

CIHI's Health Data and Information Governance and Capability Framework



Canadian Institute
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Institut canadien
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Executive summary

A consensus is emerging among Canadian health information organizations — ministries and departments of health, health agencies and authorities, health delivery organizations and research organizations — that there are significant opportunities for realizing greater value from health data and information (HDI). Examples of such opportunities are supporting evidence-based decision-making in areas of social and economic policy, research on population health, evaluating health system performance and improving care for Canadians, while keeping data protected.

There is an increased focus on analytics, including emerging areas such as the application of artificial intelligence to health care. Generating value from these advanced techniques requires effective and efficient processes to collect, prepare, link, protect and distribute trusted data. This requirement has been echoed in numerous Canadian papers that have called for a strategic and coherent approach to organizing and governing Canada's HDI assets.

To help advance this discussion, the Canadian Institute for Health Information (CIHI) hosted the Privacy and Health Data Access Symposium in October 2018. As a result of the direction received, CIHI convened further consultations between October 2018 and March 2019 with more than 200 health systems leaders and reviewed relevant literature to identify practical actions to systemically improve the use of HDI in Canada. These consultations demonstrated that data and information are already contributing to improving health in abundant and innovative ways.

A consistent theme emerged: the need to improve the quality and consistency of HDI governance practices across organizations seeking to share data and realize its strategic value. To address that challenge, the following core ideas were set out for health information organizations:

- Review and describe the meaning, completeness and quality of data assets to optimize their use internally and with trusted partners;
- Prioritize sharing data, information and algorithms to achieve common aims, while maintaining strong privacy and security controls and harmonizing policies, practices and standards where practical and valuable; and
- In consultation with the public, develop plain language communication to define the governance and capabilities necessary to generate value from data and information, as well as the controls required to earn and retain public trust.

All of the ideas heard during the consultations were compiled into an initial data governance and capability framework in September 2019, with limited distribution. This was subsequently refined based on feedback from early adopters.

The current version of the framework, along with its companion toolkit, enables health information organizations to

- **Self-assess** their current HDI governance and capabilities;
- **Envision** a related target state that will meet the needs of the organization;
- **Prioritize** areas of improvement for investment; and
- **Develop** an effective and pragmatic action plan for improvement informed by commonly used HDI practices and artefacts.

Further, networks of organizations (e.g., multiple agencies within a jurisdiction) will be able to **identify the level of alignment required** across the network for the HDI governance and capabilities in service of their overall objectives to improve trust, effectiveness and efficiency.

Finally, the framework provides a **common language** for inter- and intra-organizational collaboration as a basis for exchange of leading practices and lessons learned in a meaningful and constructive way that fosters alignment.

Mobilizing value by sharing knowledge

Health systems across Canada are seeking greater value from their health data and information (HDI) assets in an effort to achieve sustainable, effective and impactful outcomes, resulting in better individual and population health and better health system planning and delivery. At the same time, it is essential to continue to keep personal health information protected in order to earn and retain public trust. There is a consensus that it is time for Canada to take action.

This document

- Summarizes how better HDI benefits stakeholders in Canada's health systems;
- Provides insights from pan-Canadian consultations on better management, sharing, governance and use of HDI;
- Introduces a capability framework and self-assessment tool that will help health information organizations understand and improve their capabilities in managing and sharing HDI within and across organizations;
- Describes a network alignment assessment tool that will help networks of organizations design and implement the capabilities across their network, leading to increased efficiency, effectiveness and trust; and
- Proposes a common language to share knowledge and leading practices.

Evolving value of health data and information

Several changes in health care around the world are shining the spotlight on HDI.

Advances include

- A shift to a learning health system;
- Increased focus on person-centredness;
- Simplifying the path for technical innovation; and
- Enabling artificial intelligence.

