Data Governance Working Group – OHDC Final Report

Table of Contents

1.0 Executive Summary

This report summarizes the recommendations of the OHDC Data Governance Working Group. In alignment with global best practices, as well as the findings of the pan-Canadian Health Data Strategy, the Data Governance Working Group (DGWG) advances the following vision for Ontario:

> Ontario must establish a trustworthy, integrated health data ecosystem where health data is governed as an essential public good and a strategic provincial asset.

To help achieve this vision, the DGWG recommends the creation of system-level data governance for Ontario's health data to:

1. Foster a trustworthy health data ecosystem that will cultivate trust in health data sharing, access, and use among all Ontarians.
2. Enable appropriate data access and use while protecting individual privacy and securing health data.
3. Establish responsive health data governance at a system level that reflects the needs of all Ontarians and can ally with and support First Nations, Inuit, and Métis data governance.

2.0 Background

The Data Governance Working Group was struck in September 2021. It was tasked with the following design challenge: "How might we design a business and data governance model that treats data as a valuable asset of provincial significance and fosters the availability of data for use, promotes public trust and transparency, and strengthens data-sharing mechanisms across Ontario?"

2.1 Definition

Data governance refers to the rules, structures, policies, processes, programs, and people in place to manage and oversee the collection, sharing, access, and use of data.[1] The DGWG has used the following definition of health data governance: "who has access to what data, for what purposes, and how will that data be managed and used."

2.2 Barriers and Issues

Ontario does not currently have clear, coherent system-level data governance for provincial

---

[1] [Health data governance: a playbook for non-technical leaders - Data Governance Playbook (gitbook.io)](#)

health data. Although Ontario's health system has robust health data governance structures and practices in place across many institutions, the lack of data governance at a system level hampers the ability to share, access, and use health data.

Emerging best practices demonstrate that clear data governance can enable health data sharing, access, and use.[2] As the pan-Canadian Health Data Strategy (PCHDS) puts it:

> Clear accountability and governance in the health sector for its fastest growing asset –data – is essential. Every health outcome, policy decision, and innovation should rely on timely, quality data. […] Effective accountability and governance must learn from past experience – not only ensuring sound privacy protections but also prioritizing the achievements of better health outcomes and more cost-effective health care from opening up the collection, sharing, and use of data.[3]

The gap in system-level health data governance must be addressed if Ontario hopes to leverage the full value of its health data assets.

3.0 Jurisdictional Scan

Many jurisdictions have launched initiatives to better leverage health data, foster trustworthy health data ecosystems, and ensure health data is governed as an essential public good and strategic asset across Canada[4] and the world.[5]

3.1 Pan-Canadian Health Data Strategy

In fall 2020, federal/provincial/territorial (FPT) tables called for the co-development of a pan-Canadian Health Data Strategy to articulate and address short-term data-related priorities for COVID-19 and to address systemic issues affecting the collection, sharing and use of health data through the development of a longer-term strategy. The PCHDS has struck an expert advisory group (EAG) to guide the longer-term strategy.

As of early 2022, the EAG has released two reports highlighting the challenges facing health data collection, access, and use across Canada and foregrounding the urgent need for action. The PCHDS has identified the following five essential components of a health data strategy:

1. Clear health data accountability and governance
2. Built and sustained trust
3. Digital-age health data policies

---

[2] [CIHI's Health Data and Information Governance and Capability Framework](#)
[3] [Expert Advisory Group Report 2: Building Canada's Health Data Foundation - Canada.ca](#)
[4] [Moving Forward on a Pan-Canadian Health Data Strategy - Canada.ca](#)
[5] [Health Data Governance Summit: Health Data as a Global Public Good](#)

4. Coherent and regulated interoperability standards
5. Common language and health sector and public data literacy

The PCHDS has called on each jurisdiction and government across Canada to start building the foundations of a health data ecosystem. In particular, the PCHDS calls for:

1. The public to be meaningfully engaged in health data strategy to ensure that their needs, requirements, and aspirations are clearly articulated, understood, and respected
2. Governments to commit to addressing the "privacy chill" surrounding health data to be able to give their constituents a more targeted, responsive health sector.[6]

