

HDRN Canada

Strategic Plan

2021-2026



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

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A Message from our Scientific Director & CEO

It is my pleasure to share this update to our **Health Data Research Network Canada (HDRN Canada) Strategic Plan 2021-2026**. This plan describes our vision, mission, values and strategic goals and how we will achieve those goals. We updated it to reflect the outcomes of a year-long consultation process around inclusion, diversity, equity and accessibility.

We originally developed this strategic plan during the most pointed phases of the COVID-19 pandemic, at a time when health data was a frequent topic of conversation, including among the public. While the challenges and opportunities related to multi-regional research have preoccupied our member organizations for some time, they became and continue to be, top of mind for policy-makers, communities and members of the public. The need for data to support health and health equity remains apparent and pressing. The gaps in our current systems are equally obvious, including not having data that could help identify and address inequities, not having needed structures to support community involvement in data use and a long road on our commitments to reconciliation and Indigenous data sovereignty.

We developed this strategic plan collectively with our member organizations, advisory committee and partners, along with guidance and direction from our Leads Team, Executive Committee, Public Advisory Council and Board of Directors. Throughout the strategic planning process, we heard about the opportunities for and potential of multi-regional data use and how HDRN Canada can help achieve this broad shared vision.

We see HDRN Canada as a collaborative learning network. This means having an inward focus for sharing current practices and continuous learning across our data- and community-focused network organizations. Our collaborations are also external since we understand that HDRN Canada is part of a larger health data ecosystem and that our success is inherently intertwined with the success of other networks and platforms. Our five Strategic Goals reflect this dual focus and will help us prioritize our areas of work in the coming years:

- Develop and Improve Services and Supports for Data Access.
- Diversify and Harmonize Data and Support Innovative and Privacy-Sensitive Data Use.
- Establish and Strengthen Partnerships and Provide Leadership for Evolving Data Practices.
- Strengthen Data Use to Improve Equity and Support Indigenous-led Data Sovereignty.
- Ensure Purposeful and Ongoing Public and Community Involvement.

Our commitments to collaboration and sustainability stem directly from our awareness that relationships are critical to our success. We look forward to working with others on areas of common and collective interest.



KIM MCGRAIL
Scientific Director & CEO

Our Story

We started in 2015 when leaders of provincial, territorial and multi-regional organizations began working together as the Pan-Canadian Real-World Health Data Network (PRHDN). We established this network recognizing both the strengths of our individual organizations and the barriers facing researchers interested in multi-regional research. We believed that we could work together to strengthen our existing connections and create new ones to enable the best use of the impressive data resources and analytic capabilities across the network.

In 2019, we began working more formally with the support of funding through a seven-year grant to build and operate the Strategy for Patient-Oriented Research (SPOR) Canadian Data Platform. The SPOR Canadian Data Platform, funded by

the Canadian Institutes for Health Research and in-kind contributions from partners, is focused on enabling high-quality, innovative and multi-regional research. With this funding in place, we renamed ourselves Health Data Research Network Canada (HDRN Canada) and incorporated as a not-for-profit entity in early 2020. HDRN Canada is a distributed network of people and partner organizations working together to help Canada derive more—and more equitable—public benefits from data, beginning with creating the SPOR Canadian Data Platform.

We are also intentionally working to better support inclusion, diversity, equity and accessibility (IDEA) through data use and supporting Indigenous-led data governance priorities that advance First Nations, Inuit, and Métis data sovereignty.

Who We Are

We are a distributed network of organizations and people who come together with common objectives related to data and multi-regional research. Our network includes clinicians, decision-makers, members of the public and researchers from across Canada. Today, our members include provincial, territorial and multi-regional organizations that hold health and health-related data for entire populations.

Notes on the Text

We strive to be careful, thoughtful and deliberate in our word choices throughout this document. Below are **key terms** used in the document and the explanation for choosing them.

MULTI-REGIONAL

Data use is subject to laws and policies of our network organizations and partners. When we refer to “data use” it is always in that context and does not imply data all being in one location.

MULTI-REGIONAL DATA USE

HDRN Canada focuses on research that spans multiple areas or partners in Canada. We wished to find a term that would include and be acceptable to provinces, territories, pan-Canadian organizations and Indigenous communities.

INDIGENOUS DATA SOVEREIGNTY

The right of Indigenous nations to govern the collection, application and ownership of Indigenous data.

PUBLIC

We use the word “public” rather than the more limiting “patient” or “citizen”. People who are “patients” are clearly members of the public; “patient” suggests a more limited, though very important, perspective. “Citizen” excludes people who are temporary residents, permanent residents and refugee claimants.

