



# Data Governance and Stewardship Working Group Report

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## Executive Summary

Everyday across Ontario, health data is collected from multiple sources, for multiple uses, in multiple ways. However, not all health data is collected, stored, and used in a standardized, streamlined way, which makes sharing high-quality, real-time health data across Ontario very difficult. The resulting fragmentation of health data impacts patient and provider experience, hampers clinical outcomes, undermines the response to major public health events such as COVID-19, and delays research and innovation. In short, it means that health data is not available when, where, and in the way it is needed.

In 2022, the Ontario Health Data Council (OHDC) acknowledged these challenges and laid out a vision for Ontario where integrated health data is seamlessly shared for multiple uses and stewarded as a public good. To help realize this vision, the OHDC launched a Data Governance and Stewardship Working Group (the Working Group). Tasked with addressing the lack of provincial oversight and accountability for health data and to enable sharing by default for care provision and other appropriate purposes, the Working Group met many times between December 2022 and March 2023 to develop a provincial health data governance and data stewardship model.

This report outlines the recommendations of the Working Group, which include:

1. A provincial health data governance structure built on collaboration, flexibility, and partnership that leverages existing governance bodies and expertise focusing initially on advancing interoperability and streamlining data access for care provisioning.
2. A provincial health data stewardship model to foster shared accountability for standardized, accurate, and fit for purpose health data.
3. Modernizing provincial data infrastructure to enable data collaboration and to integrate and use high-quality health data for health and equity outcomes for individuals, communities, and populations.

Additionally, this report proposes that several domain-level working groups be formed to serve as a test case to demonstrate the value of provincial health data governance. This report also provides a high-level implementation plan and measures for success.

Ontario's health system has the expertise and knowledge to realize the OHDC's vision for Ontario. However, no single institution, organization, or body will be able to address these challenges or realize this vision alone. Success requires commitment, collaboration, engagement, and dialogue from all stakeholders across the health system and beyond.

Ontario needs collaborative, non-invasive, and clear provincial health data governance – not bureaucracy – to enable standardized, integrated health data and streamlined data access that complies to privacy laws and regulations. The Working Group believes this is the most efficient path forward to quickly ensure Ontario’s health data assets meet the needs of patients and are used in the public interest while leveraging existing Ontario capacity and expertise.

## Background

### OHDC Report and Recommendations

This report builds upon the OHDC’s vision for Ontario where standardized, integrated health data is used to generate timely actionable insights, enhance care experiences and outcomes, improve system performance, support organizational performance, and address health inequities.

To achieve this vision, the OHDC advanced five strategic recommendations:

- Standardize, integrate, and use health data to advance health and equity outcomes for people, communities, and populations.
- Promote health equity through appropriate data collection, analysis, and use.
- Establish system-level trustworthy governance and policies for health data as a public good in a privacy-sensitive manner.
- Respect and support First Nations, Inuit, and Métis People’s data sovereignty.
- Build data stewardship capacity and enable sharing by default in compliance with privacy laws and regulations.

To read more about the OHDC’s vision for Ontario, please refer to the [Report](#).

In line with the OHDC report, the Working Group recognizes that fostering and maintaining public trust will be foundational to any successful data governance structure. To do this, health data stewardship must be based on the ethical principles outlined in the OHDC report (i.e., Data for Good; Respect for Persons, Groups, and Communities; Protect against Harms; Equity; and Transparency and Accountability). Abiding by these ethical principles of the OHDC report, engaging with communities as well as respecting First Nations, Inuit, and Métis (FNIM) data sovereignty will be paramount in the success of any data governance structure. The Working Group believes that Ontario needs to develop a provincial health data equity framework that will provide guidance to stakeholders on ensuring these principles measurably inform implementation and practice.

## Current State of Health Data Governance

Across Ontario's health system, governance for health data assets and infrastructure remains fragmented, byzantine, and confusing. Although data governance structures, policies, and practices are in place in many individual organizations, the province lacks common data governance to ensure adoption of common standards, practices, and norms around data collection for sharing and re-using. No single body is responsible for ensuring these different investments result in an accountable, interoperable, complementary, collaborative, and comprehensive approach across Ontario's health system. In Ontario, the responsibility for collecting, processing, and sharing health data is diffused across many different health information custodians (HICs) as well as several prescribed bodies, all of which are defined in Ontario's *Personal Health Information Protection Act* (PHIPA, 2004). PHIPA, as a consent-based statute, serves the dual purpose of protecting personal health information while enabling data sharing for prescribed purposes; however, each individual HIC must bear the ultimate responsibility and regulatory burden of data sharing as currently prescribed PHIPA. Interpretations and implementation of PHIPA can vary widely across different organizations, depending on their capacity and expertise. This, among other reasons, can result in needless, harmful delays in data sharing and information gaps. Ontario needs clear provincial health data governance to address these challenges, ensure standardization, make data fit for use, incorporate the needs and expectations of all stakeholders, and adjudicate and clarify conflicting interpretations.

Ontario's immature governance for health data is in marked contrast to the mature governance frameworks in place to manage physical infrastructure like roads, power grids, and railroads. For instance, when a road is built in Ontario, it must meet certain well-established standards to ensure high-quality and the public safety. We know what makes a safe asphalt mix, how fast different classes of vehicles should go, how wide roads should be, how to engage the public, and what are the enforcement mechanisms. These standards, supported through provincial legislation, regulation, policies, and procedures, ensure public trust and safety while enabling seamless travel across the whole of Ontario. Achieving this goal will not be easy and will require consistent collaboration. Today, as the importance, volume, and significance of health data continues to grow, Ontario needs to ensure the same type of provincial standards are in place for health data collection, storage, sharing, and use. This must be achieved through collaborative approach to provincial data governance that leverages existing expertise for Ontario to ensure high-quality health data is responsibly used to improve individual and population health, support research and development, foster public trust, and fit for purpose.

## Expected Outcomes

A system-wide data governance structure will enable real-time linkage and use of high-quality, standardized, and integrated data to support a wide spectrum of health data users, from individual Ontarians, their health care providers and care coordinators, through to public health, provincial planners, and decision makers. To be clear, provincial data governance is not designed to centralize Ontario's health care delivery system – it is designed to streamline and enable effective data sharing for a variety of purposes.

Ontario's health system is complex and multi-layered. Achieving a standardized, integrated, and comprehensive patient health record that ensures data gets where it is needed when it is needed requires continual collaboration, coordination, and commitment of resources across varied organizations and institutions.

Broadly speaking, a provincial health data governance structure authorized under PHIPA would enable lawful sharing of PHI by default for prescribed purposes under a robust PHIPA framework which would also support the development of an integrated health record which can enable the following outcomes:

- Empower patients and caregivers to better participate in the management of their care and ensure all individuals and health care providers in the circle of care have access to an integrated health record spanning the continuum of care.
- Enable ongoing and meaningful involvement of diverse communities to ensure that governance and stewardship practices align with their values.
- Reduce duplication, burden, and errors by enabling COUMT (Collect Once, Process Once, and Use Many Times) paradigm.
- Support the timely sharing of health data across different settings to improve outcomes, efficiencies, and results.
- Allow us to better understand what is happening in our health care and public health systems, to plan and react to challenges (e.g., Health and Human Resources, vaccination rates) and to transparently report on results to Ontarians.
- Increase responsible, inclusive, and ethical access and use of health data in the public interest including research, innovation, etc.
- Continuous cross-institutional data quality improvement.