Underlying these changes is an increasing reliance on trusted data and information shared in a way that protects the safety of individuals and the public. A common management approach simplifies and accelerates the integration of data, information and algorithms within and across organizations. This also enables the sharing of data, as well as the creation of collective insights and the ability to scale their impact. Improving HDI governance and capabilities will generate many benefits for health information organizations, Canada and Canadians:

- **Trusted quality insights** — Quality data that is understandable and linkable to other data sets will enable the generation of insights that can be communicated and replicated, leading to trusted and impactful actions.
- **Improved efficiency and effectiveness** — Through consistent approaches and clear accountabilities for health data management, data flows will be more transparent, resulting in faster data flow availability and reduced data redundancy.
- **Enabling leading research** — Easier access to trusted HDI will allow researchers to spend less effort acquiring and preparing data, and more time generating insights, leading to impactful scientific discoveries, devices and tools.
- **Rapid inclusion of new data types** — By clarifying data flows and associated accountabilities, new data types such as genomics or patient-generated data will be transparently integrated, resulting in more comprehensive health records for care, planning and research.
- **Better vendor experience** — A common approach to HDI will give vendors more clarity and consistency in working with health information organizations, thus leading to expanded products and faster update cycles at lower cost.
- **Increasing personalization** — With integrated data about an individual, algorithms can determine personalized and precise recommendations to improve individuals' health.
- **Stimulation of innovation** — Simplified, appropriate access to HDI will enable innovation within the health sector and beyond.

Value of health data

In the fall of 2019, Ernst & Young (EY) estimated that the potential value to be gained through the appropriate use of the National Health Service (NHS) longitudinal patient records would be £5 billion per annum for the NHS (e.g., only necessary procedures, operational efficiencies) and an additional £4.6 billion per annum of benefits for the public (e.g., fewer sick days).¹

Scaling to Canada (population and exchange rate), this would result in \$4.9 billion per annum savings for Canada's health systems and \$4.5 billion per annum for the public if we had base infrastructure comparable to the NHS.

All these benefits are achievable, while protecting data privacy. Other benefits will be discovered as HDI are increasingly used to advance health care.

While the benefits are clear, many organizations are experiencing challenges in obtaining, sharing, linking and using HDI. To help address these challenges, the Canadian Institute for Health Information (CIHI), a trusted partner in data quality and standards, began a conversation about a revitalized approach.

Insights from pan-Canadian consultations

In October 2018, CIHI hosted the Privacy and Health Data Access Symposium. Attendees generally agreed that broader access to HDI, accompanied by appropriate privacy and security requirements, would benefit all Canadians.

It was also agreed that a wide group of health system stakeholders, including the public, health care providers, researchers and the private sector, would need to work together to identify and implement appropriate policies and processes to achieve common goals across regions, jurisdictions and Canada. The consensus from participants was that the time to start building momentum is now.

Following the symposium, between October 2018 and March 2019, CIHI consulted with more than 200 leaders in health information organizations (ministries and departments of health, health agencies and authorities, health delivery organizations and research organizations) over the course of about 50 meetings involving every province and territory.ⁱ CIHI also completed a review of relevant literature that included the experiences of other countries and industries.

Many of those consulted were of the opinion that significantly more value could be generated from HDI, while keeping the data secure. Participants were asked what practical actions could generate additional value. The diverse set of ideas outlined a set of policies, processes and practices (collectively referred to as “capabilities”) that a health information organization could use to sustainably, effectively and efficiently generate greater value from HDI while continuing to protect its sensitivity and integrity. These were compiled into an initial governance and capability framework.

The initial framework had a limited distribution in September 2019 in an effort to learn from early adopters. Those experiences resulted in several updates, including the addition of a companion toolkit. Together, this document and the toolkit form the first complete version of CIHI's Health Data and Information Governance and Capability Framework.

i. Individuals in Quebec were engaged; however, the position of the Quebec government, which is solely responsible for all aspects of health information that affect the health and social services network, led the ministère de la Santé et des Services sociaux (MSSS) du Québec to decline participation in this pan-Canadian consultation.

CIHI's Health Data and Information Governance and Capability Framework

Audience

The audience for this framework is health information organizations in Canada, such as ministries and departments of health, health agencies and authorities, health delivery organizations and health-related research organizations.

The framework

- Provides **context** for a health information organization to realize opportunities from HDI through **questions** that help organizations reflect on their own practices;
- Provides **guidance** on the depth, diversity and complexity of governance and capabilities, including criteria to assess the degree to which the capability is **mature** and **consistently applied** across an organization's data assets and processes; and
- Has a companion toolkit with templates for organizations to **self-assess** their most important HDI governance and capabilities, **envision** their evolution and **prioritize** areas for improvement.

The framework also helps networks of organizations (e.g., multiple agencies within a jurisdiction) understand the alignment required within the network for a given HDI capability through

- The **toolkit**, which can assist in identifying the **need for and extent of alignment** required of their HDI principles, practices and content where it is practical and beneficial toward achieving common aims; and
- A **common language** for multi-organizational collaboration as a basis for exchange of leading practices and lessons learned in a meaningful and constructive way that fosters improvement and alignment.

