

A Path Forward

Toward Respectful Governance of First Nations, Inuit and Métis Data Housed at CIHI

Updated August 2020

We acknowledge and respect the land on which CIHI offices are located. Ottawa is the traditional unceded territory of the Algonquin nation and Toronto is the traditional territory of the Wendat, the Anishinabek Nation, the Haudenosaunee Confederacy and the Treaty land and territory of the Mississaugas of the Credit. We acknowledge with respect the traditional territory of the Kanien'kehá:ka, where our Montréal office is located. In Victoria, we acknowledge with respect the traditional territory of the Songhees, Esquimalt and WSÁNEĆ peoples, whose historical relationships with the land continue to this day. We recognize that these lands are home to many diverse First Nations, Inuit and Métis and we embrace the opportunity to work more closely together.



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About CIHI

The Canadian Institute for Health Information (CIHI) is an independent, not-for-profit organization that provides essential information on Canada's health systems and the health of Canadians.

We provide comparable and actionable data and information that are used to accelerate improvements in health care, health system performance and population health across Canada. We protect the privacy of Canadians by ensuring the confidentiality, security and integrity of the health care information we provide.

CIHI is a federally incorporated not-for-profit corporation. As such, records held by CIHI are not subject to the federal *Access to Information Act* and provincial and territorial freedom of information legislation.

Our broad range of health system databases, measurements and standards, together with our evidence-based reports and analyses, support decision-making processes across Canada.



First Nations, Inuit and Métis health and CIHI

CIHI recognizes First Nations, Inuit and Métis health and wellness as a priority, as reflected in our strategic plan for 2016 to 2021. CIHI is developing relationships and partnerships with First Nations, Inuit and Métis to support their health data priorities and their pursuit of health and wellness. We acknowledge that CIHI is on a learning journey, and we are guided by what we continue to learn through engagement with Indigenous individuals, communities and organizations. We also endeavour to respect the values, principles and calls to action laid out in the Truth and Reconciliation Commission's report¹ and the United Nations Declaration on the Rights of Indigenous Peoples.²

CIHI's approach to contributing to First Nations, Inuit and Métis health and wellness

- **Develop foundational capacity within CIHI** by embedding cultural responsiveness within the organization. This includes training and processes to promote cultural safety and humility.
- **Build relationships and partnerships** locally, regionally and nationally with First Nations, Inuit and Métis to identify opportunities to work together in pursuit of Indigenous health and wellness.
- **Develop a respectful approach to the governance of First Nations, Inuit and Métis data housed at CIHI** by working to align policies, practices and procedures with Indigenous data sovereignty principles.
- **Enable actionable analyses and capacity-building** by working in collaboration to support First Nations, Inuit and Métis health and wellness priorities through relevant analyses, products, services, training, data infrastructure and tools.

Developing a respectful approach to the governance of First Nations, Inuit and Métis data at CIHI

CIHI's approach to contributing to First Nations, Inuit and Métis health and wellness is grounded in what we are learning about Indigenous data sovereignty and Indigenous data governance. This paper outlines some of the work that CIHI is doing to move toward aligning our organizational policies and procedures with principles of Indigenous data sovereignty.

We are working to apply what we are learning to our internal data governance practices, including processes for data collection, analysis, interpretation and disclosure. This work is intended to facilitate appropriate use of First Nations, Inuit and Métis data and information held at CIHI and to reduce the risks and potential harms of inappropriate use and disclosure. This work is in a developmental stage, particularly as it relates to legacy databases and reporting tools, which include data collected without the benefit of involvement of First Nations, Inuit and Métis. We look forward to further engagement with Indigenous peoples, communities and organizations to improve our practices and identify opportunities to support appropriate use of First Nations, Inuit and Métis data held at CIHI.

Understanding Indigenous data sovereignty

As part of our learning journey, we are developing an understanding of Indigenous data sovereignty principles, such as the First Nations principles of OCAP®,^{i, 3} Manitoba Métis principles of OCAS^{ii, 4, 5} and Inuit Qaujimajatuqangit.⁶ We have learned that these principles reflect “the right of Indigenous Peoples to control data from and about their communities and lands, articulating both individual and collective rights to data access and privacy.”⁷ We understand that Indigenous data sovereignty represents the right of each nation to govern the collection, ownership and application of its data, regardless of where that data is housed.

Guiding principles

- **The inherent right to self-determination** of First Nations, Inuit and Métis reflects their right to freely determine their political status and freely pursue their economic, social and cultural development.²
- **Data and information about individual and community health and wellness** are critical tools for self-determination.
- **Indigenous data sovereignty principles** assert that First Nations, Inuit and Métis have collective sovereign rights and the fundamental authority to own and govern their data, regardless of where their data is housed.
- **A distinctions-based approach** acknowledges the distinct histories, interests and priorities of First Nations, Inuit and Métis. For data to be relevant and useful to the people who own it, First Nations, Inuit and Métis data needs to be delineated.
- **Partnerships with Indigenous organizations** are foundational to the appropriate use of data held at CIHI. Partnerships require full engagement and co-development at every stage of a project.

i. The 4 components of OCAP® are ownership, control, access and possession. OCAP® is a registered trademark of the [First Nations Information Governance Centre \(FNIGC\)](#).

ii. The 4 principles of OCAS are ownership, control, access and stewardship.