Health data access and use in the public interest is broadly supported, provided robust privacy and security requirements are in place and the public is engaged in a

meaningful way.<sup>12</sup> Indeed, there is increasing consensus that health data should be shared in the public interest due to the strong public ownership claim to health data collected within publicly funded infrastructures and institutions as well as a broad duty to increase health knowledge to support better health.<sup>3</sup> More work needs to be done to meaningfully engage with the public, in part through the OHDC's civic engagement strategy, to discover what (if any) other uses are deemed to be in the public interest.<sup>3</sup> Strong data governance mechanisms and structures are required to establish the conditions, constraints, requirements, safeguards, and protective measures to ensure health data access occurs in the public interest.

## Proposed Provincial Health Data Governance Framework

The proposed Provincial Health Data Governance Framework refers to a health system data governance for Ontario. This “Provincial” governance is distinct from local data governance that exist in health organizations and institutions. This governance is designed to supplement and support, not replace, institutional or organization data governance. Each institution and organization will still be responsible for developing, maturing, and maintaining their own data governance structures and will also be expected to adopt and be compliant with the standards and policies<sup>4</sup> collaboratively developed through the provincial data governance structure. Guidance and engagement with organizations will be critical for the success of data governance.

## Health Data Governance Mission, Goals, and Scope

**Mission:** Enable ethical, timely, and responsible access and use of health data for individuals, communities, and populations in Ontario.

### Goals:

- Empower patients to have appropriate control over their health data in accordance with applicable legislation.
- Steward health data as a public good.

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<sup>1</sup> *Healthy Data, an online citizen consultation about health data reuse – intermediate report* (Towards European Health Data Space Consortium Partners, 2022)

<sup>2</sup> *Social Licence for uses of Health Data: A report on public perspectives*. (Health Data Research Network Canada, 2020)

<sup>3</sup> Same as above.

<sup>4</sup> Standards and policies would be similar to the Digital Health Information Exchange Regulation that came into effect on January 1, 2021.

- Integrate and use health data to advance health and equity outcomes for people, communities, and populations through appropriate data collection, analysis, and use and meaningful engagement.
- Respect and support First Nations, Inuit, and Métis peoples' data sovereignty.
- Enhance accountability for health data through building data stewardship capacity to enable sharing by default. It will ensure that right stakeholders have access to right data when they needed while abiding by “privacy by design” principles.
- Advance intra- and inter-jurisdictional interoperability of health data.
- Foster a data-driven culture of excellence across Ontario’s health system.

## **Health Data in Scope:**

Although data governance will be provincial in scope, this does not mean that this structure will govern all data across Ontario’s health system. Instead, the data governance structure will focus on what is necessary for interoperable data sharing and provide strategic guidance on data collection, storage, linkage, transmission, use, analysis, and reporting on the following:

- Clinical Patient-Level Data
  - Encounter-based data (e.g., primary care, acute care)
  - Service-based data (e.g., lab, drug, immunization, DI)
  - Patient-generated data (e.g., family history, lifestyle choices)
  - Device-generated data (e.g., medical devices, health apps)
  - Social determinants of health data (e.g., race, ethnicity)
  - Genetic data (e.g., genetic test result)
- Contextual Data (e.g., patient demographics, provider registry)
- Public and Population Health Data (e.g., encounter-based data, service-based data, social determinants of health data)
- Administrative Data (e.g., Ontario Health Insurance Plan claims database, Discharge Abstract Database, National Ambulatory Care Reporting System)
- Other Sectors Data relevant to understanding of health outcomes (e.g., data from other Ministries and publicly funded organizations)
- Other health data that might be relevant in the future

## **Data Governance Principles**

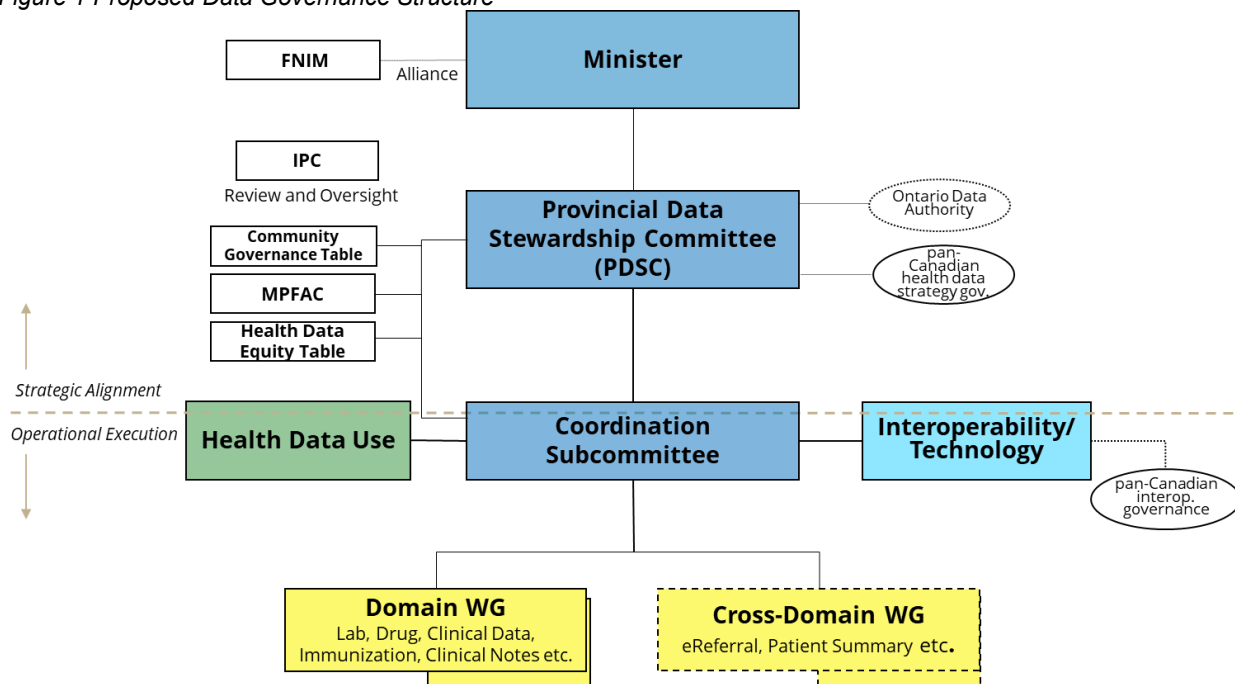
To fulfil this mission and meet these goals, Ontario needs a data governance structure that makes timely and accountable decisions inclusive of meaningful stakeholder engagement. Accordingly, the Working Group proposes that data governance structure itself should operate according to the following set of data governance principles:



- **Right-Sized & Able to Evolve**
  - Governance should proportionally address existing issues while remaining flexible enough to address new use cases as they arise.
  
- **Timely, Accountable & Use Case Driven**
  - Decision-making should be oriented towards delivering timely results that address existing barriers and challenges.
  
- **Transparent, Trusted, & Aligned**
  - Ensure provincial alignment while also coordinating with federal and international jurisdictions.
  - Ensure alignment and partnership with FNIM peoples and communities.
  
- **Balanced & Expert-based**
  - Incorporate meaningful input from all relevant stakeholders, with an emphasis on balancing patient, public, and expert engagement.
  
- **Valued & Trustworthy**
  - Foster a common understanding of the value and use of health data by increasing data literacy and demonstrating the practical value of health data.
  
- **Sustainable & Pragmatic**
  - Identify actionable priorities while remaining mindful of existing capacity, available funding, and long-term strategic directions.

# Data Governance Structure

Figure 1 Proposed Data Governance Structure



The proposed Data Governance Structure (the Structure) will develop, adopt, and implement provincial standards and policies in a collaborative fashion, meeting the needs and capacities of the health system as it exists today while also building towards the vision of a health system advanced by the OHDC.