3.2 Newfoundland & Labrador

NLCHI Data Governance Framework

The Newfoundland and Labrador Center for Health Information (NLCHI) established Data Governance NL, a principle-based framework to serve as guidelines for appropriate and responsible use of provincial data. Supported by an emphasis on "data for good," the framework is intended to support programs, projects, and initiatives that promote responsible innovation through the use of a provincial Data Lab.[7] Acknowledging that "effective data governance requires reimagining how the province enables access to data in an ethical, privacy sensitive and expeditious, innovation-friendly manner," the NLCHI framework aims to balance oversight, prioritization, and consistency and ultimately maintain a "social licence" for health data use.[8]

3.3 European Union

European Health Data Space & Data Governance Act

The European Union has prioritized the establishment of a common European Health Data Space (EHDS). Through a data governance framework, the EHDS will promote better exchange and access to different types of health data to support better healthcare delivery, better health policy making, and better health research and innovation.[9]

In 2021, the European Commission published the Data Governance Act (DGA). Building on the General Data Protection Regulations (GDPR), the DGA sets out to incentivize and support data sharing across Europe by providing clear, common data governance regulations.[10]

3.4 United Kingdom:

---

[6] [Expert Advisory Group Report 2: Building Canada's Health Data Foundation - Canada.ca](#)
[7] Data Governance NL: Harnessing Data for Innovation and Health System Transformation, 2
[8] Data Governance NL: Harnessing Data for Innovation and Health System Transformation, 11
[9] [European Health Data Space (europa.eu)](#)
[10] [Data governance act | Shaping Europe's digital future (europa.eu)](#)

Data Saves Lives: Reshaping Health and Social Care with Data

The United Kingdom has established a single data strategy for health and care entitled "Data Saves Lives: Reshaping Health and Social Care with Data." The strategy's primary goal is to deliver "truly patient-centered care, which puts people before systems."[11] This strategy provides an overarching data governance action plan to address current cultural, behavioural and structural barriers in the system to achieve a health care system that is supported by high quality, readily available data. Three key priorities underpin this strategy:

1. Improve transparency and trust so the public has control over how their data is used
2. Make appropriate data sharing the norm, rather than the exception
3. Build the right foundations – technical, legal, regulatory – to make the above possible.

3.5 Findings

Ontario's Digital and Data Strategy has the ambitious aim of transforming the province into a world-leading digital jurisdiction, and its Digital First for Health Strategy seeks to modernize and improve the patient and provider experience. Despite these ambitious goals, Ontario is at risk of lagging behind peer jurisdictions in ensuring system-level data governance.

This scan of international and domestic jurisdictions has identified three clear trends:

1. An emphasis on building, maintaining, and fostering trust in health data sharing, access, and use and a need to build a trustworthy health data ecosystem.
2. Balancing security and privacy of health data with the need to ensure appropriate use, access, and sharing.
3. Establishing strong system-level health data governance that is responsive to the public interest and manages health data as an essential public good and strategic asset.

4.0 Key Recommendations:

4.1 Vision

The Data Governance Working Group advances the following vision for Ontario:

Ontario must establish a trustworthy, integrated health data ecosystem where health data is governed as a public good and a strategic provincial asset.

To achieve this vision, the DGWG provides the following key recommendations:

---

[11] [Data saves lives: reshaping health and social care with data (draft) - GOV.UK (www.gov.uk)](https://www.gov.uk)

4.2. Foster a trustworthy health data ecosystem that will cultivate trust in health data sharing, access, and use among all Ontarians.

"Systemic ways to build trust and identify individual and community requirements for health data are needed. This extends well beyond communicating the benefits of data use and how data are protected."[12]

Implementing a robust data governance framework is one of the mechanisms by which trust can be built and trustworthiness can be assessed and demonstrated.[13]

Trust in the collection, sharing, access, and use of health data must be earned, built, and continually sustained. A trustworthy health data ecosystem must have the appropriate infrastructure, standards, and policies in place to ensure timely, secure, and privacy-protective access to health data.

