HDRN Canada

Health Data for All of Us: Earning Trust through Transparency

Summary Report

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Table of Contents

[Introduction 3](#_Toc189134658)

[Nurturing Inclusive Knowledge Dialogues 4](#_Toc189134659)

[Two-spirit Wellness & Health: Better Relations Through & By Data Management & Research 5](#_Toc189134660)

[Implementing the Pan-Canadian Health Data Strategy: Public Assemblies, Involvement & Trust 7](#_Toc189134661)

[Public Expectations and the Use of Health Information in Research: Québec’s New Approach 8](#_Toc189134662)

[Respect My Data! Strategies to Mitigate Harms of Data Use in Health Research 10](#_Toc189134663)

[What’s Mine is (Not) Yours 12](#_Toc189134664)

[Lost in Translation: The Importance of Trust in the Era of Big Data & AI 14](#_Toc189134665)

[Reflections & Looking Ahead 18](#_Toc189134666)

[Appendix A 20](#_Toc189134667)

[Accessibility Tips 21](#_Toc189134668)

[Two column layout: 22](#_Toc189134669)

[P 22](#_Toc189134670)

**Health Data for All of Us: Earning Trust Through Transparency** was the second annual public 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:

* Emphasize the importance of trust between patients/the public, caregivers, researchers and policymakers.
* Highlight the need for transparency in data collection, management and usage, including the integration of ethical data practices and the role of public and patient involvement.

Discussion topics centered on the integration of ethical data management practices, the role of cultural sensitivity in health research, and the impact of emerging technologies on privacy, with overarching themes of trust, transparency and equitable access.

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 enhance public engagement and to support artificial intelligence and technology integration. View the [Health Data for All of Us Forum agenda](https://hdrn.ca/en/public/public-engagement-working-group/public-forum/) on the HDRN Canada website for a detailed agenda and more information.

# Introduction

The Forum’s Emcee, **Bill Pratt** (HDRN Canada’s PAC Chair), introduced the event and **Elder Otsi’tsaken”ra** (Charles Patton), an elder of the Kanien'keha:ka community of Kahnawa:ke, on the south shore of Otsira:ke (Hochelaga/Montréal)). **Elder Otsi’tsaken”ra** offered an Indigenous opening protocol for the Forum, highlighting the importance of roots, identity and cultural teachings for strength and resilience.

“Everything draws its energy from roots. Even for you, your roots is your identity, where your mother came from. You follow your mother to your grandmother, your great-grandmother, all the way to the Sky Woman. Your language and your culture and your identities; that’s what makes you strong. The teachings of your people, that's what makes you strong” ~ **Elder Otsi’tsaken”ra**

We acknowledge that **Health Data for All of Us: Earning Trust through Transparency** was hosted in Montréal on the ancestral and traditional territory of the Kanien’kehà:ka, a place which has long served as a site of meeting and exchange amongst many First Nations including the Kanien’kehá:ka of the Haudenosaunee Confederacy, Huron/Wendat, Abenaki, and Anishinaabeg. We recognize and respect the Kanien’kehà:ka as the traditional custodians of the lands and waters on which we meet today. Attendees joined online from across Turtle Island.

[View the Indigenous Welcome & Protocol recording](https://www.youtube.com/watch?v=jEXZHIc0_QE)

# Nurturing Inclusive Knowledge Dialogues

#### Presenters:

**Dr. Antoine Boivin,** Practicing physician | Co-director, Canada Research Chair in Partnership with Patients and Communities | Co-founder, Unité de soutien SSA Québec (Quebec SPOR SUPPORT Unit)

**Farin Shore,** Harm Reduction Peer, Doctors of the World

The Forum’s morning plenary session focused on different approaches to data management that centre on nurturing trusting relationships between patients, caregivers, researchers, policymakers and marginalized communities. By emphasizing the integration of care principles, ethical data use and the inclusion of diverse voices, this session reflected the key themes for the forum – the importance of trust and transparency in health data use.

