized the experiences of systemically marginalized populations that often have an historical distrust of a health care system that has not served them well. Many also shared concerns that data collected from the health care system could be (and has been) used against these groups.

Several people emphasized that the responsibility for demonstrating and ensuring trustworthiness lies with data collectors and holders, not members of the public. They also suggested shifting the dialogue around health literacy so that blame is not assigned to members of the public who have “low health literacy.” Instead, responsibility should be placed on organizations to share information around data collection and use in a way that is accessible and understandable to everyone.

**Question 3: What should the collectors, holders and users of administrative health data do to overcome these barriers?**

Suggestions for overcoming barriers to public support for data-intensive health research included transparency, communication and meaningful public engagement. Attendees noted the importance of integrated knowledge translation and of ongoing engagement with key publics impacted by data collection and use.

# Public Perspectives on Acceptable Uses of Health Data

#### Presenters:

#### **Julia Burt**, Public Engagement Fellow, HDRN Canada,

#### **Dr. P. Alison Paprica**, Adjunct Professor, University of Toronto,

#### **Dr. Annabelle Cumyn**, Associate Professor, Université de Sherbrooke,

#### **Roxanne Dault**, Research Officer, Université de Sherbrooke.

This session presented findings from [*Social Licence for Uses of Health Data: A Report on Public Perspectives*](https://www.hdrn.ca/en/reports/social-licence-uses-health-data-report-public-perspectives)*5,* which was prepared by HDRN Canada for the Public Health Agency of Canada to inform the Pan-Canadian Health Data Strategy. Building on a decade of research into publicly supported uses of health data, the report adds the voices of 20 experienced public and patient advisors (“participants”) to the discussion about which uses and users of health data have “social licence”.

**Health data social licence:** Describes which uses and users of health data members of the public support – and under what conditions

The presenters outlined the process of capturing the participants’ perspectives, which followed [inclusive design principles](https://medium.com/fwd50/the-three-dimensions-of-inclusive-design-part-one-103cad1ffdc2)6 such that all views were captured, not just those supported by the majority. Through facilitated, deliberative dialogue sessions, participants involved in the project explored concerns related to privacy, commercial motives, equity and fairness, and tried to come to consensus in two main areas: 1) essential requirements for health data social licence; and 2) uses and users of health data they perceived to be within or not within social licence.

Key themes emerging from the participants’ input on health data social licence were presented, and included the importance of trust, transparency and access to personal health data.

*“Build trust with the populations who provide health data. The entitles who collect health data should be held accountable for how these data are used…”*

***~ Forum Attendee***

The discussion period of the session focused on the diversity of the participants involved in the process and how the process could be adapted to different populations, the importance of Indigenous-led work and of engaging with members of the public who do not have prior experience with health data.

Read the full report.

[View the Public Perspectives on Acceptable Uses of Health Data session recording](https://youtu.be/GRATzc6wwO0)

# Panel – Making Health Data an Ally for All of Us

Moderator:

**Dr. Nathan Nickel**, Executive Member, HDRN Canada and Director, Manitoba Centre for Health Policy

Panelists:

**Maureen Smith**, *HDRN Canada Public Advisory Council member,*

**Stephanie Sinclair**, *Research Coordinator, First Nations Health & Social Secretariat of Manitoba,*

**Hani Ataan Al-Ubeady**, *HDRN Canada Public Advisory Council member*

In this interactive panel discussion moderated by **Dr. Nathan Nickel**, three panelists provided their perspectives on issues regarding the use of data from or about specific populations – specifically, the rare disease community, Indigenous peoples and refugees. The panelists were guided by the question: *“*What can we do to ensure that the correct data are collected so that accurate stories can be told and acted upon?*”*

*“Data can tell stories that are no longer viewed as anecdotal…”*

***~ Forum attendee***

**Maureen Smith** opened the discussion by emphasizing the importance of data-intensive health research to the rare disease community. She noted that despite the name, one in 10 Canadians suffer from a rare disease. That’s why it is imperative to have case studies, effective data collection and interoperability that can capture the experience of having a rare disease and greatly increase the evidence base for treatments.