Putting principles into practice at CIHI

The application of these guiding principles requires new organizational policies and procedures for the respectful governance and management of First Nations, Inuit and Métis health data held at CIHI. CIHI is currently working to update existing data management and governance policies to reflect Indigenous data sovereignty principles. This work is expected to evolve over time as we learn more about how CIHI can ensure appropriate use of data that can identify Indigenous individuals and communities.

CIHI data holdings



Types of care

- Hospital and emergency
- Mental health
- Home care
- Long-term care
- Rehabilitation
- Pharmaceuticals
- Clinical registries: organ transplant/renal, hip and knee replacements; trauma
- More



Patient-reported data

- Patient-reported outcome measures (PROMs)
- Patient-reported experience measures (PREMs)



Health spending

- Patient costing data
- Hospital and regional health authority financial accounts
- Physician billing
- System-wide health expenditures



Health workforce

- Physicians
- Nurses
- Occupational therapists
- Pharmacists
- Physiotherapists
- Allied health professionals
- More

Within CIHI's data holdings, Indigenous individuals, communities and facilities can be identified in a number of different ways:



Individual identifiers

(e.g., Indigenous self-identifiers, client language, responsibility for payment coded as First Nations and Inuit Health Branch)



Community identifiers

(e.g., geographic identifiers such as client postal codes)



Facility identifiers

(e.g., long-term care homes in First Nations communities)

CIHI's policy on the release and disclosure of Indigenous-identifiable data

CIHI's policy aims to ensure appropriate access to, and use of, any information that identifies, or could be used to identify, Indigenous individuals or communities. The policy requires that any request for Indigenous-identifiable data at CIHI be accompanied by approvals from appropriate Indigenous authorities (i.e., First Nations, Inuit and/or Métis governments, communities and/or organizations).

CIHI also strives to support Indigenous-driven use of data through partnerships, data requests and data-sharing agreements. Indigenous advisors will provide input on engagement with First Nations, Inuit and Métis communities and organizations on data governance issues, including the collection, access, analysis, interpretation and dissemination of Indigenous data at CIHI. Advisors will also guide other components of CIHI's Indigenous Health Strategy.

Examples of partnerships at work

Indigenous data sovereignty principles support the ongoing strengthening of our working relationships and help guide our work.



Lydia Hwitsum (FNHA) and Janet Davidson (CIHI) perform a ceremonial basket exchange while David O'Toole (CIHI) looks on.



David O'Toole (CIHI), Lydia Hwitsum (FNHA), Janet Davidson (CIHI) and Joe Gallagher (FNHA) sign memorandum of understanding.

Partnership with the First Nations Health Authority in British Columbia

CIHI is working with the First Nations Health Authority (FNHA) to improve the health and well-being of First Nations individuals, families and communities in B.C. and to contribute to the broader national process of reconciliation. In 2017, the FNHA and CIHI entered into a memorandum of understanding⁸ formalizing a partnership for collaborative work on health data in 3 streams: data and analytics, performance reporting and shared learning. The FNHA, B.C. Ministry of Health and CIHI are also working toward a joint statement on First Nations health data governance.

Partnership with the First Nations Health Managers Association

In 2019, CIHI and the First Nations Health Managers Association (FNHMA) entered into a memorandum of understanding to strengthen our mutual commitment to addressing the need for quality data that is actionable to support informed decision-making. Our common interests include advancing First Nations' health; strengthening capacity for First Nations leaders and communities; strengthening First Nations' ability to access and use data for planning, health service management and decision-making; and contributing to the broader national process of reconciliation.



Marion Crowe (FNHMA), Jean Harvey (CIHI) and Patricia Thomson (FNHMA) sign partnership agreement.

Respecting OCAP® and supporting Indigenous data governance: First Nations home care project

First Nations communities in Alberta have chosen to work with CIHI to implement interRAI home care assessments to improve access to home and community care that is comprehensive, culturally safe, accessible, effective and equitable. The project is a collaboration between First Nations communities, the First Nations and Inuit Health Branch, Momentum Healthware, the First Nations Technical Services Advisory Group (Alberta), Alberta Health Services, Alberta Health, interRAI and CIHI. The communities receive training from CIHI on how to use the assessment tools and have the option to share data with CIHI for community-specific reporting. Since implementation, wait times for assisted living and long-term care have decreased significantly in participating First Nations, and community nurses now have the tools to assess the care needs of their diverse client populations.

Through this project, CIHI has demonstrated an ability to align with OCAP® principles by ensuring that

- Information management agreements are signed with each community;
- Data from First Nations communities is separated from provincial home care data;
- Data is stored securely, adhering to CIHI's privacy and security policies;
- Reports are community-specific;
- Communities can access their data any time;
- Communities determine whether and how their data is shared; and
- Data is not available for third-party data requests.

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