Farin Shore shared his personal journey navigating through various levels of the health care and welfare systems while receiving treatment for advanced HIV. He raised important concerns about the types of data health care providers use to make decisions about a patient's health and welfare. Current data systems often only reflect the time patients spend within the hospital, missing key information about their health changes during recovery and outside of clinical settings. Effective health care requires data that is properly contextualized to include all aspects of a patient's life, including physical, emotional, mental and spiritual health.

To improve health care outcomes, dialogues must include a diverse range of voices, not just those of doctors. Nurses, social service providers and peer support workers play crucial roles in understanding and supporting patients. Farin emphasized the essential role of nurses, who often provide the emotional and practical support that doctors may overlook.

“While doctors focus on treating illness, nurses treat the patient.” **~** [**Farin**](mailto:rachel.plachcinski@gmail.com) **Shore**

The session highlighted the divide between social services and the health care system. There is need for a more integrated approach where all data related to a patient's health is understood. This can be achieved with ethical data management practices that prioritize nurturing trusting relationships between patients and providers.

During the question and answer period, attendees discussed the need for public health agencies to consider broadly all avenues that impact social determinants of health, such as housing, food and job security. They also emphasized the importance of meaningful patient-provider interactions, ultimately aiming for a health care system that naturally includes diverse voices and fosters trusting relationships.

“If we can get to where peer workers are not necessary, all the people who are going to be unemployed are proof of a job well-done” **~** [**Farin**](mailto:rachel.plachcinski@gmail.com) **Shore**

[View the Nurturing Trusting Relationships for Caring Health Data Systems session recording](https://www.youtube.com/watch?v=prtZcWBBC3c)

# Two-spirit Wellness & Health: Better Relations Through & By Data Management & Research

Presenters:

**Harlan Pruden,** Indigenous Knowledge Translation Lead, BC Centre for Disease Control

**Dr. Teddy Consolacion,** Epidemiologist, BC Centre for Disease Control in HIV

This session explored the concept of Two-Spirit within Indigenous communities, addressing common Western misunderstandings and emphasizing its cultural significance. Two-Spirit is not merely an LGBTQI+ Indigenous identity, but an organizing strategy with distinct roles across different Indigenous nations, some recognizing up to 12 genders. Historically, Two-Spirit individuals served as mediators between genders in Indigenous communities, a role disrupted by colonial practices like residential schools, which enforced rigid gender norms.

Harlan and Dr. Consolacion explored the importance of culturally sensitive data collection in health research. Current national surveys, such as Sex Now about GBT2Q men, often misrepresent Two-Spirit identities by listing them as gender or sexual identity options without considering their cultural context. Surveys and data collection strategies must respect Two-Spirit as a gender analysis understood within Indigenous cultures rather than a general sexual orientation, and ensure that data accurately reflects the communities it aims to represent. Data collected with poorly designed questions is incomplete data that creates more problems than solutions. For example, Indigenous people access mental and spiritual health support through Elders and Knowledge Keepers, which is often not an option in surveys.

“If we are collecting data that don’t reflect the data the population that we are collecting data from then what is the use and purpose of that data and what pictures do those data create?” **~ Dr.** [**Teddy Consolacion**](mailto:kim.mcgrail@ubc.ca)

Harlan also touched on the challenges of traditional data analysis, which often uses the majority group as a standard for comparison. This produces biased results and further reinforces the inequities in the system. The presenters advocated for reconciliation in research, focusing on creating new frameworks that honour Indigenous perspectives rather than simply deconstructing existing colonial structures. They talked about the concept of syndemic theory, which has existed in Indigenous communities since long before the scientific definition, as *Mitakuye Oyasin* (“All my relations”). This concept emphasizes interconnectedness and the need for Indigenous knowledge to be integrated into recognized Western health research practices. By collecting Two-Spirit data in a culturally safe way, researchers can set an example of data collection to promote more equitable health outcomes for all communities.