The Structure can be split into two layers, a strategic layer (shown at the top of the diagram) and an implementation layer (shown at the bottom). The top layer will provide strategic guidance and ensure system-level alignment, while the bottom layer ensures appropriate implementation and adoption while enabling domain-level collaboration and input. In practice, the Structure is designed to ensure continual communication and feedback between these two layers and across all domains ensuring the needs of both are met.

In keeping with the Data Governance Principles, the intention is not to have all bodies engaged for a minor change, such as a change to a data element, that can be managed at an individual data domain. Additionally, this approach to data governance model is not designed to be a top-down approach, but instead to ensure shared decision-making and change management. In many cases, there are existing structures and bodies that that can be and will be leveraged to fulfill these functions. This structure will not duplicate work, nor create additional layers of bureaucracy, but will integrate existing work more clearly and effectively across the entire health system while also addressing

existing gaps that hamper standardization and data sharing.

### **Strategic Layer:**

The **Minister of Health** sets the strategic direction and priorities, establishes legislation and regulation, and provides funding.

The **Provincial Data Stewardship Committee (PDSC)** will provide strategic advice to the Minister of Health and perform the following tasks:

- Health system stewardship of health data as a public good.
- Approval of frameworks, road maps and standards tabled by the Coordination Subcommittee (CS).
- Provide guidance on prioritization of data domains, with an emphasis on sustainability, impact, and achievability.
- Provide resources and advice to support the implementation and adoption of standards and policies.
- Ensuring Ontario's provincial health data governance are proactively brought into alignment with the pan-Canadian framework.
- Engaging with stakeholders, including patients, equity-deserving communities, and FNIM peoples.

The **Coordination Subcommittee** (the Subcommittee or CS) reports to the PDSC and liaises with data domains to:

- Co-design, advise PDSC, and operationalize system-level common data governance policies and strategies.
- Provide guidance and coordination of projects and activities based on priorities and strategic directions set by PDSC. Enable data exchange interoperability in alignment with the pan-Canadian framework.
- Ensure standardization of health data in alignment with the pan-Canadian framework.
- Resolve or escalate cross-domain issue resolution.

**Health Data Use** provides provincial support and guidance to clinical practitioners to ensure alignment and change management, including:

- Specification of system-level clinical and health use requirements for health data, including uses at the pan-Canadian level, in a manner that minimizes practitioner burden.
- Clinical guidance on adoption of standards, digital tools, and change management.
- Clinical guidance on aligning clinical and digital programs.

- Translation of clinical quality standards into digital tools/templates.

**The Interoperability/Technology** group is responsible for:

- Development and maintenance of interoperability standards.
- Development and execution of interoperability roadmaps based on a common data infrastructure and business architecture, in alignment with the pan-Canadian interoperability roadmap.
- Technical guidance and alignment across health informatics standards.
- Compliance to standards verification and certification services along with interoperability policies and processes.

The Working Group recognizes that independent oversight of data governance is necessary to ensure public trust and transparency and constitutes an essential component of this data governance structure. The **Information and Privacy Commissioner (IPC)** will fulfil this function. The Working Group recommends further engagement with the IPC to clarify and refine the roles and responsibilities of the IPC.

Ensuring robust civic engagement, addressing equity concerns, and supporting FNIM data sovereignty are essential components of this data governance structure. However, the Working Group recognizes that these are complex subjects that require meaningful and lasting engagement with a broad range of stakeholders. On an interim basis, the Working Group has proposed a series of placeholder bodies that will need to be clarified through further collaboration and engagement with appropriate stakeholders. Some of this clarification work is already taking place under the sponsorship of the OHDC. For instance:

- The **Minister's Patient and Family Advisory Council (MPFAC)** is developing a health data public engagement strategy that will provide input on data governance, data literacy, and transparency.
- The OHDC is sponsoring a distinction-based **FNIM engagement** that will establish relationships with First Nation, Inuit and Métis peoples.
- **Community Governance Tables** will represent the perspectives of peoples and communities across Ontario.

Additionally, recognizing the need to respect and support FNIM data sovereignty and governance, the Working Group anticipates that the PDSC will liaise directly with First Nation, Inuit, and Métis representatives.

To ensure equitable stewardship of health data, **Health Data Equity Tables (HDET)** will provide advice on appropriate uses of data and ensure equity considerations are

incorporated throughout data governance policies, practices, and standards. Details that will clarify the roles, responsibilities, and functions will expand and evolve over time.

### **Implementation Layer:**

**Data Domain Working Groups** exist to ensure a common definition of data across the health system so health data can be consistently understood, easily shared, and accurately interpreted by both information systems and data users. Working Groups will bring together representative expertise to support:

- Standardization of domain-specific data in alignment with provincial principles/direction (e.g., terminology standards).
- Domain-level data quality assurance.
- Alignment to provincial and pan-Canadian reference models, data models, frameworks, roadmaps, etc.
- Domain issue resolution and escalation.
- Domain liaison and stakeholder engagement.

**Cross-Domain Working Groups** are ad hoc structures that co-develop business, clinical, technical, and data requirements for a well-defined data exchange purpose. Cross-domain working groups will be responsible for:

- Compliance to provincial methodology standards (e.g., Integrating the Healthcare Enterprise profiles).
- Specification of data workflow business requirements and data content which will come from two or more data domains.
- Engagement with stakeholders (clinical and technical), Subject Matter Experts (SMEs), domain working groups, etc.
- Issue resolution and escalation.

## **Proposed Provincial Data Stewardship Function**

### **Differentiating Data Governance from Data Stewardship:**

Data governance specifies principles, policies, procedures, and structures in place to manage and oversee health data collection, storage, sharing, and use. Those policies and structures are executed by people, enabled by processes, and supported by technology. Specifically, data governance provides the structures, procedures, and mechanisms to ensure data, business, and Information Technology teams work as one collaborative team towards shared goals.

Data Stewards are accountable for developing, implementing, and adopting data standards, definitions, and quality at the domain level. They ensure domain data is protected according to applicable laws and shared responsibly in the public interest, ensuring transparency about how data is being used. They are responsible for implementing appropriate privacy controls and cybersecurity measures. They will also represent and advocate on behalf of their respective data domain, where appropriate and necessary across the data governance structure. Ideally, Data Stewards would have hands-on experience with data from a particular domain, as well as health informatics background or training. They would be the SMEs on the data domain they represent. They would understand the data elements, data flows and the safeguards around that data inside and out.

Realizing the mission and goals of data governance will require shared accountability and responsibility across the health system.

The Working Group proposes that health data accountability and responsibility could be distributed across the following functions:

1. An Executive Data Steward, at the provincial sector level, is responsible for:
  - Ensuring optimized, responsible, and ethical data sharing across the sector.
  - Mandating health informatics standards to ensure data standardization and seamless data exchange.
  - Approving data governance policies, co-developed with stakeholders throughout the data governance structure.
  - Overall management and building of data stewardship in Ontario.
  - Representing Ontario's health sector at other provincial or pan-Canadian data governance bodies.
  - Transparent and meaningful engagement with individuals, groups, and communities, including FNIM and equity-deserving communities.
  
2. A Domain Steward, at data domain level, is responsible for:
  - Implementing the domain-level data governance.
  - Representing the interest of the domain at the provincial and/or pan-Canadian data governance bodies.
  - Co-designing data standards for a data domain, in alignment with provincial and pan-Canadian direction.
  - Supporting implementation of provincial standards in a respective data domain.
  - Developing domain data maps to understand how domain data flows and is used across the system and inform potential future data uses.
  - Ensuring transparency about how data is being used.

