

Health Data Research Network Canada

Strategic Plan 2021–2026



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



Land Acknowledgement

We acknowledge that the activities of Health Data Research Network Canada are taking place on the traditional, ancestral, and unceded territories of First Nations, Inuit, and Métis Peoples across Canada.

Our commitment to advancing Indigenous rights and interests informs all aspects of this strategic plan and its related activities.

Contents

A Message from our Scientific Director and CEO	4	Strategic Goals	
Notes on the text.....	5	Develop and Improve Services and Supports for Data Access	12
Our Story	5	Diversify and Harmonize Data, and Support Innovative and	
Who We Are.....	5	Privacy-Sensitive Data Use.....	13
What We Do.....	7	Establish and Strengthen Partnerships, and Provide Leadership	
Our Strategic Framework.....	8	for Evolving Data Practices	14
Our Vision and Mission	9	Strengthen Data Use to Improve Equity, and Support	
Our Values	10	Indigenous-led Data Sovereignty	15
Our Strategic Goals And Success Factors	11	Ensure Purposeful and Ongoing Public and Community Involvement	16
		Success Factors	
		Cohesive Network with Effective and Sustainable Operations	17
		Supportive and Engaged Legislative and Policy Ecosystem	
		and Community of Data Users	18

A Message from our Scientific Director and CEO

It is my pleasure to share the Health Data Research Network Canada (HDRN Canada) strategic five-year plan for 2021 to 2026. This plan describes our vision, mission, values, and strategic goals and how we will achieve those goals.

We worked on this strategic plan during an extraordinary time. The COVID-19 pandemic affected how we developed this plan and continues to shape the context in which we are working. While the challenges and opportunities related to data and multi-regional research have been front and centre for our member organizations for some time, they are now also top of mind for policy-makers, communities, and members of the public. The need for data to support health and health equity is now far more apparent and pressing. The gaps in our current systems are equally obvious, including not having data that could help identify and address inequities and not having needed structures to support community involvement in data use and to achieve Indigenous data sovereignty.

We developed this strategic plan with input from our member organizations, working groups, advisory committee and partners and 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 about the ways HDRN Canada can help achieve this broad collective vision.

We see HDRN Canada as a collaborative 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 ecosystem and that our success is inherently intertwined with the success of other networks and platforms. Our five Strategic Goals – *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; and Ensure Purposeful and Ongoing Public and Community Involvement* – reflect this dual focus and will help us prioritize our areas of work in the coming years. Our commitment to collaboration and sustainability stems directly from our awareness that relationships are critical to our success.

As Scientific Director and CEO for HDRN Canada, I am excited to see our network members drawing from their collective experiences to articulate this vision. We look forward to seeing the outputs and outcomes of our work over the coming years.



Kim McGrail, Scientific Director and 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 were fortunate to begin 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, in early 2020, incorporated as a not-for-profit entity. 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 actively 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.

HDRN Canada is supported by CIHR's Strategy for Patient-Oriented Research (SPOR) and by federal, provincial, and territorial partners.



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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

HDRN Canada is focused 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.

Multi-regional data use

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.

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.

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 or viewpoint. "Citizen," on the other hand, excludes people who are temporary residents, permanent residents and refugee claimants.

Indigenous Data Sovereignty

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

Member Organizations





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.

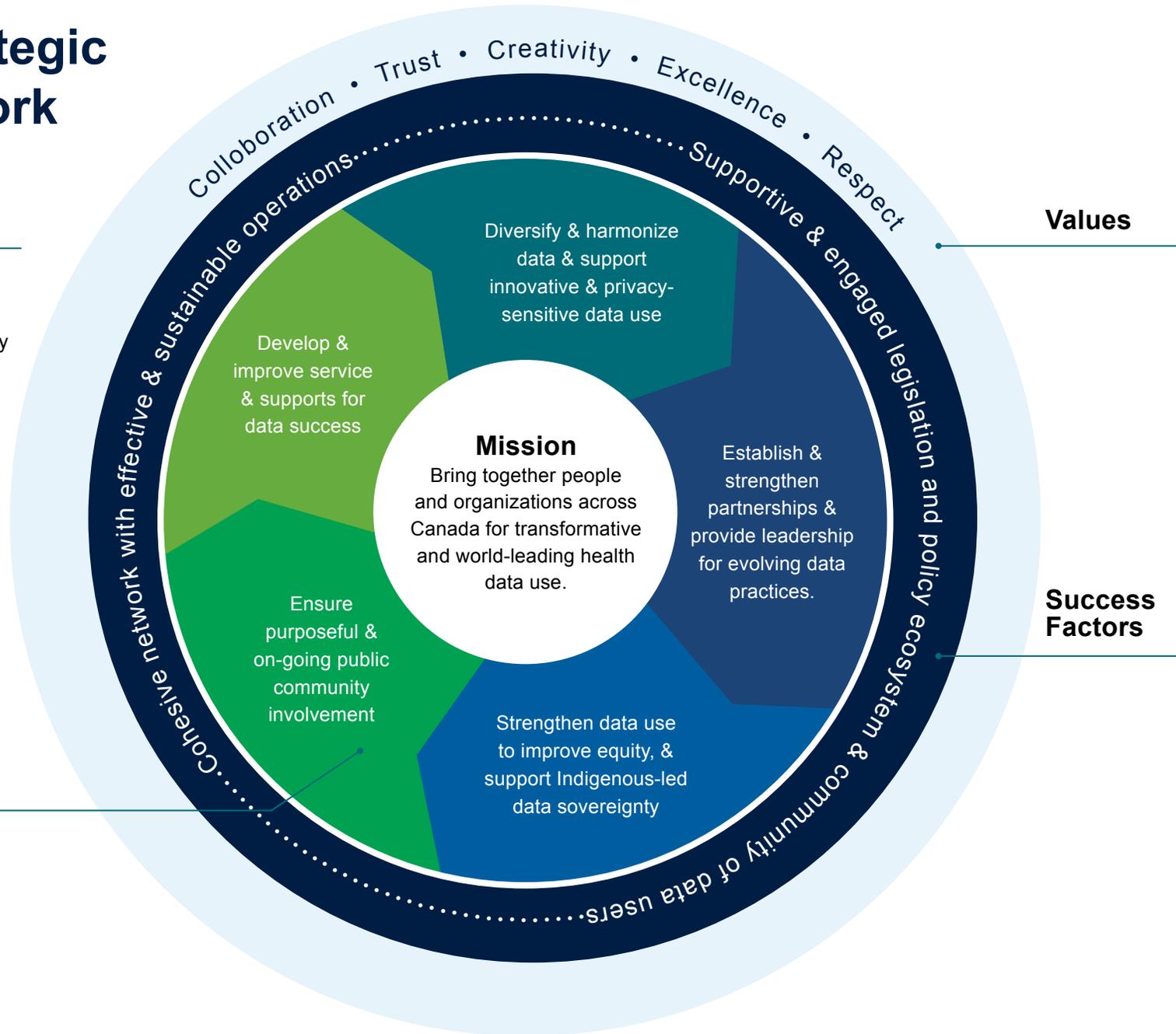
Our commitments include respecting local policies and processes, leveraging our knowledge and assets, and learning from each other. We bring together multiple stakeholders with similar ambitions and respond to priorities from our partners, researchers, policy-makers, and the public. We are developing the SPOR Canadian Data Platform, including the Data Access Support Hub, or DASH, which is the entry point to that platform. We are approaching our work in ways that are both socially responsible and ethical. Our work is 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