During the Q&A session, attendees raised the challenges faced by those identifying as Two-Spirit who did not grow up in their culture. The discussion highlighted the importance of culturally sensitive data collection and analysis, as well as the need to ensure that Indigenous identities and experiences are respected and accurately represented. The session also emphasized that building relationships, advocating for large-scale change, and creating safe spaces for open dialogue are essential for improving health equity and ensuring culturally safe health care.

[View the Two-Spirit Wellness & Health: Better Relations Through and By Data Management & Research session recording](https://www.youtube.com/watch?v=1_eVB7qcIt8)

# Implementing the Pan-Canadian Health Data Strategy: Public Assemblies, Involvement & Trust

Presenters:

**Dr. Kim McGrail**, CEO and Scientific Director, HDRN Canada

**Alies Maybee,** Patient partner | Co-founder, Patient Advisors Network

The session explored the current landscape of health data systems, emphasizing the importance of public involvement in shaping a trustworthy and equitable health data ecosystem. The discussion highlighted that not all uses of health data are equal, and how involving the public can guide policies on fair trade-offs. These concepts help make the system more open and inclusive.

Topic areas discussed included the [Pan-Canadian Health Data Strategy (PCHDS)](https://www.canada.ca/content/dam/phac-aspc/documents/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-03-toward-world-class-health-data-system/expert-advisory-group-report-03-toward-world-class-health-data-system.pdf), various methods of public engagement (PE) and patient involvement (PI), and the critical role of trust in these systems. In poll questions, attendees rated the transparency of data collection and usage as generally low to moderate, reflecting a broader issue of trust in health data systems. It was noted that data are essential for both individual care and understanding population health, but challenges arise when data are not organized effectively. This leads to issues like "binder medicine" where individuals become overly responsible for their own health data and have to carry around binders of their medical information for their various health care providers.

“Data reflect systems, and if the data are telling us things about inequalities and inequities in people’s experiences, it doesn’t mean we need to change the data, we actually need to change the systems in order to make change for people’s lives.” **~ Dr. Kim McGrail**

The session also discussed the importance of the [Health Data Charter](https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html) and its ten principles, which emphasize people-centricity and inclusion of diverse populations. Methods like the [IAP2 spectrum](https://cdn.ymaws.com/www.iap2.org/resource/resmgr/pillars/Spectrum_8.5x11_Print.pdf) and public deliberations were highlighted, with particular attention to the challenges of engagement in Canada. The discussion underscored the need for learning health systems (LHS) that continuously improve through learning, and are built to include everyone. It is important to involve a wider range of people in health research, especially because many feel left out of health care decisions.

During the question and answer period, differences between public and patient perspectives were highlighted, including the role of patient advocates in engaging with the health system. Attendees discussed the importance of deliberately choosing whether to engage people with lived experience or the general public, depending on the specific issues at hand. Questions also addressed the need for improved data literacy among policymakers and the importance of linking social data with health data to better address prevention and social determinants of health. The session emphasized that while trust in health data systems is currently moderate to low, enhancing transparency and public involvement can help rebuild this trust.

[View the Implementing the Pan-Canadian Health Data Strategy: Public Assemblies, Involvement & Trust session recording](https://www.youtube.com/watch?v=_Rdym4cFEYA)

# Public Expectations and the Use of Health Information in Research: Québec’s New Approach

#### Presenter: **Dr.** **Jean-Frédéric Ménard,** Groupe de recherché interdisciplinaire en informatique de la santé (GRIIS), Center for Research on Regulation and Governance Law at the University of Sherbrooke

Dr. Jean-Frédéric Ménard presented the research carried out by his team to understand the expectations of the Québec population on regulating health data. The presentation explored the implications of recent legislative changes in Québec, particularly focusing on the *Act Respecting Health and Social Services Information* adopted in 2023. The session highlighted the reforms within the Québec health care system and provided an in-depth analysis of public perspectives on data usage.