IDEA

There are a number of variations on acronyms related to equity, diversity and inclusion. We chose IDEA to reflect the importance of including “accessibility” and to differentiate this work from its origins in human resources practices, specifically related to hiring. That focus is important but incomplete for our purposes.

Our Members



What We Do

We work within our network and with partners outside HDRN Canada to support innovation in the use of data. Our focus is on multi-regional data use, recognizing that Canada's status as a federation, existing legislation, evolving relationships with Indigenous nations and long-standing practices all contribute to challenges with data sharing. These challenges are also opportunities for shared learning and new approaches to supporting the use of data that may not all reside in a single location.

Our commitments include respecting local policies and processes, leveraging our knowledge and assets and learning from each other.

We bring together multiple stakeholders with similar ambitions and respond to priorities from our partners, researchers, policy-makers and the public. We are building the SPOR Canadian Data Platform, including the Data Access Support Hub, or DASH, which is the entry point to that platform. We approach our work in ways that are both socially responsible and ethical, guided by public input and priorities, by our commitments to inclusion, diversity, equity and accessibility, and by a commitment to support First Nations, Inuit and Métis data sovereignty. Our ambition is to shape a data future that better supports health and health equity.

Our Strategic Framework

Vision

Data across Canada drive improvements in health and health equity.

Values

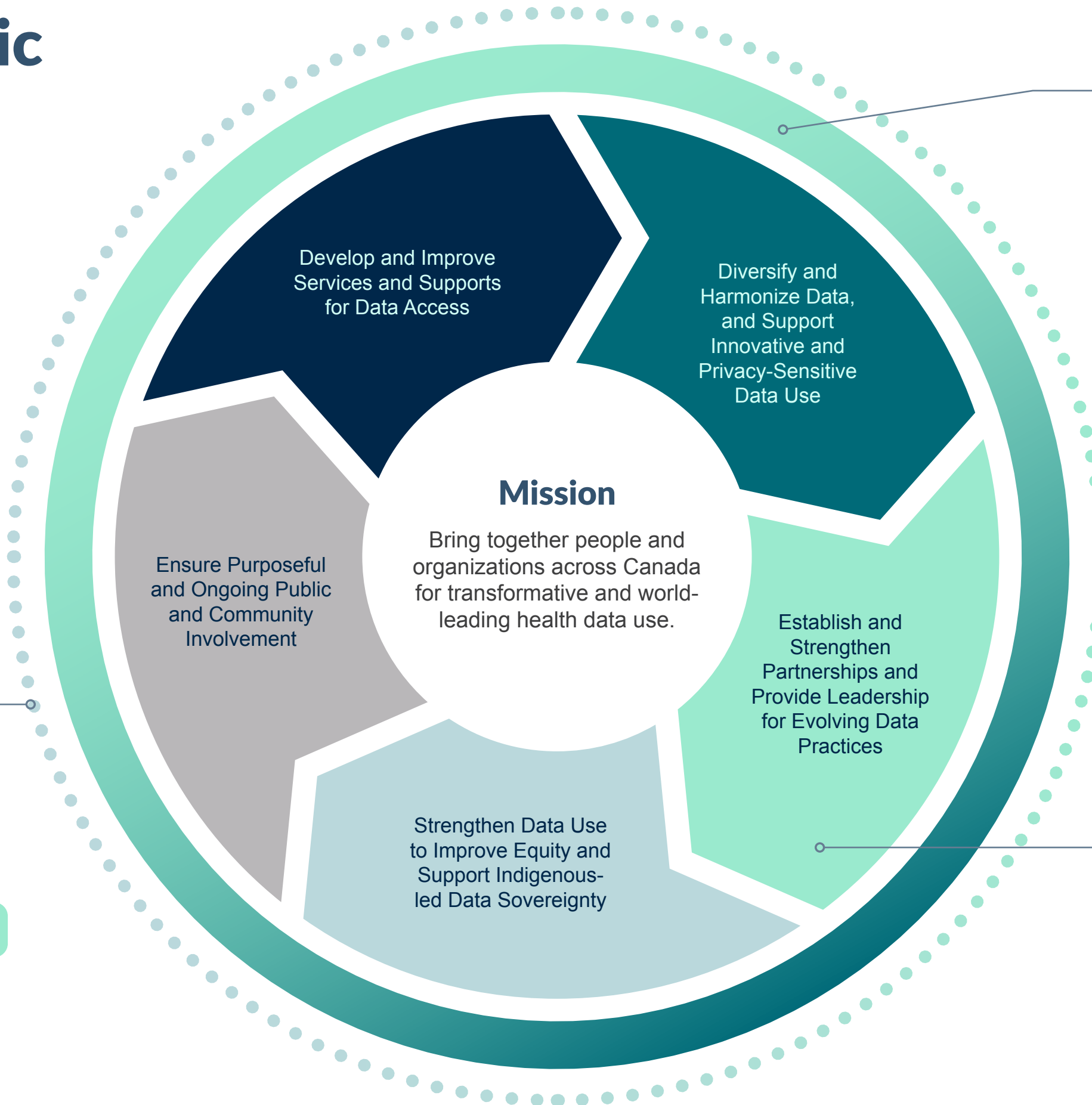
COLLABORATION

TRUST

CREATIVITY

EXCELLENCE

RESPECT



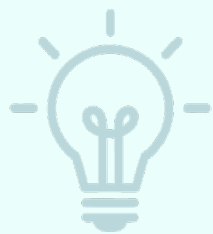
Success Factors

- Cohesive Network with Effective and Sustainable Operations
- Supportive and Engaged Legislative and Policy Ecosystem and Community of Data Users

Strategic Goals

Our Mission & Vision

We see a future where people in Canada derive health benefits from greater and more equitable use of data. Our mission speaks to our role as a distributed network in achieving this vision related to data and multi-regional data use.



Our vision is that:

Data across Canada drive improvements in health and health equity.



Our mission is to:

Bring together people and organizations across Canada for transformative and world-leading health data use.

Our Values

Our work is grounded in five core values that are informed by best practices in inclusion, diversity, equity and accessibility (IDEA) as well as by commitments to Indigenous-led research practices and Indigenous-led data sovereignty. We are a large, distributed network of member organizations and our values exemplify how we will continue to build on our collective strengths and experiences. They guide how we plan, act and engage with our partners and each other and work together towards our shared goals. **Our values are:**



COLLABORATION



TRUST



CREATIVITY



EXCELLENCE



RESPECT

Collaboration

We support equity in participation from all HDRN Canada partners. We embrace working openly and transparently with internal and external partners to find common ground, negotiate terms and co-determine our collective path towards accomplishing our stated goals.

Trust