Ontarians must have on ongoing, sincere opportunity to express their requirements, desires, hopes, and concerns regarding their health data. The health sector must incorporate these requirements into policies, processes, and practices and have the capacity to measure whether they have earned the trust of the public and communities.[14]

Building a trustworthy health data ecosystem will require:

- Empowering Ontarians to improve health outcomes through increased access to their health information, and awareness about how health data and its uses.
- Setting standard, permanent and meaningful advisory roles for the public in health data governance structures.
- Ensuring secure and privacy-protected health data exchange and processing infrastructure.
- Ensuring independent oversight. The IPC would continue to provide oversight of Ontario's privacy and access laws.
- Strengthening data and digital literacy and capacity across the health system and Ontario at large.
- Addressing digital capacity gaps, especially for equity-deserving communities.
- Defining clear accountabilities for health data at a system level through a data stewardship framework.

---

[12] Expert Advisory Group Report 2: Building Canada's Health Data Foundation - Canada.ca, 15
[13] The value of data governance for data-informed healthcare projects - Data Governance Playbook (gitbook.io)
[14] Expert Advisory Group Report 2: Building Canada's Health Data Foundation - Canada.ca, 15

4.3. Enable appropriate data sharing, access and use while protecting individual privacy and securing health data

While considerable health data is collected and shared across Ontario today, significant gaps remain unaddressed and challenges remain in accessing health data in a timely, cost-effective way. Ontario must develop well-established roles and responsibilities relating to system-level and provincial data governance and stewardship to better enable data sharing, access, and use.[15]

Enabling appropriate health data access will require:

- Establishing data stewards and structures to identify, share, and adopt system-level data policies that benefit all users of health data.
- Developing a sharing and "privacy by design" approach
- Transitioning health information custodians to health data stewards.
- Adopting common data standards to enhance data quality and interoperability.
- Establishing a streamlined pathway for data access requests.
- Leveraging pre-existing assets, resources, and capacity

4.4. Establish responsive health data governance at a system level that reflects the needs of all Ontarians and can ally with and support FNIM data governance approaches.

"A strong data governance program allows an organization to navigate regulatory disruption, operational transition, and innovation and digital transformation."[16]

Ontario should develop shared, responsive governance for the creation, implementation, and sustainment of a trustworthy, integrated health data ecosystem while maintaining a best effort, good will philosophy among partners. As literacy and capacity around health data is strengthened in Ontario, and as new technologies and uses for health data arise, the requirements for health data may change and adapt. Health data governance must remain agile and responsive to these changing circumstances.

Meaningful relationships, partnerships, and alliances with First Nations, Inuit, and Métis are a key element of health data governance. Ongoing engagement, informed by a distinctions-based approach, is required to establish and implement common understandings of data governance principles.

---

[15] Statistics Canada Data Strategy (statcan.gc.ca)
[16] Data Governance NL, 6

Responsive data governance will require:

- Developing shared, responsive governance for the creation, implementation, and sustainment of a trustworthy, integrated health data ecosystem.
- Supporting equity-deserving communities. Ensure culturally appropriate data governance structures are in place, in part by engaging communities.
- Allying with First Nations, Inuit, and Métis communities. Data governance structures must respect First Nations data sovereignty and collaborate with communities to address data capacity gaps.
- Adopting an iterative approach to developing clear health data governance at a system level.
- Setting standard, permanent and meaningful advisory roles for the public in health data governance.