The discussion covered two key legislative pieces: Bill 3 and Bill 15.

* Bill 3 focuses on health and social service information, establishing a new framework for data sharing and use within the health care system.
* Bill 15 is aimed at making the health care system more efficient, highlighting the necessity of having a legal structure that supports the system's optimization.

Dr. Ménard discussed the importance of legal safeguards for individuals, emphasizing that each person holds rights over their health data, akin to human rights. This includes the right to control and consent to the use of their health information.

The research presented showed that 92 percent of Québec residents support the secondary use of their health data in research. However, this acceptability decreases when a medical director or other authority figure can consent on their behalf. Acceptability increases again if there is assurance that an ethics committee is involved in the process.

The concept of “meta consent” was also discussed. “Meta-consent” refers to a broad-based consent approach where individuals provide a more general form of consent that covers various uses of their health data. This approach could potentially increase public trust and the acceptability of health data use.

The session provided valuable insights into the expectations of the Québec population regarding health data regulation, particularly in the wake of recent legal reforms. The discussion emphasized the need for a balanced approach that respects individual rights while enabling the efficient use of health data to improve the Québec health care system. The research findings highlight the importance of ethical oversight and transparent consent processes to maintain public trust and support for data-driven health initiatives.

“The collection of health data [can be] a “double infringement” of personal rights… the individual is the holder of rights (their data), just like human rights” **~ Dr. Jean-Frédéric Ménard**

[View the Public expectations and the use of health information in research: Québec’s new approach session recording](https://www.youtube.com/watch?v=6byWk3zwzX8)

# Respect My Data! Strategies to Mitigate Harms of Data Use in Health Research

#### Presenters:

**Carrie-Anne Whyte**, Data Access Support Hub (DASH) Program Lead, HDRN Canada | Senior Analyst, Canadian Institute for Health Information

**Dr. Laura Bee**, HDRN Canada Inclusion, Diversity, Equity and Accessibility (IDEA) Team member | Data Equity Specialist, Manitoba Centre for Health Policy

In this session, Carrie-Anne Whyte and Dr. Laura Bee explored how complexities in health data can affect health equity. They focused on administrative health data and highlighted how ignoring biases in the data can lead to ongoing unfairness in health outcomes. Health data, particularly administrative data, is important for research, policy-making, and health care interventions. However, this data often lacks consent and input from the communities it represents. As a result, it only tends to represent individuals’ interactions with health care systems rather than their holistic health care experience, which can reinforce deficit-based narratives.

Health equity data, which includes social determinants of health such as age, education and race, plays a vital role in reducing disparities in health outcomes between different population groups. However, the ways in which data are collected and used can introduce bias. For instance, people from certain demographics may be disproportionately tested for issues like substance abuse, leading to skewed data that further marginalizes these groups. Alternatively, some populations may struggle to have their health concerns recognized in research, further increasing existing inequities.

Both presenters emphasized a need to reframe how research is conducted by focusing not only on improving overall outcomes but also on reducing inequities. This approach influences the design of health care interventions, ensuring they better align with the needs and desires of communities. An example given was the harm reduction approach to drug use, which emerged from the voices of affected communities.

A critical challenge in administrative data research is the lack of direct involvement from researchers in data collection. This makes it necessary to apply an equity lens to the analysis, ensuring that biases are addressed throughout the process. Misconceptions that “administrative data are objective” can lead to further harm, especially when data reinforce negative stereotypes or overlook important community experiences.

Dr. Bee underscored the importance of engaging communities at every stage of the data lifecycle—collection, analysis, dissemination and storage. Meaningful partnerships with stakeholders ensure that the data reflect the lived experiences of communities and reduce the risk of perpetuating inequities. Health care providers must also be trained to collect data empathetically and responsibly, with clear communication on how the information will be used and protected.