Strategic Goals





Our Vision and Mission

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, engage with our partners and each other, and work together towards our shared goals.

Our values are:

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 and Success Factors

We have five strategic goals and two success factors that align with our vision, mission, and values. These goals and success factors are all 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 and is, as well, 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



Strategic Goal – 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, which misses 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; and
- Communicate appropriate expectations for access to and use of data that are sensitive to and/or consistent with rights and responsibilities.

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.

Strategic Goal – 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 organizations. 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;
- 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; and
- Share leading practices with data research communities across Canada and be responsive to their needs.

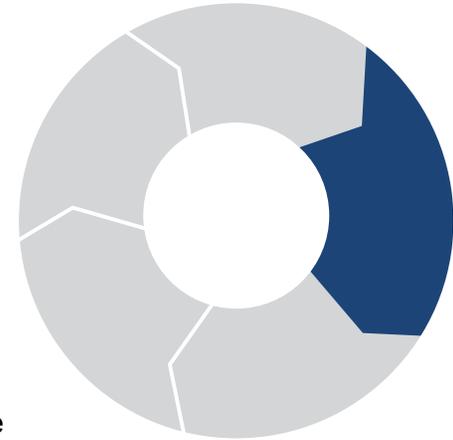
Expected outcome:

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 data sets and harmonized measurement tools to support multi-regional data use; and
- Develop and share knowledge of approaches to distributed analytics, and create technical infrastructure for that.

Strategic Goal – 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 also 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); and
- Share that expertise in the form of policy briefs, recommendations, and best practice documents.

Expected outcome:

Data users, sector organizations, governments, and international partners will work together to improve policies and advance data practices that ultimately improve 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; and
- Develop and support the Canada Health Data Research Alliance.

Strategic Goal – Strengthen Data Use to Improve Equity, and Support Indigenous-led Data Sovereignty

We recognize that advancing equity as well as human and Indigenous-specific rights means creating data structures conducive to both the principles of IDEA and rights to Indigenous data sovereignty. Doing so will create opportunities for innovation and change that can address existing inequalities in health. The work we do will support anti-racism and anti-oppression of all people. Promoting both 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 understanding of, and advance excellence in, Indigenous-informed and IDEA-informed research;
- Advance and prioritize Indigenous-led Data Sovereignty initiatives of First Nations, Inuit, and Métis People 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;
- Contribute to data-related collaborative and trust-building efforts with diverse members of the public including (but not limited to) Indigenous Peoples, people with different racial and ethnic backgrounds, people with disabilities, and people with different gender identities; and
- Ensure that the commitments to IDEA and Indigenous Data Sovereignty are evident in the choice of HDRN projects and in the process of making those choices.

Expected outcome:

A network that makes steady progress toward meeting the governance requirements of Indigenous-led Data Sovereignty and the principles of IDEA.

Action we will take to achieve this:

- Provide and point to resources for learning about respectful practices that promote data for equity and Indigenous Data Sovereignty;
- Develop and deliver HDRN Canada's Indigenous Data Team Strategy;
- Develop and deliver HDRN Canada's IDEA strategy; and
- Support Indigenous-led data sovereignty.

Strategic Goal – 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 the work we do. 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 priorities, policies, and activities; and
- 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 Public Advisory Council (PAC) and provide multiple mechanisms for the PAC's advice to inform HDRN Canada decisions; and
- 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.

Success Factor – 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 a newly incorporated Not-For-Profit organization, we understand that to achieve our shared vision and objectives, we will need to operate effectively and with a commitment to sustainability.



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 inclusivity, diversity, equity, and accessibility (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; and
- Collaborate with our member organizations to advance the dialogue on data use and practices.

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 working groups and teams;
- Create a talent growth and retention plan; and
- Strengthen knowledge-sharing opportunities with member organizations.

Success Factor – 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; and
- 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; and
- Create mechanisms that invite and facilitate responses to comment and feedback from all of our partners and stakeholders.





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