We are transparent in our practices and hold ourselves accountable to our many stakeholders. We strive to earn and maintain the trust of our internal network organizations, our external partners, Indigenous communities, stakeholders and members of the public. All of them have a vested interest in the work we do.

Creativity

We are innovative, open-minded and responsive to our changing environments. We learn from our experiences and are willing to take informed risks. We develop novel solutions to long-standing challenges.

Excellence

We align our work with and also help develop leading worldwide data practices. We provide data-related services that are timely, responsive and efficient.

Respect

We value, support and protect the rights, perspectives and interests of the diverse regions, communities and populations across Canada.

Our Strategic Goals

We have five strategic goals and two success factors that align with our vision, mission and values. These goals and success factors are interconnected and we view all as equally important to achieving our mission and realizing our vision. Supporting Indigenous-led data sovereignty, for example, informs our approach to developing and improving data access supports and services while being a focus in its own right.

Our five Strategic Goals prioritize our focus areas and actions for the coming years:

- Develop and Improve Services and Supports for Data Access
- Diversify and Harmonize Data and Support Innovative and Privacy-Sensitive Data Use
- Establish and Strengthen Partnerships and Provide Leadership for Evolving Data Practices
- Strengthen Data Use to Improve Equity, and Support Indigenous-led Data Sovereignty
- Ensure Purposeful and Ongoing Public and Community Involvement

Our two Success Factors are what ground us to ensure that, as a network, we can achieve our mission and strategic goals and realize our vision:

- Cohesive Network with Effective and Sustainable Operations
- Supportive and Engaged Legislative and Policy Ecosystem and Community of Data Users

Develop and Improve Services and Supports for Data Access

There are numerous challenges to accessing and using data for multi-regional analyses. Data users in Canada often opt for using data from a single region or jurisdiction for their analysis, missing the potential of leveraging assets that, when used together, would offer multi-regional population-wide health perspectives and findings. A key strategic goal for HDRN Canada is, where possible, to enhance data access processes by providing insights into available data, streamlining delivery of data and facilitating access to trusted research environments for distributed analyses.

For HDRN Canada, this means we will:

- Develop and make available catalogues of datasets, algorithms and other resources that facilitate data use.
- Provide end-to-end support to researchers and other data users for multi-regional data requests.
- Streamline and automate processes for data access.
- Communicate appropriate expectations for access to and use of data that are sensitive to and/or consistent with rights and responsibilities.
- Disseminate resources that guide and enhance researchers' capacity to consider and integrate IDEA into multi-regional research, including engagement with communities and clearly connecting the purpose of research to equity.
- Develop use cases and facilitate discussions for implementing IDEA in data research.