Safeguarding personal health information is essential. With data stewards across provinces and territories overseeing data use, researchers need ethics approval and partnerships with data holders to access datasets. The session emphasized that advancing health equity through data requires a shift in research approaches, meaningful community engagement, and reducing biases in data collection and analysis. Only through mutual trust, respect and reciprocity with communities can health research effectively address disparities while minimizing harm.

During the question and answer session, participants raised important questions about how large pan-Canadian organizations can adopt more equitable practices in their data collection and dissemination processes. There is a need for these organizations to engage in meaningful, two-way partnerships with communities and to incorporate community voices at all stages of research. Participants also discussed the importance of cultural safety within organizations, urging for accountability and the implementation of protocols that ground researchers in the humanity of the data they handle.

The challenge of integrating Indigenous data governance frameworks without overwhelming communities and ensuring that funding supports Indigenous data sovereignty effectively was also highlighted. The need for community engagement and inclusion of positive data outcomes was emphasized. Discussions also covered how large pan-Canadian organizations can model equitable research practices, highlighting the importance of collaboration, addressing power imbalances and using mixed methods for a fuller understanding of data. The session stressed the need for ongoing reflection and cultural safety in data work.

“Every time you go to do the work you have to take a grounding moment and think about the people that are in that data.” **~ Dr. Laura Bee**

[View the Respect my data! Strategies to mitigate harms of data use in health research session recording](https://www.youtube.com/watch?v=t4jp6bDU-go)

# What’s Mine is (Not) Yours

#### Presenter: **Dr. Donna Curtis-Maillet,** HDRN Canada Privacy Team Lead | Manager, Data Privacy Program, NB-Institute for Research Data and Training

This session explored the importance of privacy and data protection in health research, with a focus on personal health information (PHI) and how it is managed throughout its life cycle. Dr. Curtis-Maillet began by discussing the data life cycle, emphasizing that personal health information has a beginning and an end, from collection to disposal, and requires constant safeguarding. Various mechanisms, such as administrative, physical and technical safeguards, were discussed to ensure data protection at every stage. Privacy laws and fair information principles guide how data is collected, accessed, used and shared. Every piece of legislation on personal health information generally covers these key elements, although the exact definitions can vary.

She elaborated on the types of research that involve personal health information, such as clinical trials, observational studies and large cohort studies, explaining that health research inherently requires the use of personal health information. Therefore, privacy practices must be embedded in every research activity. Whether it is biological samples, interview data or large datasets, researchers must comply with privacy laws and consent must always be obtained. The distinction between general personal information and personal health information was highlighted, noting that health data often have stricter regulations due to their sensitivity.

Informed consent was a key theme, with Dr. Curtis-Maillet emphasizing that participants in health research have the right to understand what data are collected, how they will be used and how they will be protected. This includes the entire data life cycle—from collection to storage and eventual disposal. She also stressed that informed consent is not just a formality but a requirement to ensure participant autonomy and trust. Administrative data, such as health care records and social services information, are collected without explicit individual consent but are essential for large-scale population health studies. Access to such data is strictly regulated.

“Regardless of whether it is personal information, identifiable information, it has to be protected.” **~ Dr. Donna Curtis-Maillet**

Dr. Curtis-Maillet also discussed the challenges posed by new technologies and how they affect privacy protection. While legislation attempts to keep pace with technological advancements, it often falls short. She emphasized the importance of individuals becoming more mindful of their personal information and being cautious about sharing it through digital platforms.

During the question period, participants raised concerns about the ownership and sale of anonymized personal health data without explicit consent. Dr. Curtis-Maillet emphasized the need to respect individual ownership of health information. Questions also focused on the lack of trust from governments in sharing data for research, with suggestions for a stronger culture of data stewardship to address privacy law concerns.

A key issue raised was privacy in rare disease research, where the small size of study populations can make individuals easily identifiable. Collaborative efforts across regions to pool data can help ensure both privacy and research accuracy.