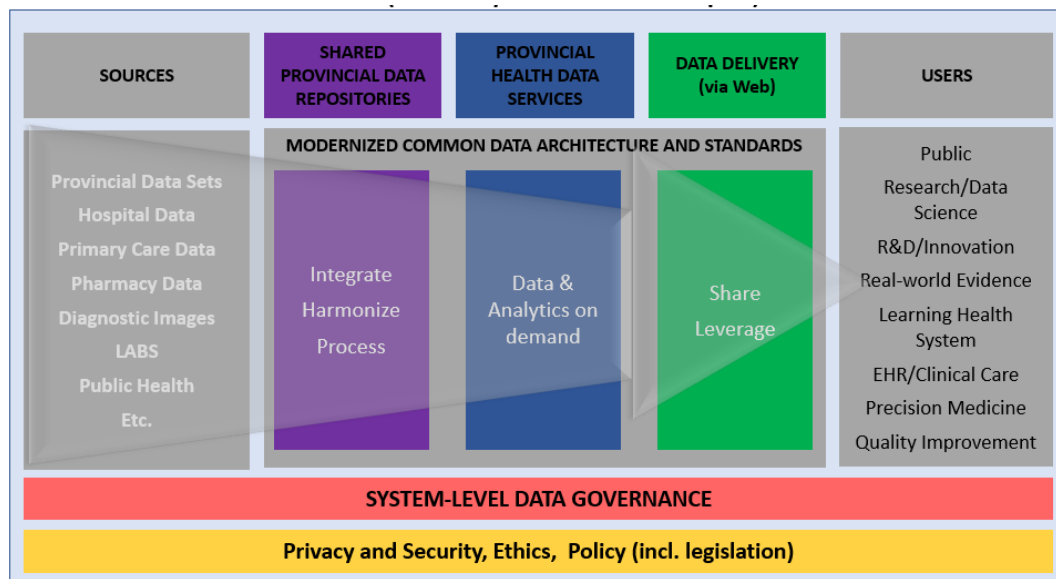
- Understanding and enforcement of privacy security, and cyber security requirements according to authorized data uses.
  - Monitoring domain-level data quality ensuring data is fit for use.
3. Health Information Custodians will continue to adhere to responsibilities under PHIPA, including:
- Ensure they do not collect, use, or disclose personal health information (a) unless they have consent and/or it is necessary for a lawful purpose, or (b) it is permitted or required by PHIPA.
  - Where applicable, maintain PHIPA data minimization requirements including not to collect, use or disclose personal health information if other information will serve the intended purpose or not to collect, use or more personal health information than is reasonably necessary to meet the purpose intended.
  - Take reasonable steps to safeguard and ensure the accuracy of personal health information in their custody or in the custody of their PHIPA agents.
  - Give individuals lawful access to their own personal health information (subject to certain exceptions).
  - Make available to the public a written statement summarizing their information practices on how personal health information and any personal information are managed.

## **Proposed Provincial Health Data Infrastructure**

Clear provincial health data governance is required to achieve integrated health data that is seamlessly shared for multiple uses and stewarded as a public good. However, the Working Group believes that data governance alone is not enough: Ontario also needs to take a modern and thoughtful approach to health data infrastructure and architecture to enable data to be collected and processed once and used multiple times.

The modernized data infrastructure will require both a well-defined data governance founded on ethical and 'privacy by design' principles, underpinned by an appropriate legal framework, as well as a high degree of standardization of data and data exchange mechanisms.

Figure 2:2 Data Infrastructure Concept (Datasphere). Diagram modified from *Public Service Commission Data Management Strategy: Components and Enablers*.



In this proposed approach, data would be collected by various sources and made available to various users based on data access rules and well-defined policies established by the data governance structure.

## Proposed Test Case – Primary Care Data Sharing

The Working Group suggests that core primary care data sharing could serve as a test case to test that the data governance structure can support shared, collaborative decision making from across the health system and enable implementation. The Working Group recognizes the complexity and challenges of this proposed priority use case, but also recognizes the rewards for successfully enabling better sharing of primary care data.

In Ontario, 89% of primary care physicians use Electronic Medical Record (EMR)<sup>5</sup> systems to capture clinical patient-level data related to service encounters, allergies, immunization, family medical history, medication, etc.. But these EMRs were not developed with data sharing in mind. Data definitions in EMRs differ across vendors and data are not documented or codified in a standardized way - and frequently differ from instance to instance of the same vendor product. Two clinicians using the same EMR in

<sup>5</sup> See *How Canada Compares: Results from the Commonwealth Fund's 2019 International Health Policy Survey of Primary Care Physicians*. (Canadian Institute for Health Informatics, 2020)



Ontario can enter the same data in different places – or different data in the same place. Most EMR systems were not designed to make transmitting data out a simple or cost-effective exercise. Consequently, the EMRs are frequently data islands, isolated from the rest of health data in the health system and are not integrated into a comprehensive electronic patient health record. Enabling this primary care data sharing use case would ensure this data would be processed and made available to patient, caregiver, and care continuity teams to facilitate care.

For the primary care data sharing test case to be successful, the Working Group recommends that the following data governance bodies be in place:

Responsible Body	Type of Work and Decision-Making
PDSC	<ul style="list-style-type: none"> <li>• Approval body for health informatics standards and system-level common data policies.</li> <li>• Data stewardship oversight.</li> </ul>
CS	<ul style="list-style-type: none"> <li>• Development of system-level policies for primary care data collection, access, and permissible use:               <ul style="list-style-type: none"> <li>▪ Data collection to consider:                   <ul style="list-style-type: none"> <li>– Mandatory data contribution for the direct care provisioning and legislative changes to support it.</li> </ul> </li> <li>▪ Permissible data uses to consider:                   <ul style="list-style-type: none"> <li>– Consent-based use – empowering patients with appropriate control over their data in accordance with the applicable legislative restrictions, e.g., mandatory reporting of diseases of Public Health significance, “break the glass” access.</li> <li>– Social license-based use - no explicit consent required for service delivery; healthcare system improvement and university-based researchers to understand the drivers of disease and wellbeing.<sup>6</sup></li> </ul> </li> <li>▪ Access to consider:                   <ul style="list-style-type: none"> <li>– Access by other providers who provide services to patients (e.g., social workers, dietitians).</li> <li>– Individual-level versus aggregate data.</li> <li>– Personal information versus personal health information.</li> </ul> </li> </ul> </li> <li>• Engagement with communities-based tables to ensure communities’ perspective on primary care data collection, sharing and use.</li> <li>• Development of guidelines on PHIPA interpretation.</li> <li>• Scope out legislative changes required to support the above considerations.</li> </ul>