REFERENCES

Canadian Institute for Health Information. (2020). *CIHI's Health Data and Information Governance and Capability Framework*. Available online at https://www.cihi.ca/sites/default/files/document/health-data-info-capability-framework-en.pdf

European Commission. (2021). *European Health Data Space*. Available online at https://ec.europa.eu/health/ehealth-digital-health-and-care/european-health-data-space_en

---. (2021). *Shaping Europe's digital future: European data governance act*. Available online at https://digital-strategy.ec.europa.eu/en/policies/data-governance-act

Open Data Institute. (2021). *Health data governance: a playbook for non-technical leaders*. Available online at https://open-data-institute.gitbook.io/data-governance-playbook/

Public Health Agency of Canada. (2021). *Pan-Canadian Health Data Strategy: Building Canada's Health Data Foundation. Expert Advisory Group – Report 2*. Available online at https://www.canada.ca/en/public-health/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-02-building-canada-health-data-foundation.html

---. (2021). *Moving Forward on a Pan-Canadian Health Data Strategy*. Available online at https://www.canada.ca/en/public-health/programs/pan-canadian-health-data-strategy.html

Statistics Canada. (2020). *Statistics Canada Data Strategy: Delivering insight through data for a better Canada 2019 to 2022*. Available online at www.statcan.gc.ca/en/about/datastrategy

Newfoundland & Labrador Centre for Health Information. (2021). *Data Governance NL: Harnessing Data for Innovation & Health System Transformation.*

World Health Organization. (2021). *WHO Health Data Governance Summit: Data Governance maturity and best practices*. Available online at https://cdn.who.int/media/docs/default-source/world-health-data-platform/events/health-data-governance-summit/preread-3-who-data-governance-summit_data-governance-of-health-data.pdf?sfvrsn=ffbd4a33_10

---. (2021). *WHO Health Data Governance Summit: Health Data as a Global Public Good.* Available online at https://cdn.who.int/media/docs/default-source/world-health-data-platform/events/health-data-governance-summit/preread-2-who-data-governance-summit_health-data-as-a-public-good.pdf?sfvrsn=2d1e3ad8_8

United Kingdom Department of Health & Social Care. (2021). *Data Saves Lives: reshaping health and social care with data (draft).* Available online at https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data-draft/data-saves-lives-reshaping-health-and-social-care-with-data-draft

Appendix A - Terminology

For the purposes of this document, terms used throughout this document are defined as follows:

Terminology	Definition
Access	is the act of providing access to the data for authorized individuals. Access can be achieved by data visiting (where data remain in place) or physical data sharing (where data are copied). *Source: Pan-Canadian health data strategy*
Health Data	refers to publicly and privately held data related to health care, public health, population health, and health research, inclusive of relevant socio-demographic factors (e.g. race, ethnicity, gender, age) and data from other sectors. *Source: Pan-Canadian health data strategy*
Health Data Ecosystem	is the set of governance, policies, processes, designs, and data flows for an interoperable network designed and developed to ensure the best possible health services and outcomes for Canadians based on excellent research, population and public health services and policies, and delivery, organization and management of health care approach *Source: Pan-Canadian health data strategy*
The Public	includes individuals and their families and caregivers and encompasses all persons living in Canada, including those who have contact with health services as a result of disease or injury, as well as maintaining and promoting health for all. *Source: Pan-Canadian health data strategy*
Public Good	In economic terms, public goods have two key attributes: They are non-exclusionary (no one can be excluded from using them) and non-rivalrous (one person or entity's use does not prevent anyone else's use). Due to health data's sensitivity and privacy, it should not be open to everyone, but its use can still bring benefits to everyone. Source: World Health Organization.

Appendix B – DGWG Membership

Membership Chart

Organization	Name	Title	Role
UTOPIAN	Dr. Michelle Greiver	Director	Facilitator
Civic Digital	Andy Best	CEO	Contributor
IPC	Dr. Debra Grant	Director of Health Policy	Contributor
ICES	Dr. Michael Schull	CEO	
Ontario Ministry of Health	Dr. Michael Hillmer	Executive Director	Contributor
Unity Health Toronto	Dr. Muhammad Mamdani	Vice President, Data Science and Advanced Analytics	Contributor
PointClickCare	Mike Wessinger	Chairman	Contributor
CIO Strategy Council	Keith Jansa	Executive Director	Contributor

Appendix C - Further Reading and Resources:

[CIHI's Health Data and Information Governance and Capability Toolkit](#)

[CIHI's Health Data and Information Governance and Capability Supplementary Toolkit](#)

[Statistics Canada's Trust Centre](#)