The session concluded with a discussion on the problem of mindless consent in the digital age, where people often give away personal information without understanding the implications. There is need for greater awareness and stronger legislative protections to ensure informed consent becomes the norm, not just a formality.

[View the What’s Mine is (Not) Yours session recording](https://www.youtube.com/watch?v=xvE9WNqPg68)

# Lost in Translation: The Importance of Trust in the Era of Big Data & AI

#### Moderator: **Rob Semeniuk,** HDRN Canada Public Advisory Council member

#### Panelists: **Dr. P. Alison Paprica**, Adjunct Professor and Senior Fellow, University of Toronto

#### **Dr. Andrew Pinto,** Founder and Director, Upstream Lab | Family Physician, St. Michael's Hospital

#### **Dr. Cécile Petitgand,** President and Founder, Data Lama

In this interactive panel discussion moderated by **Rob Semeniuk**, three panelists provided their perspectives on the complexities and ethical considerations surrounding the role of artificial intelligence (AI) in health care. The panelists explored how AI can enhance administrative efficiency and patient care. They also addressed significant concerns related to bias and moral decision-making, as well as the potential over-reliance on technology. The panelists were guided by the question: *“What is one thing that you trust AI to do with health data, and what is one thing that you do not trust AI to do with health data?”*

**Dr. Alison Paprica** began by emphasizing the need for AI to align with appropriate tasks, data and methods. She highlighted the benefits of AI in monitoring complex health conditions, such as congestive heart failure, where AI’s ability to detect complex patterns beyond human capacity is invaluable. However, she cautioned against using AI in areas like skin cancer detection, where the data often lacks diversity, leading to inaccuracies and potential harm to non-white patients.

**Dr. Andrew Pinto** supported the integration of AI in administrative tasks, provided there are strict assurances around privacy and confidentiality. He pointed out that AI can streamline processes like scheduling and form completion, improving efficiency in primary care. Yet, he expressed deep concerns about fully autonomous AI systems, such as counseling bots, which he believes could negatively impact both patients and the health care workforce due to past issues with misdirection and inadequate responses.

**Dr. Cécile Petitgand** reiterated the potential for AI to support health researchers in certain administrative tasks that can facilitate the research process. She also highlighted some of the benefits and pitfalls of generative AI tools, such as ChatGPT. She encouraged individuals to think critically about the results delivered by these generative tools and the data used to produce these results. At the same time, she also acknowledged that many people trust their health care providers’ recommendations without questioning how they made those decisions or the information they used.

When discussing AI's role in policy creation, the panelists agreed that AI could assist in analyzing and summarizing large volumes of existing policy data but should not be trusted to craft new policies on its own. They stressed the importance of using AI to complement human expertise, especially in complex tasks involving non-digitized records and multilingual data.

The conversation also explored AI's potential to address rare health care scenarios and improve pandemic preparedness. The panelists noted the advantages of AI in predicting patient outcomes and identifying early warning signs during pandemics. However, they warned of the risks associated with "model drift"—the gradual decline in AI model performance over time—and emphasized the need for continuous human oversight to ensure AI tools remain effective and unbiased.

##### “We always have to keep the human connection. The hope is that these tools help us focus our energy where it is needed, giving us back more time for the more human aspects of medicine.” **~ Dr. Andrew Pinto**

A recurring theme was the moral implications of AI in health care. Dr. Pinto raised concerns about AI systems being used to make critical decisions in areas such as criminal justice and health care resource allocation, where biases could lead to inequitable outcomes. All panelists agreed that AI should support, not replace, human decision-making in these sensitive areas.

The discussion concluded with a call for stronger regulatory frameworks to oversee AI in health care, ensuring that these technologies are implemented equitably and with a focus on reducing disparities. Dr. Paprica highlighted the risk that new technologies might exacerbate existing inequities if not carefully managed, particularly for marginalized groups who could benefit most from AI advancements.