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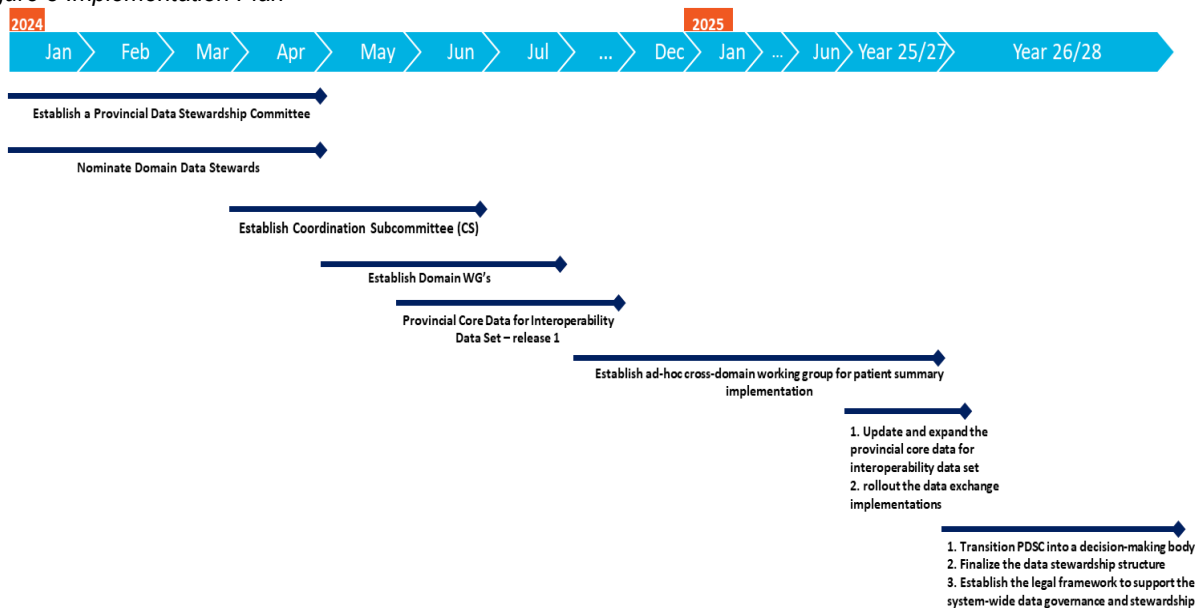
<sup>6</sup> See [Citizen Access to Health Data: An international review of country approaches to citizens access to health data](#). (Global Digital Health Partnership, 2020)

Ad Hoc Working Group	<ul style="list-style-type: none"> <li>• Development of <b>provincial core data for interoperability data set</b> that will standardize clinical data about patient exchanged among different care settings for a wide range of uses, e.g., care coordination, care transitioning, analytics.</li> <li>• To consider: <ul style="list-style-type: none"> <li>▪ Data set to account for all care settings.</li> <li>▪ An iterative approach to the development of data set focusing on high-priority primary care data needs (e.g., current medications, problems list and allergies/intolerances).</li> <li>▪ Alignment with pan-Canadian data set.</li> </ul> </li> </ul>
Interoperability/ Technology	<ul style="list-style-type: none"> <li>• Development and maintenance of interoperability standards ('Patient Summary specification' FHIR interoperability standards) while maintaining alignment with pan-Canadian approach.</li> <li>• Development of the implementation guide for primary care data exchange</li> <li>• Agreement on unique identifiers standards.</li> <li>• Implementation of system-level policies on access, sharing, and use.</li> <li>• Interoperability standards compliance verification.</li> <li>• Vendor support, coordination, and certification aligned with the pan-Canadian approach.</li> </ul>
Ad Hoc Cross-Domain Working Group	<ul style="list-style-type: none"> <li>• Development of data content and data flow requirements for data flowing from EMR to the Electronic Health Record (EHR)/Datasphere and vice versa.</li> <li>• Implementation of the Patient Summary workflow at vendor's site(s).</li> <li>• Support collaboration between vendors and health information custodians during the implementation of the Patient Summary workflow.</li> </ul>
Health Data Use	<ul style="list-style-type: none"> <li>• Clinical standardization and translation of technical standards into digital tools and templates to increase adoption and lessen burden on clinicians.</li> <li>• Development of change management and adoption plan for clinicians.</li> <li>• Engagement with colleges and associations, e.g., Ontario Medical Association, College of Physicians and Surgeons of Ontario, OntarioMD, to facilitate change management and adoption.</li> </ul>
MPFAC	<ul style="list-style-type: none"> <li>• Development of patient requirements for accessing primary care data.</li> <li>• Validation of patient requirements against a use case/digital solution.</li> <li>• Co-development of patient-friendly content/education material with clinical educators.</li> <li>• Advising on system-level data policies e.g., consent, data uses.</li> </ul>
HDET	<ul style="list-style-type: none"> <li>• Assessment, if appropriate, data uses that support equity and conform to the provincial health equity principles and framework.</li> </ul>

## Proposed Implementation Plan

The Working Group recommends the following implementation plan for immediate action in next 6 to 12 months. The data governance model will evolve iteratively to a mature state.

Figure 3 Implementation Plan



Year 1-2:

1. Establish **PDSC**, as a recommending body to the Minister, responsible for:
  - a. Implementation of the provincial data strategy.
  - b. Implementation of the provincial data governance framework.
  - c. Ensuring alignment between existing provincial data governance bodies with the proposed data governance structures (e.g., Ontario Health, Intellectual Property Ontario etc.).
  - d. Selection of a data governance maturity model including a minimum set of capabilities.
  - e. Data stewardship oversight.
  
2. Establish Domain Steward functions:
  - a. Clearly define data domains comprising the patient integrated record that can be scaled up in the future.
  - b. For the priority domains supporting current system-level priorities, establish **Domain Working Groups**:
    - i. Clearly define the domain steward roles and responsibilities along with delegated decision-making power via the domain working group terms of reference that will require approval by PDSC.
    - ii. Ensure a broad representation based on geographic location and care setting.
    - iii. Develop an annual work plan requiring approval by PDSC.
  - c. Decide if the Domain Steward functions reside within MOH or OH.

3. Establish **Coordination Subcommittee (CS)** that will be comprised of a Secretariat plus Domain Stewards and be responsible for:
  - a. Approval of the implementation project plans and coordination of activities.
  - b. Cross-domain data issues resolution.
  - c. System-level data policy development.

Establish an **Ad-Hoc Working Group reporting to CS** comprised of Domain Stewards, data SMEs, vendors, standards SMEs, researchers, analytics users, and other data users to develop **Provincial core data set for interoperability** (key clinical data about patient that is exchanged among different care settings for a wide range of uses, e.g., care coordination, care transitioning, analytics). It will require:

- d. An iterative approach: The first iteration to focus on the patient summary interoperability spec. data needs (e.g., medications, problems list and allergies and intolerances).
  - e. Alignment with the pan-Canadian core data for interoperability data set.
  - f. Mapping to the pan-Canadian common data model.
  - g. Developing provincial terminology sets in alignment with the pan-Canadian approach by harmonizing various terminology sets that are currently in use by different care settings (initial focus on harmonization of primary care and acute care data categories and terminology sets).
4. Establish **Ad-Hoc Cross-Domain Working Groups** to implement the data sharing for workflows deemed as priority for the province (e.g., EMR data flowing in and out of the provincial EHR) that is comprised of relevant Domain Stewards, technical SMEs, and key vendor representatives responsible for:
  - a. Specification of data content and business requirements for a particular workflow (data content will come from the provincial core data for interoperability data set and reside in multiple domains).
  - b. Development of the data exchange specifications that is an industry standard and aligned with the pan-Canadian baseline standards (e.g., 'Patient Summary Standards' interoperability specifications).
  - c. Coordination and support to the vendor-based implementations through a **vendor-specific working group** comprised of clinical and technical SMEs representing all sites for a particular vendor responsible for:
    - i. Championing the data exchange implementation at the point of care.
    - ii. Developing terminology mapping between the local codes at the point of care and provincial terminology sets that may be shared at the provincial level.
    - iii. Translating health informatics standards into local templates and toolkits that may be shared at the provincial level.

- iv. Supporting clinical adoption and change management through the development of plans, toolkits, training material etc. that may be shared at the provincial level.
- v. Supporting data quality improvement
- vi. Participating in the cross-domain working group.
- d. Regular reporting on progress to the Coordinating Subcommittee which may escalate issues to PDSC, if deemed necessary.

Year 2-3:

1. Update and expand the provincial core data for interoperability data set based on the system-level priorities and feedback from data exchange implementations.
2. Rollout the data exchange implementations across more vendors and sites.