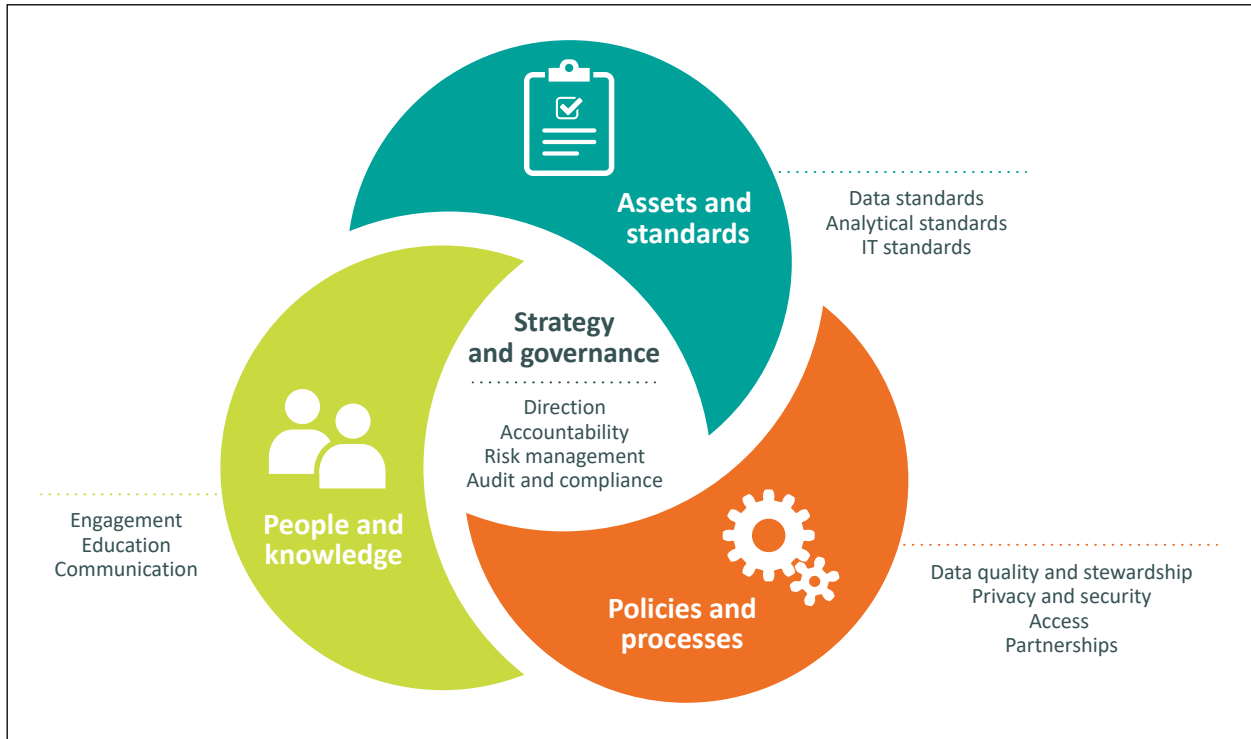
The framework is not intended to prescribe how these capabilities and related processes should be implemented. Individual organizations will need to design or refine their own policies, processes and practices given their scope, mandate, priorities and legislative authorities.

This HDI governance and capability framework has been compared with other similar frameworks to ensure its comprehensiveness, including the Organisation for Economic Co-operation and Development (OECD) guidance on health data governance. Uniquely, this framework includes aspects of data management, privacy, access, communication and governance. By focusing on policies, processes and practices and their consistency, rather than exclusively on maturity, it intends to help provide a clearer path to tangible HDI governance and capability improvement action.

Framework areas and components

CIHI's Health Data and Information Governance and Capability Framework consists of 4 subject areas, each area covering a subset of the 28 HDI capabilities.

CIHI's Health Data and Information Governance and Capability Framework



- **Strategy and governance** provide the overall direction, accountability and oversight for an effective HDI program. Capabilities in this area include a clearly articulated strategy for the intended outcomes of the strategic use of HDI, governance and accountability models, and processes to monitor and report compliance.
- **Policies and processes** define activities for appropriate collection, processing, analysis and sharing of trusted HDI. Capabilities in this area include data management, quality, conformance, privacy, security, access and partnerships that collectively define the way the organization operates internally and externally to ensure efficiency, effectiveness, integrity and protection.
- **Assets and standards** establish the HDI assets required by the policies and processes to enable strategic and operational outcomes. Capabilities include enterprise data assets, standards, data models and analytics insights that form the collective data foundation of the organization or network.
- **People and knowledge** empower people, from stakeholders to the workforce, to facilitate and evolve policies, processes, designs and governance to be effective and sustained. Capabilities include engagement, education and communication both within and external to the organization.