[View the Lost in Translation: The Importance of Trust in the Era of Big Data & AI session recording](https://www.youtube.com/watch?v=hPfIV99RhQE&t=1s)

# Reflections & Looking Ahead

**Health Data for All of Us: Earning Trust through Transparency** provided an opportunity for patients, the public, community organizations and other interest-holders to come together to share their perspectives on ethical and equitable data practices, the role of cultural sensitivity in research and the impact of emerging technologies in health data research. The hybrid Forum fostered meaningful discussion among attendees from across Canada with diverse backgrounds and experiences.

Moving forward, HDRN Canada’s Public Engagement Working Group and Public Advisory Council commit to sharing key themes emerging from the Forum. The themes of **trust and transparency, health equity, ethical data management including AI use and integration, and public benefit and engagement** will be disseminated widely through various channels and to diverse audiences, including patients, the public, researchers and other key interest-holders.

The HDRN Canada Public Engagement Working Group and Public Advisory Council aim to turn these identified themes into actionable strategies, in collaboration with and seeking advice from other HDRN Canada Teams and Working Groups, including the Inclusion, Diversity, Equity and Accessibility (IDEA) Teamand the Indigenous Data Sovereignty Team. See Appendix A for relevant ongoing initiatives. We hope that these actions will enhance the integrity and inclusiveness of the health data ecosystem and to foster more meaningful and effective engagement with patients, the public and other interest-holders in health data.

## Health Data for All of Us: Key Themes & Reflections

**Public Involvement and Trust in Health Data Systems:** How can we improve public involvement and trust in health data systems to ensure that the data collection, sharing and use reflect diverse community needs and values?

**Equity and Inclusion in Health Data Research:** How can we provide the systems, support and capacity building to foster health data research that is conducted in a way that promotes equity and inclusion, especially for marginalized communities and populations historically underrepresented in research?

**Transparency and Ethical Use of Health Data:** How can we promote transparency and ethical practices in the collection, use and sharing of health data to build greater public confidence and support responsible data stewardship?

**Impact of AI and New Technologies on Health Data:** How can we conduct impactful discussions on the challenges and opportunities presented by AI and emerging technologies in health data research, and using these technologies responsibly and equitably?

# Appendix A

HDRN Canada’s ongoing initiatives and actionable strategies to address the identified themes and reflections

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| --- | --- |
| **Theme** | **Ongoing Initiatives / Action Items** |
| **Public involvement and trust in health data systems**– improving PI and trust in health data systems to inform practices of data collection, sharing and use to reflect diverse community needs and values  the screen reader loses count and can’t provide helpful information about the table after that point. | * HDRN Canada Public Engagement Working Group involved in the network’s IDEA strategy planning, specifically around building trust and reciprocity with community groups * Ongoing consultation with the network’s Public Advisory Council in all HDRN Canada initiatives * Development of foundational material on principles of public trust and data literacy |
| **Equity and inclusion in health data research**– providing the systems, support, and capacity building to foster health data research that is conducted in a way that promotes equity and inclusion, especially for marginalized communities and populations historically underrepresented in research | * HDRN Canada Public Engagement Working Group involved in the network’s IDEA strategy planning, specifically around building trust and reciprocity with community groups |
| **Transparency and ethical use of health data**– promoting transparency and ethical practices in the collection, use and sharing of health data to build greater public confidence and supporting responsible data stewardship | * Plain language communication around health data use – development of a glossary of health data related terms for the public by the network’s Public Advisory Council * Development of foundational material on principles of public trust and data literacy |
| **Impact of AI and new technologies on health data**– conduct impactful discussions on the challenges and opportunities presented by AI and emerging technologies in health data research, and using these technologies responsibly and equitably | * Planning for HDRN Canada’s Public Forum 2025 *Health Data for All of Us: A Public Dialogue on the Role of AI in Health*– aim to facilitate public dialogue on the key issues and impacts of artificial intelligence and emerging technologies |