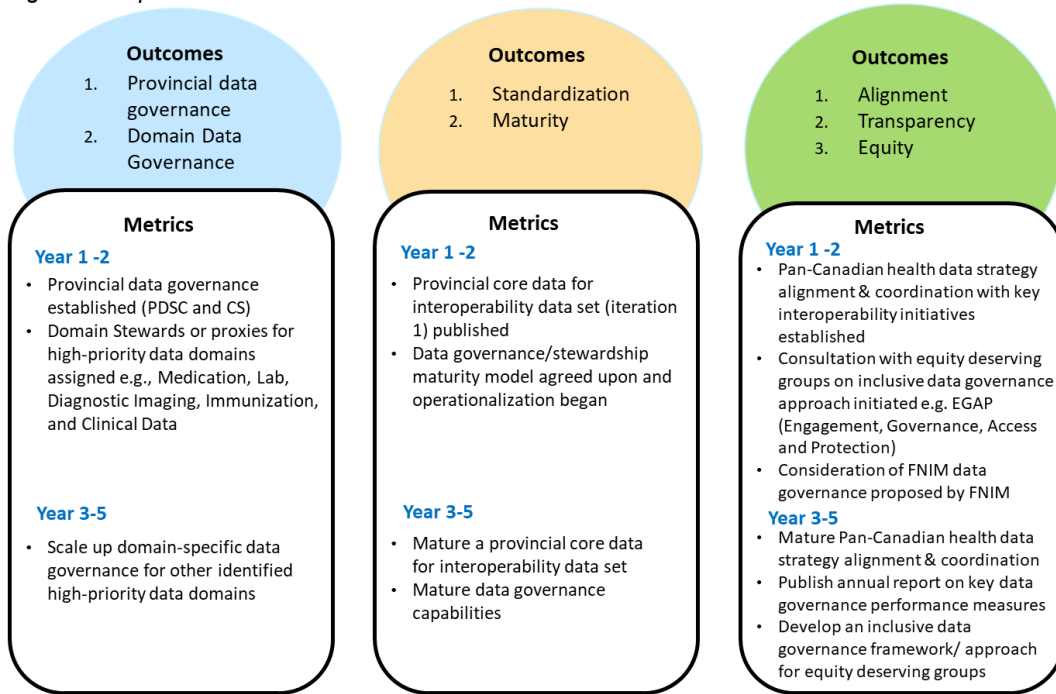
Year 3-5:

1. Transition PDSC into a decision-making body. Prior to transitioning the PDSC to a decision-making body, there will be a comprehensive review to ensure there are no overlaps or confusion between the PDSC's and the IPC's powers and functions.
2. Finalize the data stewardship structure.
3. Establish the legal framework to support the system-wide data governance and stewardship.

The Working Group recognizes that implementation will have to be supported by legislative and regulatory changes and supports the ongoing work of PHIPA modernization sponsored by the OHDC. The Ministry of Health will need to provide appropriate resources and support for the execution of the plan.

# Proposed Indicators of Success

Figure 4 Proposed Indicators of Success



In pursuit of data governance goals, the Working Group recommends that the development, establishment, and maturity of data domains be tracked, especially data content standardization within and across data domains. However, data element collection and integration from across different domains from across the health system will vary drastically. Reporting requirements must adapt and reflect those variations, including consideration of existing capacity of stakeholders to collect these data elements. The Working Group recognizes a need to advance data governance capabilities in Ontario starts with agreeing on a common maturity model and a minimum set of data capabilities. The Working Group proposes further analysis be performed and an industry-accepted data governance maturity model be recommended.

## Proposed Next Steps

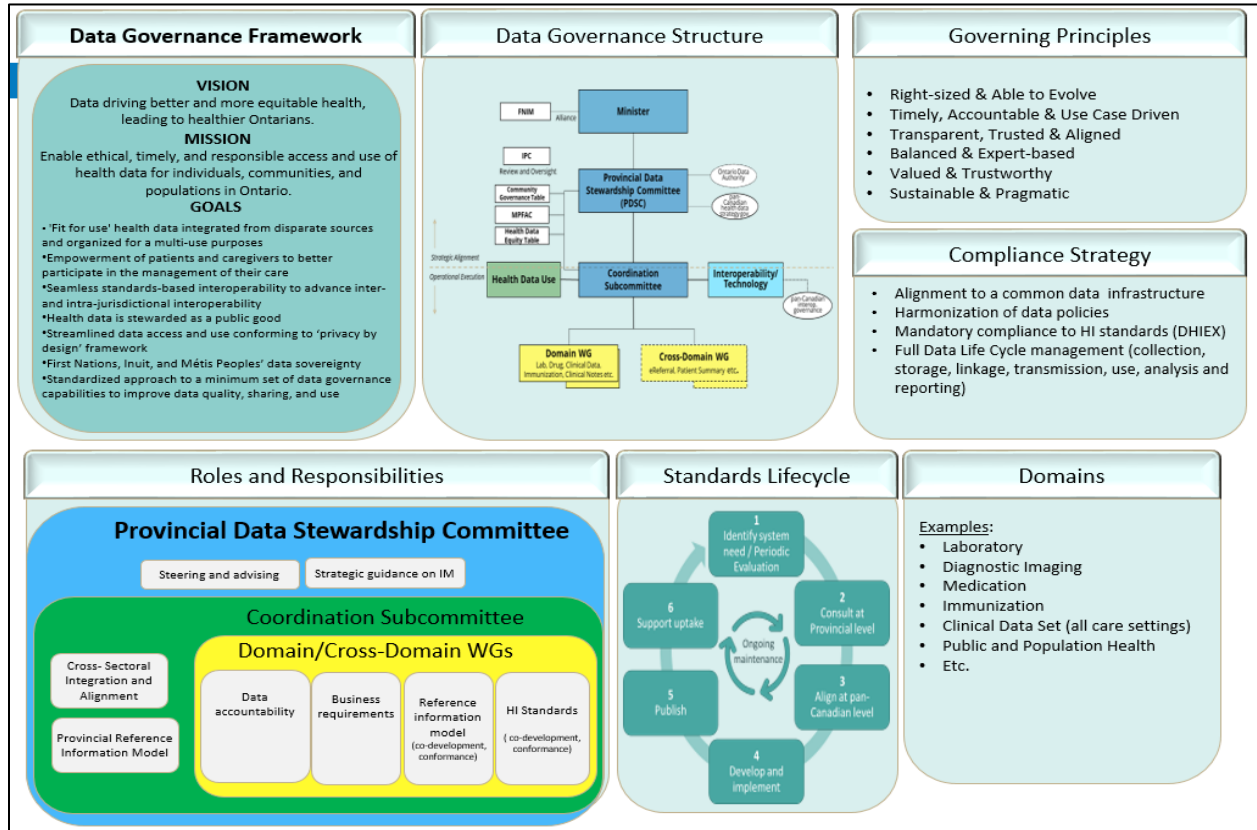
1. Submit the Working Group Report to the OHDC for consideration, revision, and adoption.
2. The OHDC submits the report to the Minister of Health for further consideration.
3. Pending approval, the Minister of Health directs the Ministry of Health to action on the Data Governance and Stewardship implementation plan.