**Stephanie Sinclair** highlighted some of the ways in which Indigenous peoples are often negatively impacted by the methods we use to collect and use health data. She emphasized the importance of Indigenous data sovereignty so that First Nations, Inuit and Métis people have access to and control over their own data. Indigenous peoples (and those from other systemically marginalized groups) need to be involved in the leadership of research projects, and results need to be disseminated in widely accessible formats.

**Hani Ataan Al-Ubeady** noted that the experience of persecution shared by many refugees and former refugees means they may not feel safe disclosing certain information to health care providers. He encouraged organizations and others involved in health data collection and use to better understand refugees’ backgrounds and reasons behind their hesitancy to share data.

**Questions raised by attendees:**

*“How can individuals and organizations involved in administrative health data use support or spearhead Indigenous data sovereignty initiatives?”*

*“How can authentic storytelling help the rare disease community emphasize the importance of health data for public good?”*

*“Is there a better way to capture data that doesn’t harm/that is safe and respectful for people who have experienced systemic harms and oppression?”*

Common themes emerging from both the panelists’ and attendees’ perspectives are highlighted below.

* It is imperative that populations have control over how their own data are collected, used and shared.
* Collecting, using and sharing health data can tell stories that portray the realities of different populations but there are negative implications (particularly for systemically marginalized populations) when data about them are collected or used incorrectly
* An inherent distrust of the health care system by many systemically marginalized populations results in missing or inaccurate data, further exacerbating the inequities of the health care system.

[View the Panel Discussion on Making Health Data an Ally for All of Us recording](https://www.youtube.com/watch?v=6L64jlf63uk).

# Reflections & Looking Ahead

**Health Data for All of Us: Sharing Ideas and Priorities** provided an opportunity for patients, the public, community organizations and other stakeholders to come together to share their perspectives on priorities for, and the challenges to, data-intensive health research. The hybrid Forum fostered meaningful discussion among attendees from across Canada and beyond with diverse backgrounds and experiences.

Moving forward, HDRN Canada’s Public Engagement Working Group and Publica Advisory Council commit to sharing key themes emerging from the Forum. The themes of **trust, health equity and equitable data collection, public benefit and transparency** will be disseminated widely through various channels and to diverse audiences, including patients, the public, researchers and other key stakeholders.

In collaboration with and seeking advice from other HDRN Canada teams and working groups, including the Inclusion, Diversity, Equity and Accessibility Teamand the Indigenous Data Sovereignty Team, the Public Engagement Working Group and Public Advisory Council will work to turn identified themes into key actions for HDRN Canada. We hope that these actions will contribute to a stronger and more equitable health data ecosystem and a deeper engagement with patients and the public within the health data space.

**Health Data for All of Us: Key Themes and Reflections**

**Trust (or lack thereof)** by the public in organizations that collect, share and use health data. How do these organizations gain or repair trust with people and communities, particularly those who have not been well-served by the health care system?

**Public benefit** as an essential requirement for health data social licence. How do we measure public benefit and does the public have a role in defining and identifying this benefit?

**The use of data from or about systemically marginalized communities.** How do we encourage equitable health data collection that will benefit, not harm, these communities?

**Transparency and clear communication** by organizations who collect, share and use health data. How can we ensure that members of the public understand how and why their data are being used, including the associated risks and benefits?

# Appendix

Visual Representation of themes emerging from the facilitated discussion on Patient & Public Priorities for HDRN Canada/Data-Intensive Health Research

**What are the two biggest barriers to gaining strong public support for the collection and use of administrative health data?**



**What are the two most important problems data-intensive health research should focus upon?** 

**What should the collectors, holders, and users of administrative health data do to overcome these barriers?** 