Within the framework, these capabilities are classified as **core**, **foundational**, **supplemental** or **enabling**. Organizations starting an HDI program should focus their early efforts on core and foundational capabilities. Details on the core and foundational capabilities are available in the companion toolkit. Additional details on supplemental and enabling capabilities are available on request to CIHI.

Gaining context to realize opportunities

Questions have been developed to help leaders gain context for the opportunities to use data and information in their organizations. 10 questions for strategic planning and 10 questions for operational oversight are provided in the tables below. Additional questions are available in the toolkit and supplementary materials.

Questions about strategic planning

Area	Strategic questions to ask
Strategy and governance	<ul style="list-style-type: none"> • For our strategic plan, how can trusted HDI be better used to help achieve our goals? What challenges are there? How can we overcome these challenges? • Are the business, IT, HDI and other plans well aligned to the strategic plan? • What are the risks if we do not use data and information more productively? • How does our strategic plan align with that of peer organizations with respect to data and insights? How can we work together to minimize redundancy and unnecessary competition?
Policies and processes	<ul style="list-style-type: none"> • How are risks managed to achieve both protection (privacy/security) of sensitive health data and enabling access to create impactful insights? • How well are we meeting our information-sharing commitments (timeliness, quality)? How can we meet these commitments without inappropriately impacting privacy and security? • How do we manage vendor relationships to share data more effectively and efficiently with partner organizations? • Do we manage Indigenous populations' data consistent with existing policies, principles and practices (e.g., the First Nations Principles of OCAP)? How have those populations been involved?
Assets and standards	<ul style="list-style-type: none"> • How do we adopt and adapt to emerging trends in data and insights? How do we do this in alignment with our scope, strategy and mandate?
People and knowledge	<ul style="list-style-type: none"> • Are we trusted by key stakeholders (e.g., patients) to collect, use and disclose personal health information? Do we have corresponding communication and engagement in place?

Questions about operational oversight

Area	Operational questions to ask
Strategy and governance	<ul style="list-style-type: none"> • Is the organizational culture ready for new data and technology advancements? How does the organizational culture support the goals of the roadmap? • Do members of strategic governance bodies have sufficient and broad understanding of organizational/business/IT/data and information objectives to provide the necessary leadership, guidance and oversight? • Do our data projects include the right data and information governance expertise for project delivery and transition to operations?
Policies and processes	<ul style="list-style-type: none"> • How do we consistently ensure that the appropriate authorities, consent and social licence are in place for the collection, use and disclosure of the data for intended purposes? • Is there a standardized and consistent system of defining critical data to the organization? Is it easily and effectively used? How does it align with those of our partners? • Are we using data standards to share and integrate data both internally and with our stakeholders and partners? Do we have policies in place to ensure that these standards are adequate for our needs, are cost effective and evolve appropriately? • How are business, data and IT policies defined and aligned across the data life cycle: creation, flow, collection, storage, use and destruction?
Assets and standards	<ul style="list-style-type: none"> • How are the data assets organized in the organization? Is there an easy-to-use organization system, such as a catalogue, across the assets? • When enabling new insights, do we reuse existing data assets, including those of partners? Do we have a plan to integrate legacy stand-alone data assets, where most impactful?
People and knowledge	<ul style="list-style-type: none"> • What are the needs for education in data and information practices across all levels of our organization? How do we assess gaps in our skill mix to be able to address future demands for trusted and timely data and information?

Next steps: Driving action

Health information organizations can use this framework, together with the companion toolkit, to perform a self-assessment of their current HDI governance and capabilities, envision a target state and develop an action plan to improve their HDI governance. Furthermore, networks of health information organizations will be able to work together to identify areas of HDI governance and capability alignment that will help achieve their common aims.

Questions or feedback on the contents and use of the framework, as well as potential improvements, should be sent to datagovernance@cihi.ca.

Reference

1. Spence P. [How we can place a value on health care data](#). *EY Global*. July 19, 2019.



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