## Appendix

### Data Governance and Stewardship Working Group Members

Name	Organization	Title	Role
Keith Jansa	Digital Governance Council	CEO	Chair
Anne Forsyth	CIHI	Manager, Data Standards	Contributor
Attila Farkas	Canada Health Infoway	Senior Director, Solution Management and Advisory Services	Contributor
Cindy Fedell	Northwestern Ontario Hospitals	Regional CIO	Contributor
Colleen Geiger	Public Health Ontario	Chief, Strategy, Stakeholder Relations, Research, Information and Knowledge	Contributor
Julie Klein-Geltink	Ontario Health	Director, Data for Connected Health	Contributor
Michael Schull	ICES	President and CEO	Contributor
Sonali Kohli	Niagara Health	VP, Diagnostics and CIO	Contributor
Steve Scott	Ontario Health	VP, Information Management, Decision Support & Analytics	Contributor
Andrew Drummond	IPC	Director of Health Policy	Ex-Officio

# Data Governance Placemat





## Data Governance vs Data Stewardship

Realm	Health Information Custodian	Domain Steward	Provincial Governance
<b>Legislation and Regulation</b>	<ul style="list-style-type: none"> <li>Implements legislative and regulatory requirements at their organizations</li> </ul>	<ul style="list-style-type: none"> <li>Implements legislative and regulatory requirements within Datasphere</li> </ul>	<ul style="list-style-type: none"> <li>Ensures compliance with applicable legislations and regulations</li> </ul>
<b>Strategy, Mission, Vision, Values</b>	<ul style="list-style-type: none"> <li>Develops organizational strategy, roadmaps, frameworks etc. in alignment with provincial direction and objectives</li> </ul>	<ul style="list-style-type: none"> <li>Co-develops frameworks, roadmaps, guidelines, etc. to achieve strategic goals</li> <li>Aligns with provincial frameworks, roadmaps, etc.</li> </ul>	<ul style="list-style-type: none"> <li>Establishes stewardship roles, committees and oversight</li> <li>Approves frameworks, roadmaps, etc.</li> </ul>
<b>Policies</b>	<ul style="list-style-type: none"> <li>Develops organizational data policies to manage data as valuable assets through the entire lifecycle</li> <li>Aligns internal data policies with regional/provincial/federal policies for data that are shared at regional/provincial/national level</li> </ul>	<ul style="list-style-type: none"> <li>Co-designs system-level cross-cutting or domain-specific data policies for the entire data lifecycle (data collection, storage, linkage, transmission, use, analysis and reporting)</li> <li>Implements and complies with data policies to ensure that data flows and high quality of data is maintained</li> </ul>	<ul style="list-style-type: none"> <li>Approves system-level common data policies</li> </ul>
<b>Data Governance Processes and Procedures</b>	<ul style="list-style-type: none"> <li>Designs organizational data governance processes and procedures</li> <li>Participates in data governance at a regional/provincial level</li> </ul>	<ul style="list-style-type: none"> <li>Co-designs system level data governance processes and procedures</li> <li>Facilitates data governance processes and procedures (at system or domain level)</li> <li>Participates in data governance committees</li> </ul>	<ul style="list-style-type: none"> <li>Ensures consensus-based decision-making and collaboration among data stewards</li> <li>Ensures relevant community engagements</li> <li>Ensures knowledge and insights sharing among data stewards</li> </ul>
<b>Data Quality</b>	<ul style="list-style-type: none"> <li>Develops organizational data quality management program</li> <li>Ensures appropriate level of data quality for core data shared at regional/provincial/national level</li> </ul>	<ul style="list-style-type: none"> <li>Co-develops system-wide or domain-specific data quality framework</li> <li>Implements data quality management and ensures acceptable level of data quality</li> <li>Resolves or escalates data quality related issues</li> </ul>	<ul style="list-style-type: none"> <li>Approves data quality framework</li> <li>Resolves data-related issues</li> </ul>

# RAID Chart

The table below shows a matrix of key responsibilities for major data governance artifacts:

Functions	Artifacts and Deliverables	PDSC	Cord. Subcommittee	MPFAC	Health Data Equity Table	Domain WG	X Domain WG	Health Data Use	Interop./Tech
<b>Data Governance</b>	Overarching principles for effective data stewardship	D	I	I	I	I	I	I	I
	Data governance framework	D	I	I	I	I	I	I	I
	Data stewardship structure	D	I	I	I	I	I	I	I
	Stakeholder engagement strategy	D	I	I	I	I	I	I	I
	Health equity framework	A	D	I	R	I	I	I	I
<b>Assets, content &amp; standards</b>	Provincial business data model	A	R/D	I	I	I	I	I	I
	Data standards (including terminology sets)	I	A	I	I	R/D		I	I
	Workflow/Integrating the Healthcare Enterprise (IHE) profile standards	I	A	I	I	I	R/D	I	I
	System-level data policies (access, consent, etc.)	A	R	I	I	D		I	I
	Cross-domain policies (e.g., consent, IP, digital ID)	A	R	I	I	I	I	I	I
	Interoperability standards	A	R	I	I	I	I	I	D
<b>Integration, interoperability &amp; adoption</b>	Compliance to interoperability standards verification	I	I	I	I	I	I	I	D
	HI standards adoption reporting	I	I	I	I	I	I	I	D
	National/international data standards alignment	I	I	I	I	I	I	I	D
	Clinical standardization	I	A	I	I	I	I	R/D	I
	Data quality framework	A	R/D	I	I	I	I	I	I
<b>Data Quality</b>	Data quality assurance	I	I	I	I	I	I	I	D

**Legend**

R - Recommend	Gather the relevant input and proposes a course of action
A - Approve	Give formal approval
I - Inform	Receive communication
D - Deliver	Implement/execute the work, including transition work to operations

## Roles and Responsibilities

The table below is a high-level encapsulation of the roles and responsibilities of each body in the Structure.

DG Body	DG Responsibilities
Minister of Health	<ul style="list-style-type: none"> <li>• Strategic direction, legislation, and regulation.</li> <li>• Budget and sector-level priorities.</li> </ul>
First Nations, Inuit, and Métis (FNIM)	<ul style="list-style-type: none"> <li>• Partner and engage with FNIM peoples and communities to develop a distinction-based approach to data governance.</li> </ul>
Provincial Data Stewardship Steering Committee (PDSC)	<ul style="list-style-type: none"> <li>• Advice and guidance on provincial health data strategy execution.</li> <li>• Oversight of Data Stewardship.</li> <li>• Strategic guidance on system level IM capabilities, roadmaps, frameworks, standards, and policies etc.</li> <li>• Partnership engagement with stakeholders, including patients, equity-deserving communities, and FNIM peoples.</li> </ul>
Coordination Subcommittee (CS)	<ul style="list-style-type: none"> <li>• Overall management and building of data stewardship.</li> <li>• Standardization of health data and enabling data exchange/interoperability in alignment with pan-Canadian approach.</li> <li>• Co-design and harmonization of cross-domain data policies (e.g., consent).</li> <li>• Guidance and coordination of projects and activities based on priorities and strategic directions set by PDSC.</li> <li>• Information dissemination, cross-domain issue resolution, and escalation.</li> </ul>
Information and Privacy Commissioner (IPC)	<ul style="list-style-type: none"> <li>• Independent oversight and review of privacy policies and information management practices.</li> <li>• Compliance with access and privacy laws as well as investigation of privacy complaints and non-compliance with interoperability specifications.</li> <li>• Educate the public, media, and other stakeholders about Ontario's access and privacy laws and related issues.</li> </ul>
The Minister's Patient and Family Advisory Council (MPFAC)	<ul style="list-style-type: none"> <li>• Providing patients' requirements for using digital solutions for self-care management.</li> <li>• Sponsor provincial health engagement strategy, providing public input on governance, system-level data policies, literacy, and transparency issues.</li> <li>• Patients' guidance on co-developing patient-friendly data literacy material.</li> </ul>