Expected outcome:

More data users will gain timelier access to a broad range of data that they can use with confidence and respect for the communities those data represent.

Action we will take to achieve this:

Operate the Data Access Support Hub (DASH) that tangibly supports navigation of multi-region requests.

Diversify and Harmonize Data, and Support Innovative and Privacy-Sensitive Data Use

A variety of sources and types of data are related to health. We are committed to expanding available data, particularly those that can be linked to foundational population-based data holdings in our network members. Data that come from different places are often collected to represent similar services or experiences (e.g., data about visits with physicians or about residents in nursing homes) but are different in how they are collected. Data may also vary in what they include (e.g., because of policies about who is eligible for a service) and what they exclude (e.g., missing meaningful information such as race or gender identity).

We catalogue and develop validated measures and document algorithms to produce harmonized—or comparable—data across regions. Because data cannot always be accessed and used in a single location or a single trusted environment, we will provide training and technical supports for robust distributed statistical analysis.

For HDRN Canada, this means we will:

- Expand data available for request, including clinical, social and other health-related data.
- Work in partnership with communities to develop safer approaches for acquisition and expansion of data assets related to social and structural determinants of health to strengthen disaggregated research and address health inequities.
- Harmonize data for priority analytic variables and create standardized terminology to assist with both data requests and data use.
- Provide training and other supports to researchers for advanced distributed analytics.
- Share leading practices with data research communities across Canada and be responsive to their needs.

Expected outcome:

Increased adoption of leading methodologies, tools and techniques to support high-quality, cutting-edge data use that improves health outcomes for all.

Action we will take to achieve this:

- Create, maintain and expand an inventory of datasets and harmonized measurement tools to support multi-regional data use.
- Develop and share knowledge of approaches to distributed analytics and create technical infrastructure for that.
- Perform data audits, including identifying what data are collected and where they are collected and advocating to address data gaps within different jurisdictions.
- Establish a format for data biographies.

Establish and Strengthen Partnerships and Provide Leadership for Evolving Data Practices

We recognize that partnerships are essential for achieving our objectives. No single organization has all the data. No single organization or network can solve all the legal, policy, ethical and technological challenges that evolve with new capabilities, demands and ambitions. A key strategic goal for HDRN Canada is to establish and strengthen partnerships that align work toward a collective vision. We will provide leadership in understanding and responding to data-related opportunities, capabilities and interests as those continue to evolve.

For HDRN Canada, this means we will:

- Establish and maintain a collaborative culture with our partners and stakeholders.
- Be a key point of contact for international collaborators and organizations seeking to partner on multi-regional data use.
- Develop ways of expanding data access while respecting local organizational policies.
- Use network expertise to understand common challenges and opportunities (e.g., current legislation, privacy practices).
- Share that expertise in the form of policy briefs, recommendations and best practice documents.
- Review policies to identify barriers to inclusive, diverse, equitable and accessible data access.

Expected outcome:

Data users, sector organizations, governments and international partners will work together to improve policies and advance data practices that improve health equity and health outcomes.

Action we will take to achieve this:

- Develop supports and appropriate privacy and compliance guidance that enables collaboration.
- Help shape data practices that reflect the expectations of stakeholders.
- Develop and support the Health Data Research Alliance.

Strengthen Data Use to Improve Equity and Support Indigenous-led Data Sovereignty

We recognize that advancing equity as well as human rights and Indigenous rights means creating a network and data structures conducive to the principles of IDEA and rights to Indigenous data sovereignty. Doing so will create opportunities for innovation and change that can address existing inequities in health and health data research. The work we do will safely and respectfully reduce barriers to access data, promote greater diversity and inclusion in data research and ensure equity is considered in both the content of the research and in how it is conducted. Promoting reconciliation with Indigenous Peoples and Indigenous-led approaches to Indigenous data sovereignty are important priorities within this, including supporting Indigenous-led data initiatives that advance the unique and inherent rights of Indigenous nations.

For HDRN Canada, this means we will:

- Promote learning and unlearning about histories of oppression as they are related to the collection and use of health data, cultural safety and humility and diversity within Canada.
- Advance excellence in research by promoting research practices that are IDEA-informed and respect Indigenous data sovereignty.
- Build trust and reciprocity with diverse members of the public including but not

limited to Indigenous Peoples, people with diverse racial and ethnic backgrounds, people with disabilities and people with different gender identities.

- Provide leadership and advocacy to champion emerging practices in the data ecosystem, working with other organizations to improve health data research and health equity.
- Advocate for data use standards that exceed legal requirements, especially as it relates to disaggregated data and Indigenous data, resulting in data use that promotes equity and protects systemically marginalized populations.
- Advance and prioritize Indigenous-led data sovereignty initiatives First Nations, Inuit and Metis Peoples in Canada.
- Recognize the unique opportunity to ensure individuals and groups working to advance both IDEA and Indigenous-led data sovereignty learn from one another and identify common and unique needs and strategies.

Expected outcome:

A network that makes continual progress toward centring and prioritizing governance requirements of Indigenous-led data sovereignty and the principles of IDEA.

Action we will take to achieve this:

- Support internal and external learning opportunities, including the IDEA Community of Practice, the Indigenous Data Learning Group and the Big IDEAs About Health Data Speaker Series.
- Develop an internal process so that all infrastructure created and supported by HDRN Canada considers IDEA and diverse public voices.
- Support Indigenous-led data sovereignty.
- Work with Indigenous communities to identify community-led research questions that can be answered collaboratively.



Ensure Purposeful and Ongoing Public and Community Involvement

Everything we do as a network is to benefit people in Canada through data use that leads to better health outcomes, greater health equity and more robust health systems. We recognize that the public must play an essential role in informing our work. A key strategic goal for HDRN Canada is to increase community and public influence on data systems.

For HDRN Canada, this means we will:

- Have purposeful involvement with the public, communities and various organizations to inform our work and goals.
- Keep track of this involvement and make public its impact on HDRN Canada priorities, policies and activities.
- Ask for and address questions from the public and from communities about how their privacy is protected, how data about them are used and whether and where they can control or influence how data about them are used.

Expected outcome:

Individuals and communities interested in or affected by our work are engaged in meaningful dialogue. Their input is incorporated (in ways they can see and understand) in our decision-making processes and both those decisions and research results are communicated back to them.

Action we will take to achieve this:

- Establish the HDRN Canada Public Advisory Council (PAC) and provide multiple mechanisms for the PAC's advice to inform HDRN Canada decisions.
- Develop and deliver an HDRN Canada Public Engagement Plan to ensure strategic coordination of multiple projects that have deep involvement of members of the public.
- Identify and develop partnerships with national organizations that represent diverse populations.
- Establish a matrix for deciding when community engagement is critical to internal initiatives.
- Develop a guidance document for researchers that outlines best practices for engaging community partners in multi-regional data research.

Cohesive Network with Effective and Sustainable Operations

Our shared purpose and principled approach to work are key ingredients for a cohesive network. Our collective scientific knowledge and expertise are critical for advancing multi-regional data practices and data use. As an incorporated not-for-profit organization, we understand that to achieve our shared vision and objectives, we need to operate effectively and sustainably.

For HDRN Canada, this means we will:

- Adopt rigorous, efficient and effective operational practices.
- Live up to our values and principles, including equity among network organizations.
- Develop an institutional culture that supports and empowers Indigenous data governance strategies and IDEA by encouraging people to develop skills and expertise in these areas.
- Work as a cohesive team with clear roles and accountabilities.
- Attract, develop and retain expert leaders and staff with appropriate capabilities and expertise.
- Collaborate with our member organizations to advance dialogue on data use and practices.
- Develop HDRN Canada-specific IDEA learning goals and outcomes, both at the organizational level and at the Team level.

Expected outcome:

Our expected outcome is to continue being a cohesive network of member organizations across Canada advancing multi-regional health data use as a permanent part of the ecosystem. We will do this efficiently and with an ongoing commitment to our core values.

Action we will take to achieve this:

- Enhance coordination and information-sharing amongst Teams.
- Create a talent growth and retention plan.
- Strengthen knowledge-sharing opportunities with member organizations.
- Provide cultural safety training and invest in "train the trainer" opportunities for staff across Teams to help foster change across the network.

Supportive and Engaged Legislative and Policy Ecosystem and Community of Data Users

We recognize that while we aim to shape the evolving data ecosystem, the existing system also shapes and constrains our activities. Our effectiveness will depend on an environment that is supportive of our role in it.



For HDRN Canada, this means we will:

- Identify areas that require modernization of policy or process to support the success of HDRN Canada and other initiatives, organizations and networks.
- Find common cause with other networks and organizations in the pursuit of foundational system change, including change that helps realize the principles of IDEA and Indigenous-led data sovereignty.

Expected outcome:

Encourage an innovative and collaborative data ecosystem in which all work together to realize a shared vision.

Action we will take to achieve this:

- Communicate clearly and candidly about our activities, including their rationale and intended impact.
- Create mechanisms that invite and facilitate responses to comment and feedback from all of our partners and stakeholders.