Community Governance Table (CGT)	<ul style="list-style-type: none"> <li>• Consultations with communities regarding data collection, sharing and use.</li> <li>• Implementing community-based data governance frameworks such as Engagement, Governance, Access, and Protection (EGAP).</li> </ul>
Health Data Equity Table (HDET)	<ul style="list-style-type: none"> <li>• Provides clinical guidance on equitable principles and practices to be incorporated throughout the entire data lifecycle.</li> <li>• Provides advice on appropriate uses of data to support health equity and escalates if there is any issue.</li> </ul>
Health Data Use (HDU)	<ul style="list-style-type: none"> <li>• Specification of system-level clinical and health use requirements for health data, including uses at the pan-Canadian level.</li> <li>• Provide clinical guidance on adoption of standards, digital tools, and change management.</li> <li>• Clinical guidance on aligning clinical and digital programs.</li> <li>• Translation of clinical quality standards into digital tools and templates.</li> </ul>
Interoperability/ Technology	<ul style="list-style-type: none"> <li>• Development and execution of interoperability roadmaps based on a common data infrastructure and business architecture.</li> <li>• Technical guidance and alignment across health informatics standards.</li> <li>• Compliance to standards verification and certification services along with interoperability policies and processes.</li> <li>• Interoperability standards development, maintenance, and conformance testing.</li> </ul>
Domain Working Group	<ul style="list-style-type: none"> <li>• Standardization of domain-specific data in alignment with provincial principles/direction (e.g., terminology standards).</li> <li>• Domain-level data quality monitoring.</li> <li>• Co-design and implementation of interoperability standards.</li> <li>• Alignment to provincial reference models, data models, frameworks, roadmaps etc.</li> <li>• Domain issue resolution and escalation.</li> <li>• Domain liaison and stakeholder engagement.</li> </ul>
Cross-Domain Working Group	<ul style="list-style-type: none"> <li>• Specification of data workflow business requirements to enable team-based care.</li> <li>• Compliance to provincial methodology standards (e.g., Integrating the Healthcare Enterprise profiles).</li> <li>• Engagement with stakeholders (clinical and technical), SMEs, Domain Working Groups, etc.</li> <li>• Issue resolution and escalation.</li> </ul>

## Stakeholders

**Patients and Caregivers** are frustrated by their lack of access to their personal health information, requiring access to dozens of online portals to achieve only a partial view of their health records with no insight into how they can take action to improve their own health. They also find it difficult to understand how well the health sector is working and how to hold decision-makers accountable for improvement and data access.

**First Nations, Inuit, and Métis** peoples suffer from health systems that perpetuate and contribute to existing structured social inequities and have difficulty exercising their right to self-determination. They want to ensure their data sovereignty is respected, while ensuring access to data and the ability to generate impactful insights.

**Providers and Health System Partners** require timely access to integrated health data on a need-to-know basis to provide the best possible quality care and proactively allocate resources where needed. Healthcare providers are challenged to incorporate new requirements for data collection while receiving few or no benefits in reduced workload nor seeing better outcomes for their patients, contributing to burnout.

**Ontario Health Teams (OHTs)** are a new model of integrated care that bring together health care providers as one collaborative team to deliver comprehensive and coordinated care to a defined regional population. To achieve their objectives, OHTs need to readily access and use data, specifically health data, with effective data governance, data stewardship, and privacy protections. Many OHTs have expressed a need for further support, due to limited health data capacity and confusion about the roles of the Ministry of Health, Ontario Health, and Ontario Health Teams. They have called for greater provincial support to bolster health data management capacity, strengthen information sharing processes, and align privacy and security approaches.

**Public Health Authorities** do not have ready access to all the data they need to provide timely, precise, and actionable insights, in particular during public health emergencies. Detecting, tracking, and preventing public health threats requires timely, relevant, and reliable population-level data and the necessary tools to respond to not only pandemic-related threats, but also infectious agents, environmental contaminants, occupational exposures, unstable housing, food insecurity, obesity, injury prevention, and morbidity and mortality factors in addition to the harms that result from these threats.

**Researchers and Innovators** need access to health data to drive improvements and innovation that bring benefits to society, communities, and individuals. Researchers spend significant time obtaining data access and sharing approvals and are unable to

complete timely and appropriately studies to improve the health of Ontarians. Additionally, innovators have great ideas that cannot always be implemented or scaled due to fragmentation across the province.

**Planners and Policy Makers** are frustrated and uncertain as to how to address data shortfalls despite serial attempts to do so, leading to below average results in health outcomes and above average costs compared to other G7 countries, to the extent these metrics can be reliably compared.

## Terminology

While interpretations of the commonly applied terms may vary with readers, below are the intended definition of the terms used in this report.

### Access

The act of providing access to the data for authorized individuals by data visiting (where data remains in a place) or physical data sharing (where data is copied).<sup>7</sup>

### Data Domain

A logical grouping of data. A set of interrelated data elements pertaining to a common purpose, object, or concept.

### Data Element

Also referred to as a **data attribute**, it is a unit of data for which the definition, identification, representation, and permissible values are specified by means of a set of characteristics.<sup>8</sup>

### Data Governance

Policies, procedures, processes, and people in place to manage and oversee the collection, sharing, access, and use of data. It also ensures data integrity, fidelity, quality, security, privacy, and retention.

### Data Infrastructure

The systems, software, and automations necessary to provide a modern data platform

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<sup>7</sup> See *Pan-Canadian Health Data Strategy. Expert Advisory Group Report 1: Charting a Path toward Ambition.* (Public Health Agency of Canada).

<sup>8</sup> From *DAMA Dictionary of Data Management* (DAMA International, 2011).

that ensures quality data is available as fast as it is needed. It encompasses such generic vendor agnostic concepts such as data mesh, data fabric, data cloud, data as a service, data lake, data access keys, etc. It is used to provide data access in support of such generic concepts such as data publication and subscription services, audit services, analytics as a service, artificial intelligence, machine learning, clinical decision support, information exchange, research, health system use, etc. In Ontario, this is referred to as ‘Datasphere’.

### **Data Model**

A model that includes formal data names, comprehensive data definitions, proper data structures, and precise data integrity rules.<sup>9</sup>

### **Data Standards**

Rules and guidelines on common data representations, formats, and definitions to ensure that data is consistent, easily shared, and accurately interpreted by different users.

### **Data Stewardship**

Stewardship is about ensuring data is fit for purpose and maturing data standards in an enabling manner for all health system users. The accountability function to ensure the authorized, appropriate, ethical, and responsible use of health data in accordance with Ontario’s data governance framework. It is the operationalization of data governance.

### **Health Data**

Publicly and privately held data related to health care, public health, publishing health, and health research, inclusive of relevant socio-demographic factors (e.g., race, ethnicity, gender, age) and data from other sectors.<sup>10</sup>

### **Health Data Ecosystem**

The set of governance, policies, processes, designs, and data flows from an Interoperable network designed and developed to ensure the best possible health services and outcomes for Ontarians based on excellent research, population and public health services and policies, and delivery, organization, and management of health care.<sup>11</sup>

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<sup>9</sup> Same as above.

<sup>10</sup> See [Pan-Canadian Health Data Strategy. Expert Advisory Group Report 1: Charting a Path toward Ambition.](#) (Public Health Agency of Canada)

<sup>11</sup> Adapted from above.

### **Interoperability Standards**

Interoperability standards specify how various standards (e.g., identifier standards, privacy and security standards, information content standards, information exchange standards) work together to enable information sharing between information systems for a specific business need.

### **Public**

These are individuals and their families and caregivers and encompasses all persons living in Ontario including those who have contact with health services as a result of disease or injury as well as maintaining and promoting health for all.<sup>12</sup>

### **Reference Model**

A framework describing the objectives shared by all stakeholders in a formal way to enable data sharing and include things like the level of security, type of communication between two systems, workflows, procedures etc.

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<sup>12</sup> Same as above.